Four-year behavioral outcomes of an intervention for parents living with HIV and their adolescent children

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Objective: The adjustment of parents living with HIV (PLH) and their adolescent children was examined over 4 years in response to an intervention. Outcomes at 2 years had been previously published.

Methods: A randomized controlled trial was conducted, with a representative sample from New York City.

Results: In the intervention condition, fewer adolescents became teenage parents, and conduct problems tended to be lower over 4 years than in the standard care condition. Fewer parents were drug dependent and tended to relapse into substance use or use passive coping styles compared with the standard care condition over 4 years. The time-trend analysis showed that the significant reductions in problem behaviors and emotional distress previously observed over 15–24 months in the intervention condition, then eroded over time and were non-significant at 48 months.

Conclusions: Ongoing support and skills are needed to maintain intervention effects over longer periods.

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Introduction

When parents are living with HIV, both the parent and their children, particularly adolescent children, face many stresses over a prolonged period of time. Parents must care for their children while simultaneously coping with ongoing physical symptoms, complex health care regimens, emotional reactions to their diagnosis, as well as reducing drug use that may have led to their infection [1].

Adolescents are typically aware of their parent’s HIV diagnosis [2] and are called upon to assist in the daily management of the household, especially caring for younger siblings, as well as providing support to their parents [3,4]. There is often a long period of anticipatory loss and anxiety about their parent’s health [5], resulting in physical symptoms for the youth [1,6]. If the parent living with HIV (PLH) dies, there is likely to be a significant negative impact on their children’s adjustment [7,8], similar to parental death from other diseases [9–11]. Adolescents may attempt to replace their parents’ love by having their own children [12, May S, et al. 2003, submitted] or may be asked to raise their siblings [13],

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challenging adolescents to complete their own developmental tasks in the context of taking care of others.

To address the potential, long-term negative impact of HIV on families, a randomized controlled trial was conducted with PLH and their adolescent children evaluating a coping skills intervention compared to a standard care condition. The intervention showed positive results over 2 years [5] in reducing parents’ and youths’ problem behaviors and emotional distress. This paper examines the impact of the intervention for PLH and adolescents’ outcomes from 2 years following recruitment until 4 years.

The intervention was delivered in two modules over 24 sessions (see Fig. 1). Module 1 aimed to reduce parents’ problem behaviors, substance abuse, emotional distress about serostatus, and disclosures to their children. Both parents and adolescents attended module 2, which aimed at decreasing adolescent’s problem behaviors, emotional distress, and teenage parenthood. Module 2 also helped with custody planning and improving their relationships with their adolescents. Both modules were based on a cognitive-behavioral, skills training model, and were delivered in small, facilitated groups, similar to other successful HIV interventions [14]. Whereas the National HIV Consensus Development Conference [15] recommended long-term interventions, the current project is the longest to date at 4 years for a social cognitive program.

**Methods**

**Participants**

From a comprehensive log at the New York City Division of AIDS Services from August 1993 to March 1995, a consecutive series of PLH were approached for participation. PLH were eligible for recruitment if they were: (1) HIV positive; (2) between the ages of 25 and 70 years; (3) had at least one adolescent child (biological or adopted) between the ages of 11 and 18 who typically lived with the parent; (4) their case manager evaluated the project as being in the client’s best interests; and (5) the PLH lived through the recruitment period. Of the 429 eligible PLH, 307 were recruited: 65 (15.2%) were untraceable, 46 (10.7%) refused participation and 11 (2.6%) were severely ill or incarcerated and were not recruited. Thus, 71.6% (n = 307 of 429) PLH were recruited, reflecting 84% (n = 307 of 364) of the traceable PLH. With Institutional Review Board approval and informed consent, permission to recruit adolescents was obtained from PLH and then from their adolescent children. Only 280 of 307 PLH agreed to allow their children to participate; the other 27 PLH agreed to participate by themselves. Even though some PLH chose not to participate, they allowed their children to participate (n = 14). The 307 PLH, resulted in 413 adolescent participants (average number per family, 1.5; SD, 0.7; range, 1–5). Families (PLH and all adolescent children) were randomly assigned by a pre-programmed laptop computer at the end of the baseline assessment session.

