

# An Intervention for Parents With AIDS and Their Adolescent Children

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In the United States, increasing numbers of parents have AIDS,<sup>1,2</sup> and these individuals will either live with a chronic, life-threatening illness or they will die. Parents with AIDS must cope with physical health symptoms, complex medication regimens,<sup>3</sup> stigma,<sup>4</sup> and fear of AIDS-related death, as well as caring for their family.<sup>5,6</sup> Parents' ability to care for their family and their illness are likely to influence their children.<sup>7,8</sup> After living with an ill parent, about 80 000 children in the United States have been orphaned by AIDS<sup>1</sup> (internationally, 13 million)<sup>9</sup>; this reflects mortality rates similar to those associated with cancer or automobile accidents.<sup>10</sup>

Parental death reduces children's self-esteem and increases depression, anxiety, conduct disturbance, academic difficulty, somatic complaints, and suicidal acts over the long term.<sup>11</sup> To help adolescents and their parents cope with parental AIDS, we evaluated the efficacy of an intervention designed to improve behavioral, social, and mental health outcomes.

As with other successful HIV intervention programs,<sup>12</sup> social learning theory<sup>13</sup> directed the intervention design. Social learning theory provides a framework for how individuals change their behavior (i.e., in small steps as behaviors are rewarded over time and goals are articulated and defined), as well as specifying a set of factors that must be changed (skills, expectations of competence and efficacy, ability to express and control one's feelings).<sup>14</sup> On the basis of these principles, a 24-session intervention was designed to be delivered over 12 Saturdays in small groups.<sup>6,15</sup> The purpose of the intervention was to help parents with AIDS and their adolescents cope with illness-related tasks. Sessions were organized into 2 modules, with each module aimed at helping parents and youths cope with different illness-related challenges.

When parents are first diagnosed with AIDS (often at the same time they learn their

**Objectives.** This study evaluated an intervention designed to improve behavioral and mental health outcomes among adolescents and their parents with AIDS.

**Methods.** Parents with AIDS (n = 307) and their adolescent children (n = 412) were randomly assigned to an intensive intervention or a standard care control condition. Ninety-five percent of subjects were reassessed at least once annually over 2 years.

**Results.** Adolescents in the intensive intervention condition reported significantly lower levels of emotional distress, of multiple problem behaviors, of conduct problems, and of family-related stressors and higher levels of self-esteem than adolescents in the standard care condition. Parents with AIDS in the intervention condition also reported significantly lower levels of emotional distress and multiple problem behaviors. Coping style, levels of disclosure regarding serostatus, and formation of legal custody plans were similar across intervention conditions.

**Conclusions.** Interventions can reduce the long-term impact of parents' HIV status on themselves and their children. (*Am J Public Health.* 2001;91:1294-1302)

HIV serostatus),<sup>16</sup> they must decide whether and how to tell their children about their health status. Most parents disclose their HIV illness to their adolescents.<sup>17</sup> These adolescents must then cope with HIV-related stigmatization,<sup>4</sup> their grief concerning their parent's life-threatening illness, and their anxiety about their own welfare. Module 1 (8 sessions over 4 Saturdays) of the intervention addressed parents' issues of disclosure, emotional reactions to AIDS, and coping with stigma.

In 1994 (when data collection was initiated), individuals with AIDS lived about 14 months (New York City Human Resources Agency, Division of AIDS Services, unpublished data, 1993). Making custody-related plans was a challenge that parents faced about 6 months after being diagnosed with AIDS. Research has shown that children of parents with AIDS are at higher risk for long-term negative outcomes if their parents do not make custody plans.<sup>18</sup> Children bereaved by sudden, unexpected parental loss demonstrate more negative outcomes than children who have been prepared,<sup>19,20</sup> and the legal complications are greater.<sup>18</sup> In addition, seriously ill parents have difficulty maintaining positive daily routines, such as having family dinners. Module 2 addressed making custody plans, expressing love and affection, and

maintaining positive family routines with a very ill parent.

This report summarizes the efficacy of the intervention in terms of reducing behavioral, social, and mental health symptoms over 2 years among adolescents and their parents with AIDS.

## METHODS

### Participants

From August 1993 to March 1995, all financially needy persons with AIDS who requested services were logged at the Division of AIDS Services in New York City. From this log, 429 eligible parents with AIDS were identified: those who were alive during the recruitment period, were aged 25 to 70 years, had at least 1 adolescent child aged 11 to 18 years, were not institutionalized, and had the assent of their clinical social worker that study participation was appropriate. Among the 429 eligible parents with AIDS, 65 (15.2%) were untraceable, and 46 (10.7%) refused to participate. Extreme illness and incarceration resulted in an additional 11 (2.6%) not being recruited. Thus, 84% (n = 307) of the traceable parents with AIDS (71.6% of those eligible) were successfully recruited.

