Six-Year Intervention Outcomes for Adolescent Children of Parents With the Human Immunodeficiency Virus

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Hypothesis: Having a parent with the human immunodeficiency virus has a significant negative impact on an adolescent child’s adjustment.

Objective: To assess the adjustment of adolescent children to having a parent with the human immunodeficiency virus over 6 years, following the delivery of a coping skills intervention.

Design: A randomized controlled trial with repeated evaluations that was analyzed with an intention-to-treat analysis. A skill-based intervention was delivered in 3 modules over 24 sessions, with the third module being delivered only if parents died.

Setting and Patients: A representative sample of parents with the human immunodeficiency virus (n=307) and their adolescent children (n=423) was recruited from the Division of AIDS Services in New York City; 51.5% (n=158) of the parents died.

Main Outcome Measures: Employment and school enrollment, receiving public welfare support, early parenthood, mental health symptoms, and the quality of romantic relationships.

Results: Over 6 years, significantly more adolescents in the intervention condition than the control condition were employed or in school (82.58% vs 68.94%), were less likely to receive public welfare payments (25.66% vs 36.65%), were less likely to have psychosomatic symptoms (mean, 0.24 vs 0.31), were more likely to report better problem-solving and conflict resolution skills in their romantic relationships (mean score, 4.38 vs 4.20), expected to have a partner with a good job (mean, 4.57 vs 4.19), and expected to be married when parenting (mean, 3.05 vs 2.40). With marginal significance, the percentage of parents in the intervention condition (34.6%) was less than in the control condition (44.1%).

Conclusion: Physicians must consider the psychosocial consequences of illness-related challenges on children and provide interventions.

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When parents have a chronic or terminal illness, their children face many challenges. In particular, adolescent children often assume responsibility for household tasks, care for younger siblings, and provide emotional support for their parents at the expense of their own developmental needs. If a parent dies, children lose their most important bond and face various long-term stressors and adjustment problems. Parental death is considered the most difficult developmental challenge for children. This article describes the results of an intervention to mitigate the negative outcomes of parental illness on adolescent children of parents with the human immunodeficiency virus (HIV) over 6 years.

In the United States, about 125000 children have been bereaved by parental HIV,9 with about 15000 parents dying annually. Simultaneously, more children are living with a parent with HIV, because highly active antiretroviral therapies have substantially expanded the quality and lifespan of persons with HIV. At least 750000 children are coping with HIV in the United States, and their families are likely to be headed by single parents living in East Coast inner cities who are African American or Latino. In addition to HIV-related stigma, a family’s low income, ethnic minority status, and previous drug use are likely to increase the negative impact on adolescent children living with a chronically ill parent with HIV.

Given these stressors, a coping skills intervention was designed and evaluated in a randomized controlled trial for par-
ents with HIV and their adolescent children. There were significant benefits for the families over 4 years.15-17 Parents decreased their emotional distress and problem behaviors over 2 years, and they were also less likely to relapse into substance abuse or to become dependent over 4 years. Their adolescent children reported less emotional distress and fewer problem behaviors over 2 years. At 4 years, the youth were less likely to have children and were more likely to make use of positive coping styles. These benefits were substantial, leading us to examine the intervention outcomes at 6 years.

In early adulthood, the primary developmental tasks are to establish intimate relationships, make parenting decisions, and become employed.18 Therefore, to examine the intervention’s outcome at 6 years, we focused on these developmental outcomes and on indicators of positive adjustment on social, behavioral, and mental health outcomes for the young people.

The intervention was based on a cognitive-behavioral skill-building model, and was delivered in small facilitated groups, similar to other successful HIV-related interventions for adolescents.19 The intervention was delivered in 3 modules. Each module addressed either parental or adolescent tasks related to the parents’ phase of illness (eg, coping with negative emotions, planning for the future, or reducing risk acts).