![Fig. 1. Design of the study. *Number of adolescents is based on disclosure at the time of randomization.](image-url)
to the coping skills intervention condition ($n = 153$ PLH, $n = 206$ adolescents) or the standard care condition ($n = 154$ PLH, $n = 207$ adolescents). During the first 4 years of the study, 141 (46%) of the PLH died. The number of deaths did not significantly differ by condition (intervention: $n = 71$, standard care: $n = 70$).

**Intervention description**

An extensive detailed manual contained the specific goals, activities, and scripts for each session (html http://chips.ucla.edu/interventions/manuals/intervhr1.; [5, 7,16]). In module 1, PLH met together for eight sessions and focused on adapting to their HIV status (coping with feelings of anger, depression, and fear), maintaining healthy lifestyles (stopping transmission behaviors and substance use), coping with negative feelings related to their diagnosis, and making decisions about disclosing their status to their children. In module 2, both PLH and their adolescent children attended this module; some sessions were joint and other sessions separated parents and adolescents. Module 2 aimed to reduce the emotional distress of the PLHs, maintain positive family routines, assist their children to avoid high-risk behaviors, and to make custody plans for their children. For adolescents, module 2 aimed to improve the youth’s coping with their parent’s diagnosis and possible death, learn skills to reduce high-risk behaviors (e.g., sexual, substance use acts, teenage pregnancy), and to reduce emotional distress.

Adolescents were invited to attend the intervention only if PLH had already disclosed their serostatus to them (see Fig. 1). Routine quality assurance ratings indicated high fidelity to the manual and program acceptability [9]; parents received a US$20 participation incentive.

Among the 153 PLH randomized to the intervention condition, 95 (62.1%) attended at least one intervention session; 22 PLH died before attending the intervention; 17 did not attend for unknown reasons; 14 PLH refused to attend the intervention; and five were unavailable due to severe health problems or jail. Attendance at the intervention was lowest among fathers and monolingual Spanish mothers.

At the time of randomization, PLH had not disclosed to 66 of the 206 adolescents of parents in the intervention condition. When parents disclosed to adolescents, adolescents could then attend the intervention. Adolescents ($n = 126$) did not attend for the following hierarchically ranked reasons: parents did not attend ($n = 53$ adolescents); PLH died, was too sick or in jail ($n = 40$); adolescent entered late in the study ($n = 12$); adolescent refused ($n = 12$); adolescent was in jail ($n = 6$); or parent never disclosed ($n = 3$). Parents attended a mean of 5.83 of 8 potential module 1 sessions and 11.7 of 16 potential sessions in module 2; adolescents attended 10.3 of 16 potential sessions.

** Procedures**

The PLH and adolescents received US$25 per interview for each assessment conducted individually and alone by highly trained certified interviewers (in English or Spanish) using laptop computers. Participants were assessed every 3 months for the first 2 years and then at 6-month intervals.

The follow-up rates were lowest during the first year (mean, PLH 68.5%; adolescents, 66.5%), increasing with training during the second year of follow-up (PLH, 85%; adolescents, 81.5%). The rates for years 3 and 4 combined were 79% for adolescents and 87% for PLH. PLH in each intervention condition were assessed at least once annually at the following rates per year: 100, 87, 93, and 91%. Similarly, adolescents were assessed at least once annually at the following rates: 100, 92, 89, and 85%. The follow-up rates were similar in the intervention and standard care conditions for both parents and adolescents at each assessment. At least six of 13 assessments were completed by 86.2% of the PLH and 16% completed all 13 assessments.

**Assessments**

Background characteristics included data on gender, age, living situation, socio-economic status, and HIV diagnostic and health status. ‘Recent’ events reflected those occurring over the last 3 months.

**Adolescent assessments**

(1) The cumulative number of adolescents becoming parents.