After parents had been recruited (with informed consent), their adolescent children were recruited with both parental and adolescent informed consent. There were 6 cases in which the adolescent child left the study owing to age (above 18 years) before delivery of the intervention; these adolescents were eliminated from the analysis. In some cases ( $n=25$ ), parents with AIDS temporarily did not have custody of their children, or the children refused to participate. Four hundred twelve adolescents were recruited (mean per family = 1.5,  $SD=0.7$ , range = 1–5).

At the time of the baseline interview, families (parents and all adolescent children) were randomly assigned to the intervention condition (153 parents with AIDS, 205 youths) or the control condition (154 parents with AIDS, 207 youths). Over the span of 2 years, 134 (43.6%) of the parents died. Similar numbers of parents in the intervention ( $n=62$ ) and standard care ( $n=52$ ) conditions died.

## Procedures

Two-person teams conducted 2-hour home interviews with the parents and all adolescents in the household. Similar to the participants, interviewers were predominantly African American or Latino (62%); 5 of 15 were bilingual in Spanish and English. Interviewers were certified after being trained in the areas of ethics, confidentiality (particularly of parents' serostatus), child abuse, crisis protocols, and HIV/AIDS. They were also trained in conducting in-home assessments on laptop computers. Quality assurance was maintained by audiotaping all interviews and routinely monitoring randomly selected tapes (an estimated 10% of interviews were monitored).

Parents and adolescents were assessed in individual interviews at 3-month intervals over 24 months, and subjects received \$25 for each interview (\$50 for parent and youth assessment). Follow-up rates were lowest during the first year (parents, 68.5%; youths, 66.5%) and improved with training during the second year of follow-up (parents, 85%; youths, 81.5%). Rates were similar in the intervention and control conditions for parents and youths at each assessment. Within each intervention condition, 95% of parents and youths were assessed at least once annually. Seventy-five percent of the subjects com-

pleted 5 of the 9 possible assessments, and 24% completed all 9 assessments.

## Assessments

Information on background characteristics, including sex, age, living situation, socioeconomic status, and HIV diagnostic status, was collected from participants at the baseline interview.

*Adolescent assessments.* Several measures were collected at each assessment point. The 53-item Brief Symptom Inventory<sup>21</sup> assessed symptoms of emotional distress. This instrument provides a global scale score ( $\alpha=0.96$ ) and includes anxiety ( $\alpha=0.79$ ) and depression ( $\alpha=0.76$ ) subscales. Participants reported degree of distress during the previous week in regard to each symptom on a scale ranging from 0 (not at all) to 4 (extremely).

A count of multiple problem behaviors<sup>22</sup> was calculated by summing the presence (1) or absence (0) of unprotected sexual intercourse, alcohol use, drug use, contact with the criminal justice system, trouble at school, and nonenrollment at school (potential score range: 0–5). A summary score for the presence of 18 conduct problems (e.g., stealing, fighting, vandalism) was also calculated ( $\alpha=0.61$ ).

Subjects completed the Rosenberg Self-Esteem Scale,<sup>23</sup> a 10-item measure validated and found reliable with normative samples of adolescents from many ethnic and age groups ( $\alpha=0.85$ ). Ten items indicating stressful family events (e.g., increased arguments between parents, mother absent from home;  $\alpha=0.57$ ) were summed.

*Parent assessments.* The Brief Symptom Inventory was also administered to parents (global,  $\alpha=0.97$ ; depression,  $\alpha=0.85$ ; anxiety,  $\alpha=0.84$ ). Parents reported degree of distress during the previous week for each symptom on a scale ranging from 1 (not at all) to 5 (extremely). An index of adult problem behaviors was calculated by summing the presence of unprotected sexual intercourse, alcohol use, drug use, and contact with the criminal justice system. School status was not included.