METHODS

PARTICIPANTS

A representative sample of 71.6% (307/429) of parents with HIV and adolescent children (aged 11-21 years) was recruited from New York City’s Division of AIDS Services. Of the 429 eligible parents, 307 were recruited: 65 (15.2%) were untraceable, 46 (10.7%) refused to participate, and 11 (2.6%) were severely ill or incarcerated and were not recruited. With institutional review board approval and informed consent, permission to recruit adolescents was obtained from parents with HIV and then from their adolescent children. From 307 parents with HIV, 423 adolescents were eligible for participation (mean per family, 1.35; SD, 0.7; range, 1-24 sessions). During the study, 28 of these youth reached the age of 11 years and became eligible for participation, but had not been followed up for 6 years at the termination of the study. Thus, 395 adolescents were eligible for the 6-year follow-up.

As shown in the Figure, families (parents with HIV and all their adolescent children) were randomly assigned to the coping skills intervention condition or the control condition. Over 6 years, 158 (51.5%) of the parents with HIV died. The number of deaths did not significantly (P = .76) differ by condition.

Retention was high during the 6-year follow-up (Figure). For adolescents in the intervention condition, the annual re-evaluation rate ranged from 84.6% to 94.7%; the rates in the control condition ranged from 81.5% to 93.8%. While parents were not assessed after the 5-year follow-up, the reassessment rates were similarly high. The rates over 3 years ranged from 74.0% to 93.9% in the intervention and control conditions. Of the 395 adolescents eligible for the 6-year follow-up, 317 (80.3%) were assessed at 6 years, similar across the intervention and control conditions.

CONTROL CONDITION

Families in the control condition were given access to a broad range of services based on need to parents with HIV and their children, including rent subsidies, home care, child care, food banks, mental health services, and medical care. Each parent with HIV was assigned to a social worker who functioned as a case manager.

INTERVENTION: PROJECT TEENS AND ADULTS LEARNING TO COMMUNICATE

Focus groups, pilot work, and previous research informed the intervention design, which was based on social learning theory and cognitive-behavioral principles.20 A detailed manual contained the specific goals, activities, and scripts for each session (available at: http://chipts.ucla.edu).

In module 1, parents with HIV met together for 8 sessions and focused on adapting to their HIV status, maintaining healthy lifestyles, coping with negative feelings related to their diagnoses, and making decisions about disclosing their status to others. In module 2, parents with HIV and their adolescent children were invited to attend 16 sessions; some sessions were joint and others separate for parents and adolescents. For the parents with HIV, module 2 aimed to reduce their emotional distress and help them maintain positive family routines, assist their children with avoiding high-risk behaviors, and make custody plans for their children. For adolescents, module 2 aimed to improve coping with their parent’s diagnosis and possible death and learning skills to reduce high-risk behaviors (sexual acts, substance use acts, and teenage pregnancy) and emotional distress. If their parent died, adolescents in the intervention condition were invited to attend 16 sessions in module 3. The new guardian was also invited to attend, with the content focused on having a positive youth-guardian relationship and setting new life goals.

INTERVENTION DELIVERY

Quality assurance ratings were conducted on 10% of videotaped intervention settings to ensure high fidelity of the intervention delivery. Process ratings completed after each session indicated high levels of trust and cohesion among the groups.

Among the 153 parents with HIV randomized to the intervention condition, 27 were ineligible to attend the intervention because they died, were too ill, or were in jail soon after randomization. Sixty-three parents with HIV died during the next 2 years, the delivery period for modules 1 and 2. Of the 126 parents with HIV able to attend any of the modules, 95 (75.4%) attended sessions. Attendance at the intervention was lowest among fathers (9 of 30 attended) and mothers who spoke only Spanish (2 of 13 attended) compared with other parents. Parents with HIV attended a mean of 15.2 sessions (SD, 7.7 sessions; range, 1-24 sessions).

For adolescents to attend module 2 of the intervention, parents had to disclose their serostatus to the adolescent and to be in relatively good health. There were 97 ineligible adolescents for the module 2 intervention because their parent died, was too sick, was in jail, never disclosed his or her serostatus, or never attended a session. In addition, 12 adolescents aged into the study over time and had not been enrolled 6 years when data collection halted, totaling 109 ineligible adolescents. Of the 103 eligible adolescents, 84 (81.6%) attended the intervention of module 2. There were 100 adolescents eligible for module 3; 70 had guardians, 2 became guardians for siblings, and 28 lived independently. Of the eligible adolescents, 56 (36.0%) attended module 3; 26 (55.3%) of the 47 caregivers also attended.