(2) The Brief Symptom Inventory (BSI), a 53-item inventory that assesses symptoms of emotional distress [17] over the last week, is rated on a scale from 0 (not at all) to 4 (extremely), yielding a global severity index [alpha ($\alpha$) = 0.96].

(3) Multiple problem behaviors. The following behaviors were summed as present recently (1) or not (0): unprotected sexual intercourse, alcohol use, drug use, contact with the criminal justice system, trouble at school, and not being enrolled in school.

(4) Conduct problems. A sum of the presence of 18 recent conduct behaviors was calculated ($\alpha = 0.61$).

(5) The Rosenberg self-esteem scale [18] included 10 items rated on a scale of 1 (strongly agree) to 4 (strongly disagree) ($\alpha = 0.85$).

(6) Family life stressors. A sum of 10 recent stressful family events was calculated ($\alpha = 0.57$; 9).
PLH assessments
(1) Dependency on alcohol or substance abuse and relapse. After inquiries about the prevalence and frequency of recent use of alcohol and multiple drugs, parents reported the presence (1) or absence (0) of his or her dependency on drugs and relapse into use was recorded as present (1) or absent (0) over 48 months for each person.

(2) The Brief Symptom Inventory (BSI; [17]) (α = 0.97).

(3) Recent multiple problem behaviors were assessed, similar to adolescents’ reports, with the school items eliminated.

(4) Coping with Illness Questionnaire. PLH rated 37 items describing recent coping strategies on a scale of 1 (never) to 5 (always). This coping scale yields five subscale scores (self-destructive escapism, passive problem solving, passive action, spiritual hope, and seeking social support) that demonstrate adequate values of α (range = 0.76 to 0.89 [19]).

(5) Recent disclosure of serostatus occurred (1) or did not occur (0) to each adolescent and for all children in the family.

(6) Recent custody plans were summarized as (1) having a legal plan (‘1’ having made a will or designated standby guardianship) or no legal plan (0) for each child.

Data analysis
To examine the effect of the intervention over the entire 4-year follow-up period, counts of the total number of teenage parents and the proportions of events of drug dependency were compared in the intervention and standard care conditions, controlling for baseline status.

A time trend analysis (a.k.a., growth curve modeling) based on multi-level models [20] examined the rate of change on the outcome variables over time. The Proc Mixed procedure of SAS programs (SAS Inc., Cary, North Carolina, USA) was used, with AR(1) covariance structure for repeated measures. For each outcome, the measures assessed all waves (including the baseline), controlling for age, gender, and family (family-assessed as a random effect). In the outcome analyses for adolescents, parental death was also controlled as a time-varying covariate; death did not emerge as a predictor of outcomes in any analysis.

Visual inspection of the plots for each outcome over time indicated whether there was a knot in the slope at some point or there was a constant rate of change. Knots in the curve were identified for some outcomes at 15–18 months; other outcomes had knots at the 21–24 month assessments. When variations in the slopes were observed, piece-wise trends were examined using regression analyses for the two different time frames (e.g., 3–15 and then 18–48 months; 3–21 and then 24–48 months), with baseline scores covaried. The slopes for each time period were compared using a t-test to confirm the knot. While smooth curves were examined, the splines were better fits than the quadratic regression curves. Time-trend analyses based on multi-level models were employed for examining each outcome for each condition. The intervention effect was evaluated by comparing the slopes between the conditions over time using an intent-to-treat analysis [An as-treated analysis was also conducted with similar results that are available from the authors.]. The effect sizes are calculated in two steps. First, the change in each outcome from the 3-month assessment to the time-point at the end of the trend line was calculated among those in the intervention condition and subtracted from the change that was calculated in a similar manner among those in the standard care condition. Second, this change in scores was standardized by dividing the change score by the standard deviation for the baseline value in the standard care condition. The effect sizes are reported at the knot in the curve and/or at 48 months. Adjusted means were also compared at 36–48 months for PLH and adolescents in the intervention and standard care conditions. The adjusted scores for each outcome at each time point were derived from the estimated trend lines generated by the random regression models. All potential participants were included in the analysis, even if only a parent or only the adolescent children of the family were enrolled.