Five Coping with Illness Questionnaire<sup>24</sup> subscale scores (self-destructive escapism, passive problem solving, passive action, spiritual hope, and seeking social support) were calcu-

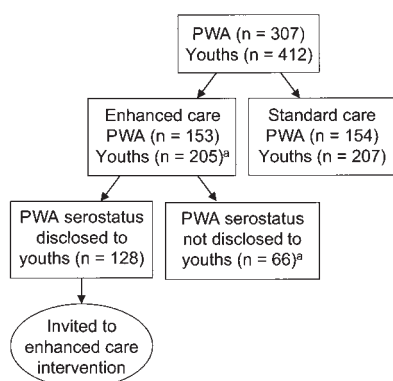
lated from 37 items rated on a 1-to-5 Likert scale. These scales had adequate alpha coefficients (ranging from 0.76 to 0.89) and eigenvalues (ranging from 2.12 to 7.94). Presence (1) or absence (0) of HIV disclosure to each adolescent and to all adolescents in the family was also calculated.

In regard to custody plans, parents provided, for each child, information on the following: (1) discussions with potential guardians about custody, (2) contacts with social service agencies, (3) wills and legal arrangements, and (4) legal standby custody agreements. (When reporting their custody plans for each child, parents of 8 adolescents failed to mention that their children were enrolled in the study. When parents failed to mention an adolescent in the interview, we presumed that no legal plan had been made. If the parent mentioned a legal custody plan at any assessment point over the 2 years and failed to mention the child and the plan again, it was presumed that the plan was still in place.)

## Intervention

On the basis of a qualitative study, pilot work, and previous intervention experience with persons living with HIV,<sup>6,25</sup> an extensive manual was written to guide delivery of the intervention (available at <http://chipts.ucla.edu>). The manual covered all activities and materials needed for each session and included sample scripts for each activity. The intervention was delivered by social workers and graduate students in clinical psychology who had completed an initial 5-day training program for each module and received ongoing supervision.<sup>26</sup> Training included didactic review of the session's goals, role-playing of each session with peers, and observations of pilot sessions.

Because AIDS was discussed in the intervention, only those adolescents to whom parents had disclosed their serostatus could attend (see Figure 1 for the design of the study). The intervention was delivered in 2 modules, the first module to parents alone (4 Saturdays) and the second module to both parents and adolescents (8 Saturdays). In module 2, each Saturday involved some time with parents meeting alone while their children met in separate groups, along with some time during which parents and youths were together in groups.



Note. PWA = parents with AIDS.

ªNo disclosure data for 11 youths.

**FIGURE 1—Study randomization design: New York City, 1993–1995.**

The groups typically met at a community center; transportation, breakfast, lunch, and child care were provided. Two sessions were held each Saturday, one 2-hour session in the morning and another 2-hour session in the afternoon (after lunch). Participants met in small groups of 8 to 10 parents or 8 to 10 adolescents, with up to 10 small-group meetings per Saturday.

Table 1 summarizes the content of each of the sessions in modules 1 and 2. The design of the intervention was based on social learning principles. Each session began with a review of behavioral successes over the previous week, after which new material was introduced, skills were practiced, and new goals were set. To facilitate skill acquisition, each group member's compliments to others were accompanied with tokens (small pieces of construction paper). A "feeling thermometer" was also routinely used within the group to assist parents and youths in recognizing their affective states and learning emotional self-control of these states. Because goal setting and problem solving were common across sessions, a method of charting problems over time was used.

In module 1, parents focused on their adaptation to positive HIV serostatus, learned to cope with negative affect related to their health status, made decisions regarding disclosure, and formulated a plan for helping their children cope with the diagnosis. In module 2, parents focused on initiat-

ing custody plans, reducing risk behaviors, and creating and maintaining positive family routines while ill. Module 2 adolescent intervention sessions focused on youths' adaptation to their parents' illness, improving parent–youth relationships, and reducing youths' risk acts.

For each content area, parents and adolescents engaged in activities designed to help them identify how HIV had influenced their social identity, social role (e.g., role as a woman or man), rules for acceptable behavior (e.g., regarding conflict resolution), and daily behavioral routines. Because time to death was much longer than expected, parents could attend makeup intervention sessions.

Of the 153 parents with AIDS who were randomized to the intervention, 27 were ineligible to attend (22 died before delivery of the intervention, and 5 were unavailable

because of illness or incarceration). Fourteen refused to attend the intervention, and 17 did not attend for other reasons; all of these individuals were either Spanish-speaking mothers (85% nonattendance rate; only 2 of 13 Spanish-speaking parents attended) or fathers (70% nonattendance rate; 9 of 30 attended). Thus, 95 of 126 eligible parents with AIDS (75.4%) who were randomized to the intervention attended at least 1 of the 24 intervention sessions. Parents who attended at least 1 session attended a mean of 17.2 sessions (SD = 11.8, median = 16).