Although there were many reasons for nonattendance, the adherence rates of attendees were high. Among the parents with HIV who attended at least one session of module 1, the mean number of sessions attended was 5.8 of a potential 8 sessions. Among the parents with HIV who attended at least one session of module 2, parents with HIV attended a mean of 11.7 of
a potential 16 sessions and adolescents attended 10.3 of a potential 16 sessions. Module 3 was attended for a mean of 10.3 of a potential 16 sessions.

**SURVEY PROCEDURES**

A baseline interview was conducted with each parent with HIV and each adolescent as soon as possible after recruitment, and randomization occurred at the conclusion of the baseline interview. Each participant interview took approximately 1 1/2 to 2 hours to complete. Follow-up interviews were conducted every 3 months for the first 2 years of the study and every 6 months thereafter, with annual reassessments for more than 80% of the participants. This report focuses on the youth’s status 6 years following recruitment. Adolescents received $25 per interview.

All assessments were conducted in participants' homes or the research office by a 2-person interview team using laptop computers. Interviewers received a minimum of 18 hours of training in conducting standardized interviews, ethics, confidentiality, HIV/AIDS, and emergency procedures. Approximately 60% of the interviewers were African American or Hispanic, and 30% were bilingual in Spanish. Survey questions were read to participants in English or Spanish (based on participant choice) and were audiotaped for quality assurance (10% were randomly selected for monitoring).

**ASSESSMENTS**

As part of the baseline interview, information was collected on background characteristics, including sex, age, living situation, socioeconomic status, and HIV diagnostic and health status. The following outcome measures were collected at each adolescent assessment.

1. Parental death. Parent’s date of death was recorded by routinely contacting the family and monitoring state records of death.
2. Employment or school attendance. Youth reported their attendance at school or on a job over the past 6 months. For those enrolled in school, youth reported their year of school attended, including year of college.
3. Public welfare. The prevalence of youth receiving any type of public assistance (including food stamps) was reported over the past 6 months.
4. Romantic relationships. Youth reported either the presence (1) or absence (0) of a primary romantic partner.

5. Quality of primary romantic relationship. For youth reporting a current romantic partner, the frequency of social support (emotional and material) and couple conflict (major and minor disagreements) experienced within the relationship was reported for the prior 6 months on a 4-item scale. Responses ranged from 1 (not at all) to 5 (once a day or more).

6. Conflict and problem solving. For those youth reporting a current romantic partner, the level of conflict regarding common challenges such as decision making, handling money, and alcohol or other drug use during the previous 6 months was reported on a 1 (not at all) to 5 (great deal) scale of 9 items. Internal consistency (α = .86) and reliability (r = .90) have been reported previously for this scale.²¹

7. Personal expectations. On an 11-item inventory adapted from Mcloyd and Hernandez Jozefowitz, youth rated their future expectations regarding financial security and family life on a scale of 1 (not very likely) to 6 (very likely). Three subscales were generated: overall expectations, expectations for finding a partner or spouse with a good job, and the likelihood of pregnancy or parenthood outside of marriage.

8. Parenthood. The number of youth who became parents and the mean number of children were reported.

9. Texas Grief Inventory. This 13-item inventory assessed the intensity and nature of grief reactions. This inventory has a reported reliability coefficient of 0.81.

10. Somatic symptoms. The Somasick Scale, a 17-item scale developed to assess the frequency of physical symptoms reported in the prior 6 months on a scale from 0 (never) to 2 (often), was completed. High scores on the Somasick Scale have shown strong and significant correlation with functional impairment and psychiatric disorder.²⁵

11. Emotional distress. Youth completed the Brief Symptom Inventory, a 53-item survey that yielded a global severity index (α = .90) and subscales of depression (α = .85) and anxiety (α = .81). Participants rated the level of severity for each symptom during the previous week on a scale from 0 (not at all) to 4 (extremely).