Results
Sample characteristics and balance across conditions at baseline
Table 1 summarizes the characteristics of PLH and adolescents in the intervention and standard care condition at recruitment. As shown in Table 1, 48% of the adolescents were male; most were students (89%) with a mean age of 14.7 years (SD, 2.0; range, 11–18). Most youth reported low rates of risk behaviors. A few adolescents were parents (6.3%, intervention; 9%, standard care). Reports of emotional distress were in the normative range [17]. The youth in the intervention and standard care conditions were similar in socio-demographic characteristics, school enrollment, emotional distress, sexual and substance use risk acts, conduct problems, self-esteem, and family-related life stressors.

Most PLH were Latino and African-American mothers with a mean age of 38.1 years (SD, 5.6; range, 25–70).
Some households included an adult partner (27.7%); 21% included a parent of the PLH or other relatives. Similar to the adolescents, the PLH in each condition were very similar at recruitment in their socio-demographic characteristics, physical health status, emotional distress, sexual and substance use risk behaviors and on each outcome measure.

**Intervention effectiveness**

**Adolescents**

Over 4 years, teenage parenthood was significantly more common among adolescents in the standard care condition (33.7%; n = 60) compared with the intervention condition (24%; n = 42; \( \chi^2 = 4.09; P = 0.04 \)), controlling for parenthood at recruitment.

Table 2 reports the adjusted mean scores and effect sizes for each significant outcome at 3 months following recruitment in the intervention and standard care condition for adolescents and PLH. Because the focus of these analyses was on change over time, we present the adjusted mean scores for the time periods at which a knot occurred, as well as at the 36- and 48-month follow-up assessments. As shown on Figures 2 and 3 and in our previous analysis of these data, the adolescents in the standard care condition increased problem behaviors from 3–21 months (slope, \( 0.0112 \)), whereas the problem behaviors decreased in the intervention condition (slope, \( -0.0292 \)), a significant difference \( [P = 0.0001; \text{effect size (ES)} = -0.4294] \). However, from 21–48 months problem behaviors increased among adolescents in the intervention condition (slope, \( 0.0295 \)), a rate that tended to be lower \( (P = 0.0748; \text{ES} = 0.2275) \) than the standard care condition (slope, \( 0.0068 \)).

Conduct problems showed a similar pattern: from 3–21 months, the intervention condition decreased significantly more in conduct problems (slope, \( -0.0381 \); \( P = 0.0013 \)) than in the standard care condition.

### Table 1. Characteristics comparing parents and adolescents at the baseline assessment among those randomized to the intervention and standard care conditions.