The 153 parents randomized to the intervention had a total of 205 adolescent children. Of these adolescents, 87 were ineligible for one of the following reasons: death of parent (n = 22), parent nonattendance (n = 51), unavailability of parent owing to institutionalization (n = 6), or parent nondisclo-

**TABLE 1—Session Content of Modules 1 and 2 of the Intervention**

Session	Parent Topic	Youth Topic
<b>Module 1: Coping with illness, disclosure</b>		
1	Coping with illness	
2	Coping with fear	
3	Coping with anger	
4	Coping with sadness	
5	Coping with meaning of illness	
6	Deciding to disclose	
7	Disclosing	
8	Planning for the future	
<b>Module 2: Planning a legacy</b>		
1	Awareness of my children's needs	Making sense of my parent's illness
2	Caring for my children	Disclosure of parent with AIDS
3	Making custody arrangements	Dealing with stigma
4	Starting my custody plan	Dealing with fear
5	Listening to my children	Coping with sad feelings
6	Sharing with my children	Coping with anger
7	Reducing problem behavior	Acting constructively
8	Creating a positive home	Creating a positive home
9	Resolving home conflicts (part 1)	Resolving home conflicts (part 1)
10	Resolving home conflicts (part 2)	Resolving home conflicts (part 2)
11	Selecting a custodian	Selecting a custodian
12	Dealing with drugs–alcohol	Dealing with drugs–alcohol
13	Preventing pregnancy–fatherhood	Preventing pregnancy–fatherhood
14	Making a custody plan	Encouraging safer sex
15	Encouraging safer sex	Encouraging safer sex
16	Setting legacy and the youth's goals	Setting my future goals

sure of serostatus ( $n=66$  at baseline,  $n=3$  at 2 years; in 11 cases, there were no disclosure data). Among the 118 adolescents who were eligible to attend, 84 (71.2%) attended at least 1 of the 16 intervention sessions. The mean number of sessions attended by adolescents was 12.1 ( $SD=8.0$ , median=11). A supervisor monitored fidelity to the intervention from videotapes of sessions; quality assurance ratings were also used in monitoring.

Supervisors used the session videotapes to rate completion of standard group activities for each session. Completion rates were as follows: token exchange, 84%; feeling thermometer, 81%; goal setting and review, 93%; and charting of problem solving, 86%. Global leader competence was rated on a scale of 1 to 5 (5=highly competent), and the resulting mean rating over sessions was 4.2 ( $SD=0.6$ ). At the end of each group meeting, participants rated their liking, trust, and group cohesion on scales of 1 to 5. The groups received very positive ratings on each item over time, with mean scores ranging from 4.5 to 4.8.

### Data Analysis

An intention-to-treat analysis was conducted to examine the differences between the intervention and standard care conditions; there was no adjustment for number of intervention sessions attended. Trend analysis,<sup>27</sup> a technique similar to random coefficient models, was used to examine the rate of change on the outcome variables over time. Outcome measures assessed at follow-up were examined with control for baseline level of variable, age, sex, and family (assessed as a random effect).

Linear and piecewise linear trends were examined. On some outcomes, slopes varied over time. When variations in slope were observed, piecewise trends were examined through the assessments conducted from 3 to 15 months and then from 18 to 24 months (covarying baseline scores). Time trend analysis based on random-coefficient regression was used in examining each outcome. The intervention effect was evaluated by comparing slopes between conditions over time. Effect sizes were calculated with Cohen's formula.<sup>28</sup>

## RESULTS

### Description of the Samples at Baseline

Most of the parents with AIDS were Latino and African American mothers. The age distribution among parents was large, from 25 to 70 years (mean=38.1,  $SD=5.6$ ). About half (54%) of the parents had graduated from high school. Household compositions varied: 94% included children, while in the remaining cases children were temporarily in foster care placements, in group homes, or incarcerated. Twenty-seven percent of households included an adult partner, 11% included a grandparent, and 10% included other relatives.

About one third of the parents had injected drugs over their lifetime, but only a small number had recently injected drugs. Fathers were significantly more likely (12%) than mothers (4%) to be injecting drugs ( $\chi^2_1 = 5.41$ ,  $P=.02$ ). Over their lifetime, most parents had had multiple sexual partners; had used condoms infrequently; and had had partners who bartered sex, were HIV seropositive, and were bisexual. However, recent sexual behavior patterns were less risky; more than half of the parents reported abstaining from sex, most used condoms in all sexual encounters, and most had only 1 sexual partner. The parents exhibited many physical health symptoms and reported emotional distress in the clinical range.