12. Smoking, alcohol, and other drug use. Young people reported their use (1) or not (0) of tobacco, marijuana, alcohol (>5 drinks), or other drugs, and the number of different drugs used was recorded.

13. The number of recent sexual partners and casual partners was reported.

14. Institutionalization. Youth reported whether (1) or not (0) they had lived within an institutional setting (jail or detention center, group home or other foster care institution, shelter, or on the streets) over the past 6 years.

**DATA ANALYSIS**

An intent-to-treat analysis was conducted to examine the differences of outcome variables between the intervention and control conditions for young people at 6 years, including examination of the impact of parental death and the effect of an intervention × parental death interaction. There were no significant differences based on parental death for any outcome and no significant interaction effects; therefore, these are not reported. To adjust for clustering of multiple adolescents in some families, we used generalized estimating equation methods for the analysis. In this generalized linear model approach, binomial distribution was used for the binary outcomes and Poisson distribution was assumed for the count variables.

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**RESULTS**

**SAMPLE CHARACTERISTICS AND BALANCE AT RECRUITMENT**

About half of the adolescents were female. The mean age of the adolescents at recruitment was 14.83 years (SD,
2.02 years; range, 11-21 years); at the 6-year assessment, their mean age was 20.9 years. At recruitment, almost all the adolescents were in school and only about half had experienced their sexual debut. About half had used alcohol by recruitment, while about two thirds reported never using other drugs. At recruitment, 7.1% of those in the intervention condition were parents. Their scores on emotional distress were comparable to adolescent norms for the general population.27 As shown in Table 1, the young people in the intervention and control conditions at recruitment were highly similar across sociodemographic characteristics and among outcomes examined (school enrollment, emotional distress, and sexual and substance use risk acts).

Although parents with HIV are not the focus of this report, it is important to describe the youths’ families. Most parents with HIV were Latino or African American mothers. There was a large variation in parental ages, from 25 to 70 years (mean age, 38.1 years; SD, 5.6 years). About half (54.0%) of the parents with HIV had graduated from high school. Almost all households (93.7%) included children living in the home, while the remainder had children who were temporarily in foster care placements, group homes, or incarcerated; about one quarter of the households (26.7%) included an adult partner, 10.6% included a parent of the parent with HIV, and 9.9% included other relatives.

As with the adolescents, the parents with HIV in each condition were similar in sociodemographic characteristics, physical health status, emotional distress, and sexual and substance use risk behaviors at the baseline assessment.13 There were no differences in the measures used to assess the intervention outcome, and their tendency to give socially desirable answers was similar.

**INTERVENTION EFFECTIVENESS**

Table 2 summarizes the mean scores on each measure for young people in the intervention and control conditions. At 6 years, youth in the intervention condition were significantly more likely to be in school or employed and were less likely to receive public assistance in the past 6 months. Intervention youth also reported more positive expectations for their future life goals.

There were no significant differences on the Texas Grief Inventory or the Brief Symptom Inventory; however, the mean number of somatic symptoms was significantly lower for youth in the intervention compared with the control condition.15

Most young people (69.3%) reported having a romantic relationship, with similar levels for those in the

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**Table 2. Developmental, Social, Mental Health, and Behavioral Outcomes at 6 Years Among Young People in the Intervention and Control Conditions**