<table>
<thead>
<tr>
<th></th>
<th>Parents</th>
<th>Adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Standard care</td>
<td>Intervention</td>
</tr>
<tr>
<td></td>
<td>(n = 154)</td>
<td>(n = 153)</td>
</tr>
<tr>
<td>Male</td>
<td>19%</td>
<td>20%</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>37.99 (5.91)</td>
<td>38.12 (5.34)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>36%</td>
<td>33%</td>
</tr>
<tr>
<td>Latino</td>
<td>43%</td>
<td>47%</td>
</tr>
<tr>
<td>White</td>
<td>10%</td>
<td>12%</td>
</tr>
<tr>
<td>Other</td>
<td>12%</td>
<td>8%</td>
</tr>
<tr>
<td>Lifetime substance use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Injecting drug use</td>
<td>41%</td>
<td>33%</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>79%</td>
<td>83%</td>
</tr>
<tr>
<td>Any drug use</td>
<td>77%</td>
<td>78%</td>
</tr>
<tr>
<td>Current substance use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abstinent alcohol and drugs</td>
<td>63%</td>
<td>60%</td>
</tr>
<tr>
<td>Injecting drug use</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>Mean no. drugs used (SD)</td>
<td>0.36 (0.74)</td>
<td>0.35 (0.73)</td>
</tr>
<tr>
<td>Lifetime sexual behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median no. sex partners</td>
<td>7</td>
<td>7.5</td>
</tr>
<tr>
<td>Abstinent</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Among active</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median no. sex partners</td>
<td>7</td>
<td>7.5</td>
</tr>
<tr>
<td>Current sexual behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abstinent</td>
<td>60%</td>
<td>54%</td>
</tr>
<tr>
<td>Mean no. sex partners (SD) (active)</td>
<td>1.31 (1.85)</td>
<td>1.22 (1.14)</td>
</tr>
<tr>
<td>100% condom use (active)</td>
<td>59%</td>
<td>65%</td>
</tr>
<tr>
<td>Brief symptom inventory (SD)</td>
<td>0.97 (0.77)</td>
<td>1.03 (0.70)</td>
</tr>
<tr>
<td>Multiple problem behaviors</td>
<td>0.69 (0.84)</td>
<td>0.76 (0.93)</td>
</tr>
<tr>
<td>Rosenberg self-esteem</td>
<td>3.05 (0.49)</td>
<td>3.02 (0.45)</td>
</tr>
<tr>
<td>Family life events</td>
<td>1.21 (1.66)</td>
<td>1.46 (1.62)</td>
</tr>
<tr>
<td>Diagnostic status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>16%</td>
<td>20%</td>
</tr>
<tr>
<td>Symptomatic</td>
<td>44%</td>
<td>40%</td>
</tr>
<tr>
<td>AIDS</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>Mean no. physical health symptoms (SD)</td>
<td>14.27 (5.60)</td>
<td>14.52 (5.74)</td>
</tr>
<tr>
<td>Mean no. health distress (SD)</td>
<td>2.85 (1.02)</td>
<td>2.86 (1.03)</td>
</tr>
<tr>
<td>Attend school currently</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct problems</td>
<td>87%</td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>1.69 (2.07)</td>
<td>1.56 (1.93)</td>
</tr>
</tbody>
</table>

\( ^* P < 0.05. \)
(slope, 0.009; ES = −0.3526). However, conduct problems tended to increase more from 21–48 months in the intervention condition (slope, 0.0127) relative to the standard care condition (slope, −0.0011; P = 0.0948; ES = 0.1657). Over 4 years, the area under the curve tended to be less in the intervention condition compared to the standard care condition (P = 0.066).

Emotional distress decreased significantly from months 3–15 for the intervention condition relative to the standard care condition (slope, −0.0545 versus −0.0263; P = 0.0361; ES = −0.2002). However, there was no difference in the rate of change for the intervention and standard care groups from 15–48 months (slopes, −0.0036 versus −0.0064; P = 0.6135; ES = 0.1462).

Self-esteem increased significantly in the intervention condition compared to the standard care from 3–24 months (slopes, 0.0255 versus 0.0112; P = 0.0227; ES = 0.2228), but there was no difference in the rate of change or in the self-esteem scores reported at 48 months between the intervention and standard care condition (slopes, 0.0049 versus 0.0061; P = 0.8422; ES = 0.2835).

Negative family life events decreased significantly more in the intervention compared to the standard care condition from 3–21 months (slopes, −0.0465 versus −0.0183; P = 0.0039), but the rate of change in life events was similar from 21–48 months (slopes, 0.0031 versus −0.0091; P = 0.1653; ES = 0.0989).

### Parents

Controlling for baseline drug dependency (13.1%, standard care; 8%, intervention), significantly more PLH in the standard care condition reported drug dependency over 48 months than in the intervention condition (P = 0.03). Among those not drug dependent at recruitment, 4.5% of parents in the standard care condition were dependent 4 years later, compared to 2.45% in the intervention condition. Among those dependent on drugs at recruitment, 29% of parents in the standard care condition and 13.9% in the intervention condition were drug dependent 4 years later.
Adolescent BSI global scores

Parent BSI global scores

Parent positive action

Parent social support

Parent passive problem solving

Fig. 2. Plots of estimated adjusted means over 48 months for adolescents. BSI, Brief Symptom Inventory.