About half of the adolescents were female. The mean age of the adolescents was 14.8 years ( $SD=2.1$ , range=11–18), and 89% were enrolled in school.

Table 2 presents comparisons of adolescents and parents in the intervention and standard care conditions at baseline. Randomization was successful in that parents and adolescents were similar across conditions in regard to all background factors and outcome measures.

### Intervention Efficacy

Table 3 summarizes the effects of the intention-to-treat analysis of changes over time for each primary outcome. Figure 2 shows estimated regression lines and adjusted mean scores for adolescents in each condition across the 2-year follow-up period. Because there were variations in slopes over time for some outcome variables,

Table 3 presents change over 3-month intervals for 2 time periods following the baseline assessment: 3 to 15 months and 18 to 24 months.

As can be seen in Table 3, there was a significantly greater reduction in emotional distress (i.e., Brief Symptom Inventory overall score) over the first 15 months after the baseline interview for adolescents in the intervention condition than for adolescents in the standard care condition ( $P<.034$ ). Reductions in emotional distress did not differ significantly between the intervention and standard care conditions after the 15-month follow-up ( $P=.40$ ). Brief Symptom Inventory depression subscale scores were not significantly different between adolescents in the intervention and standard care conditions.

However, from 3 to 15 months, symptoms of anxiety decreased at a faster rate among adolescents in the intervention condition than among adolescents in the standard care condition ( $P<.019$ ). Again, the rate of decrease in symptoms of anxiety was similar across conditions from 18 to 24 months. Female adolescents reported a significantly higher level of overall emotional distress ( $P<.0001$ ) and more depressive symptoms ( $P<.0001$ ) than did male adolescents, consistent with previous research on sex differences in adolescent depression.<sup>29</sup> Older adolescents also reported significantly higher levels of emotional distress ( $P<.01$ ) and depressive symptoms ( $P<.003$ ) than did younger adolescents.

Multiple problem behaviors decreased significantly more among adolescents in the intervention condition than among those in the standard care condition in a linear fashion over the 3- to 24-month follow-up ( $P<.001$ ). Conduct problems also decreased significantly more among adolescents in the intervention condition over time ( $P<.026$ ), with a consistent linear decline.

The decrease in multiple problem behaviors and conduct problems was twice as large in the intervention condition as in the standard care condition. At baseline, African American adolescents were significantly more likely than adolescents from other ethnic backgrounds to report conduct problems ( $P<.008$ ) and multiple problem behaviors



**TABLE 2—Sample Characteristics at Baseline, by Conditions: New York City, 1993–1995**

Characteristic	Intervention	Standard Care
<b>Parents with AIDS<sup>a</sup></b>		
Male, %	20	19
Mean age, y (SD)	38.12 (5.34)	37.99 (5.91)
Race/ethnicity, %		
African American	33	36
Latino	47	43
White	12	10
Other	8	12
Diagnostic status, %		
Asymptomatic	20	16
Symptomatic	40	44
AIDS	40	40
Mean no. of physical health symptoms (SD)	14.54 (5.75)	14.27 (5.60)
Mean no. of emotional distress symptoms (SD)	2.86 (1.03)	2.85 (1.02)
Lifetime substance use, %		
Injection drug use	33	41
Hard drug use	67	66
Alcohol or marijuana use	87	84
Current substance use		
Abstinent: alcohol and drugs, %	60	63
Alcohol abstinent, %	68	71
Drug abstinent, %	77	78
Marijuana use, %	15	14
Hard drug use, %	16	16
Injection drug use, %	5	6
Mean no. of drugs used (SD)	0.35 (0.73)	0.36 (0.74)
Mean weighted index (logged) (SD)	0.74 (1.53)	0.84 (1.79)
Median no. of lifetime sex partners	8	7
Current sexual behavior		
Abstinent, %	54	60
Sexually active parent with AIDS, no.	68	58
Mean no. of sex partners (active) (SD)	1.22 (1.14)	1.31 (1.85)
Disclosed HIV-positive (active), %	88	82
100% condom use (active), %	65	59
Mean Brief Symptom Inventory score (SD)	1.03 (0.70)	0.97 (0.77)
Multiple problem behaviors, mean (SD)	0.76 (0.93)	0.69 (0.84)
Disclosure to any adolescent, %	74	72
Legal arrangement for any adolescent, %	31	31
<b>Adolescents<sup>b</sup></b>		
Male, %	46	48
Mean age, y (SD)	14.58 (2.02)	14.77 (1.88)
Race/ethnicity, %		
African American	35	40
Latino	51	49
White	4	2
Other	10	9
High school graduate, %	3	4

Continued

( $P < .049$ ). Over time, there were no significant ethnicity  $\times$  intervention interactions in regard to conduct problems. Family life stressors were significantly less prevalent among adolescents in the intervention condition across 2 years ( $P < .0017$ ), and self-esteem scores were significantly higher across 2 years for youths in the intervention condition ( $P < .025$ ).