<table>
<thead>
<tr>
<th>Adolescent Outcomes</th>
<th>Intervention Youth (n = 156)*</th>
<th>Control Youth (n = 161)*</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), y</td>
<td>20.84 (2.19)</td>
<td>20.94 (1.90)</td>
<td>-0.11 (-0.57 to 0.35)†</td>
</tr>
<tr>
<td>Study parent deceased</td>
<td>43.2</td>
<td>46.0</td>
<td>0.88 (0.52 to 1.49)‡</td>
</tr>
<tr>
<td>Any parent deceased</td>
<td>60.0</td>
<td>68.5</td>
<td>0.78 (0.45 to 1.34)‡</td>
</tr>
<tr>
<td>In school or employed</td>
<td>82.6</td>
<td>68.9</td>
<td>2.17 (1.24 to 3.78)‡</td>
</tr>
<tr>
<td>Employed during the past 6 mo</td>
<td>69.9</td>
<td>60.9</td>
<td>1.50 (0.92 to 2.45)‡</td>
</tr>
<tr>
<td>Receiving public welfare during the past 6 mo</td>
<td>25.7</td>
<td>36.6</td>
<td>0.56 (0.34 to 0.83)‡</td>
</tr>
<tr>
<td>Personal expectations score, mean (SD)</td>
<td>4.63 (0.82)</td>
<td>4.43 (0.83)</td>
<td>0.19 (0.004 to 0.38)†</td>
</tr>
<tr>
<td>Has a primary romantic relationship</td>
<td>71.0</td>
<td>67.7</td>
<td>1.15 (0.69 to 1.89)‡</td>
</tr>
<tr>
<td>Quality of primary relationship score, mean (SD)</td>
<td>3.55 (0.65)</td>
<td>3.39 (0.65)</td>
<td>0.16 (-0.01 to 0.33)‡</td>
</tr>
<tr>
<td>Conflict and problem-solving score, mean (SD)</td>
<td>4.38 (0.60)</td>
<td>4.20 (0.67)</td>
<td>0.19 (0.01 to 0.36)‡</td>
</tr>
<tr>
<td>Expects to have a partner with a good job, mean (SD)</td>
<td>4.57 (1.63)</td>
<td>4.19 (1.72)</td>
<td>0.39 (0.01 to 0.77)‡</td>
</tr>
<tr>
<td>Expects to not be pregnant without marriage score, mean (SD)</td>
<td>3.05 (2.12)</td>
<td>2.40 (1.83)</td>
<td>0.65 (0.21 to 0.99)‡</td>
</tr>
<tr>
<td>Is a parent</td>
<td>34.6</td>
<td>44.1</td>
<td>0.67 (0.43 to 1.06)‡</td>
</tr>
<tr>
<td>No. of babies, mean (SD)</td>
<td>1.44 (0.69)</td>
<td>1.28 (0.51)</td>
<td>1.13 (0.96 to 1.32)‡</td>
</tr>
<tr>
<td>Texas Brief Inventory score, mean (SD)</td>
<td>3.86 (0.96)</td>
<td>3.74 (0.99)</td>
<td>0.11 (-0.20 to 0.42)‡</td>
</tr>
<tr>
<td>Somatic symptom score, mean (SD)</td>
<td>0.24 (0.23)</td>
<td>0.31 (0.22)</td>
<td>-0.07 (-0.13 to -0.01)‡</td>
</tr>
<tr>
<td>Overall Brief Symptom Inventory score, mean (SD)</td>
<td>0.44 (0.58)</td>
<td>0.41 (0.45)</td>
<td>0.03 (-0.09 to 0.14)‡</td>
</tr>
<tr>
<td>Smoked ≥100 cigarettes (lifetime)</td>
<td>49.5</td>
<td>48.0</td>
<td>1.05 (0.60 to 1.85)‡</td>
</tr>
<tr>
<td>Quit smoking for ≥1 d during the past 12 mo</td>
<td>80.8</td>
<td>63.3</td>
<td>2.41 (0.95 to 6.11)‡</td>
</tr>
<tr>
<td>Had ≥1 alcoholic drink during the past 30 d</td>
<td>48.4</td>
<td>57.4</td>
<td>0.69 (0.40 to 1.21)‡</td>
</tr>
<tr>
<td>Had alcohol during the past 30 d, mean (SD), d</td>
<td>2.09 (2.96)</td>
<td>4.54 (4.92)</td>
<td>-1.60 (-3.08 to -0.12)‡</td>
</tr>
<tr>
<td>Had ≥5 alcoholic drinks during the past 30 d, mean (SD)</td>
<td>0.57 (1.24)</td>
<td>1.12 (2.03)</td>
<td>-0.63 (-1.30 to 0.03)‡</td>
</tr>
<tr>
<td>Marijuana use</td>
<td>25.2</td>
<td>29.8</td>
<td>0.37 (0.49 to 1.29)‡</td>
</tr>
<tr>
<td>Hard drug use</td>
<td>6.4</td>
<td>5.6</td>
<td>1.16 (0.46 to 2.97)‡</td>
</tr>
<tr>
<td>No. of drugs used, mean (SD)</td>
<td>0.32 (0.58)</td>
<td>0.37 (0.59)</td>
<td>-0.04 (-0.17 to 0.08)‡</td>
</tr>
<tr>
<td>Sexually active adolescents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of sexual partners, mean (SD)</td>
<td>1.31 (0.94)</td>
<td>1.42 (1.92)</td>
<td>-0.11 (-0.51 to 0.30)†</td>
</tr>
<tr>
<td>Those with casual partners</td>
<td>17.0</td>
<td>20.2</td>
<td>0.89 (0.48 to 1.67)‡</td>
</tr>
<tr>
<td>Institutionalization at 6 y</td>
<td>6.4</td>
<td>6.8</td>
<td>0.85 (0.32 to 2.23)‡</td>
</tr>
<tr>
<td>6-y Cumulative prevalence of institutionalization</td>
<td>24.4</td>
<td>26.1</td>
<td>0.90 (0.52 to 1.55)‡</td>
</tr>
</tbody>
</table>