Fig. 3. Plots of estimated adjusted means over 48 months for parents. BSI, Brief Symptom Inventory.
Controlling for baseline level of substance use (37% standard care; 40% intervention), PLH in the intervention group also tended to relapse into substance use significantly less often (P = 0.09) if parents were abstinent at recruitment, 37.66% relapsed in the standard care condition and 31.17% relapsed in the intervention condition. Among parents who were substance abusing at recruitment 92.6% of parents relapsed in the standard care condition and 80% relapsed in the intervention condition).

From months 3–21, parents in the intervention condition reported significantly fewer problem behaviors (slope, 0.0226; P = 0.027; ES = −0.2738). However, from months 21 to 48, problem behaviors increased in the intervention condition (slope = 0.0099) compared to the standard care condition (slope = 0.0036; P = 0.4157; ES = −0.1518). Although the intervention effects did not persist, the area under the curve tended to be significantly less for parents in the intervention condition over 4 years compared to those in the standard care condition (P = 0.06).

Emotional distress decreased significantly from 3–15 months in the intervention condition compared to the standard care condition (slopes, −0.0644 versus 0.0132; P = 0.002; ES = −0.4037). However, the slopes were similar from 15–24 months (slopes, −0.0557 versus −0.0719; P = 0.5993; ES = 0.3406) and from 24–48 months (slopes, −0.0016 versus −0.0024; P = 0.9564; ES = −0.3326).

The rate of change in coping styles was consistent from months 3–48. Positive action coping was higher in the intervention condition compared to the standard care condition from 3–18 months (slopes, −0.0574 versus −0.0329; ES = 0.1188). However, from 21–48 months, positive action coping increased significantly more in the standard care condition compared to the intervention condition (slopes, 0.0039 versus 0.0399; ES = 0.4676) and was significantly higher at 48 months (P = 0.0191) in the standard care condition. Social support coping decreased significantly among parents in both the intervention and standard care conditions over 48 months, but tended to be higher among intervention condition parents (slopes, −0.0336 versus −0.0161; P = 0.0536). Passively solving problems was significantly less common at 48 months and decreased more among parents in the intervention condition compared to the standard care condition from 3 to 48 months (slopes, −0.0277 versus −0.0060; P = 0.0297). There were no significant differences in disclosure or custody over 48 months.

**Discussion**

When a parent is infected with HIV, their family is influenced in a fundamental and long-term fashion [21], reflecting pervasive impact of HIV on society. A small group cognitive-behavioral intervention substantially improves parent and adolescent functioning over 2 years and gains remain in several important areas. However, relapse is also observed.

From 24–48 months following the recruitment, the intervention has a positive impact that continues for both adolescents and their parents in several areas. First, fewer adolescents become teenage parents, reducing the substantial societal costs of caring for the babies of teenage parents. Second, intervention parents are less likely to report alcohol and drug dependency and tend to relapse less often than parents in the standard care condition. Because of the negative impact of parents’ substance abuse on children [22], this is an important improvement. Third, intervention parents report using a passive-withdrawal style of coping significantly less often, not only helping parents, but also providing more positive models of coping for their adolescent children. Finally, parents and adolescents tend to report fewer conduct and problem behaviors over 4 years.

While these outcomes are important, relapse also is found. We previously observed substantial and significant reductions in the rate of conduct problems, multiple problem behaviors, and emotional distress over 2 years for parents and adolescents [5]. These benefits slowly erode from 24–48 months. In addition, benefits found at 2 years in adolescents’ higher self-esteem and fewer negative family events and parents’ adoption of coping styles of taking positive actions and seeking social support have eroded.

Current HIV programs typically adopt an ‘immunization’ model: a packaged intervention is delivered and the effects are examined over time. Programs must be redesigned to ensure strategies for maintenance of the impact of an intervention over the long term, particularly since parents’ lives have been extended and families are now coping with a chronic illness over the long term [23]. Sessions that teach skills to deal with relapse incidents are not successful in achieving long-term behavioral maintenance of emotional disorders or problem behaviors. While packaged interventions provide graduation and a sense of accomplishment, interventionists must plan for ongoing support, in order to sustain the effects over time as a standard aspect of intervention delivery.

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