*Data are given as percentage of each group unless otherwise indicated.
†Data are given as mean difference (95% confidence interval).
‡Data are given as estimated risk ratio (95% confidence interval).
intervention and control conditions. Intervention youth tended to report the quality of their relationship as better and had significantly more effective conflict and problem-solving scores using the Kering measure. Young people in the intervention condition were significantly more likely to expect their partner to have a good job and believed they were less likely to become pregnant without being married. With marginal significance, intervention youth tended to be parents less frequently than control youth. Among young people who were parents, the mean number of children was similar across conditions. The mean number of recent sexual partners and the prevalence of casual sexual partners were similar for young people in the intervention and control conditions.

Almost half of the youth in each condition smoked cigarettes. Among smokers, those in the intervention condition tended to be more likely to quit smoking for more than a day in the past 12 months. Intervention youth also drank alcohol on significantly fewer days and were less likely to have 5 or more alcoholic drinks in the past month compared with youth in the control condition. Other drug use and the mean number of drugs used were similar across the conditions, as was the 6-year cumulative rate of institutionalization.

COMMENT

Few studies have examined intervention effects over a long period. When examined, there are often unanticipated intervention benefits that result in domains not initially addressed in the intervention. In the current evaluation, there were significant improvements in the developmental tasks of early adulthood, even though some of these outcomes were not directly addressed in the intervention program delivered years earlier.

There seem to be “sleeper” effects of interventions that cannot be easily explained using current theoretical models. For example, the intervention condition resulted in significant improvements in several outcomes that cost society a great deal: higher rates of employment and fewer welfare payments. These results were unexpected when the intervention was designed. Yet, these societal benefits demonstrate the importance of providing interventions to young people facing significant family challenges, such as coping with parental HIV.

While most young people in the intervention and the control conditions tended to have romantic relationships (approximately 70%), the quality of the couple’s interactions, relationship problem-solving skills, and expectations of employment and skills of their romantic partners were higher for young people in the intervention condition. Fewer young people in the intervention condition tended to have babies, which may have helped their romantic relationships be more positive, because fewer young people anticipated that they would need public assistance to raise their children.

An intervention must stimulate synergistic effects that spiral over time in positive or negative directions. Accordingly, young people in the intervention reported fewer somatic symptoms and fewer risk behaviors, as reflected in alcohol use and smoking behavior. Cumula-

What This Study Adds

Previous HIV-preventive interventions have been targeted at those at risk of acquiring or those infected with HIV. There is little information on the children of HIV-infected parents or on strategies to improve the anticipated negative outcomes for these children.

Our data demonstrate the need to address the psychosocial challenges influencing parents with HIV and their adolescent children. Adolescents who were randomized to receive an intervention demonstrated better adjustment 6 years later at work, in school, and in their interpersonal relationships. The intervention provides a model for future psychosocial interventions to improve the outcomes for young people affected by HIV.