Table 3 also summarizes the differences between parents in the intervention and standard care conditions, which were similar to the differences found among adolescents. Figure 3 shows differences over time for parents on each outcome measure, as well as adjusted mean scores for parents in each condition. Overall, Brief Symptom Inventory emotional distress scores decreased at a significantly faster rate in the intervention condition over 3 to 15 months ( $P < .006$ ); the rate of change was similar (i.e., not significant) across conditions from 18 to 24 months ( $P = .66$ ). Parents in both conditions continued to report lower levels of emotional distress from 18 to 24 months.

Changes in parents' symptoms of depression and anxiety were similar to changes in emotional distress. Depression scores decreased at a significantly faster rate among parents in the intervention condition from 3 to 15 months ( $P < .0003$ ); reductions occurred at a similar rate across 18 to 24 months for the parents in the 2 conditions ( $P = .46$ ). Self-reported symptoms of anxiety decreased at a significantly greater rate over 3 to 15 months among parents in the intervention condition ( $P < .014$ ) and then decreased at a similar rate from 18 to 24 months in both conditions ( $P = .81$ ).

Multiple problem behaviors decreased significantly more among the parents in the intervention condition than among the parents in the standard care condition over 3 to 24 months ( $P < .03$ ). As with adolescents, decreases in problem behaviors were twice as large among parents in the intervention condition as among parents in the standard care condition.

There were no significant differences in disclosure or custody plans across conditions. At the time of the baseline interview, 71% of the parents in each condition had disclosed their serostatus to at least 1 adoles-

TABLE 2—Continued

Attend school currently, %	92	87
Mean Brief Symptom Inventory score (SD)	0.66 (0.58)	0.61 (0.56)
Lifetime substance use, %		
Alcohol	48	49
Any drug	33	39
Current substance use		
Abstinent: alcohol and drugs, %	68	67
Marijuana use, %	18	22
Hard drug use, %	3	1
Mean no. of drugs used (SD)	0.21 (0.47)	0.24 (0.48)
Mean weighted index (logged) (SD)	0.43 (1.12)	0.50 (1.15)
Lifetime sexual behavior		
Abstinent, %	54	50
Among active, median no. of sex partners	3	3
Current sexual behavior		
Abstinent	72	71
Multiple problem behaviors, mean (SD)	2.04 (1.44)	2.12 (1.52)
Conduct problems, mean (SD)	1.52 (1.91)	1.67 (2.06)
Mean self-esteem score (SD)	3.06 (0.49)	3.03 (0.45)
Stressful family life events, mean (SD)	1.30 (1.36)	1.35 (1.43)

<sup>a</sup>Intervention, n = 153; standard care, n = 154.

<sup>b</sup>Intervention, n = 205; standard care, n = 207.

cent in the family, and 66% had disclosed to all adolescents in the family. At 1 year, about 75% of parents in both conditions had disclosed to all children in the family. At

2 years, 89% of the parents in the intervention condition and 85% of those in the standard care condition had disclosed to at least 1 of their adolescent children, and about

85% in both conditions had disclosed to all of their adolescents.

About one third of parents (31%) in both conditions had made custody plans for at least 1 adolescent at the time of recruitment (the baseline interview), and 28% had made custody plans for all adolescents in the family. At 1 year, 54% had made custody plans for at least 1 adolescent child (50.5% had done so for all adolescent children). By 2 years following recruitment, 67% of the parents had made a plan for at least 1 adolescent, and 63% had made plans for all of their adolescent children. There were no significant differences in coping style across conditions.

## DISCUSSION

When families were recruited into this study, the parents anticipated dying in about a year. Most had told their children about their HIV status (75%).<sup>17</sup> The children who knew about their parent's health status were exhibiting more behavior problems than those who did not know.<sup>17</sup> These families faced challenges in regard to the illness, disclosure, custody, and saying good-bye. All of the families were dependent on financial support from governmental agencies, and many were hiding their illness from extended family

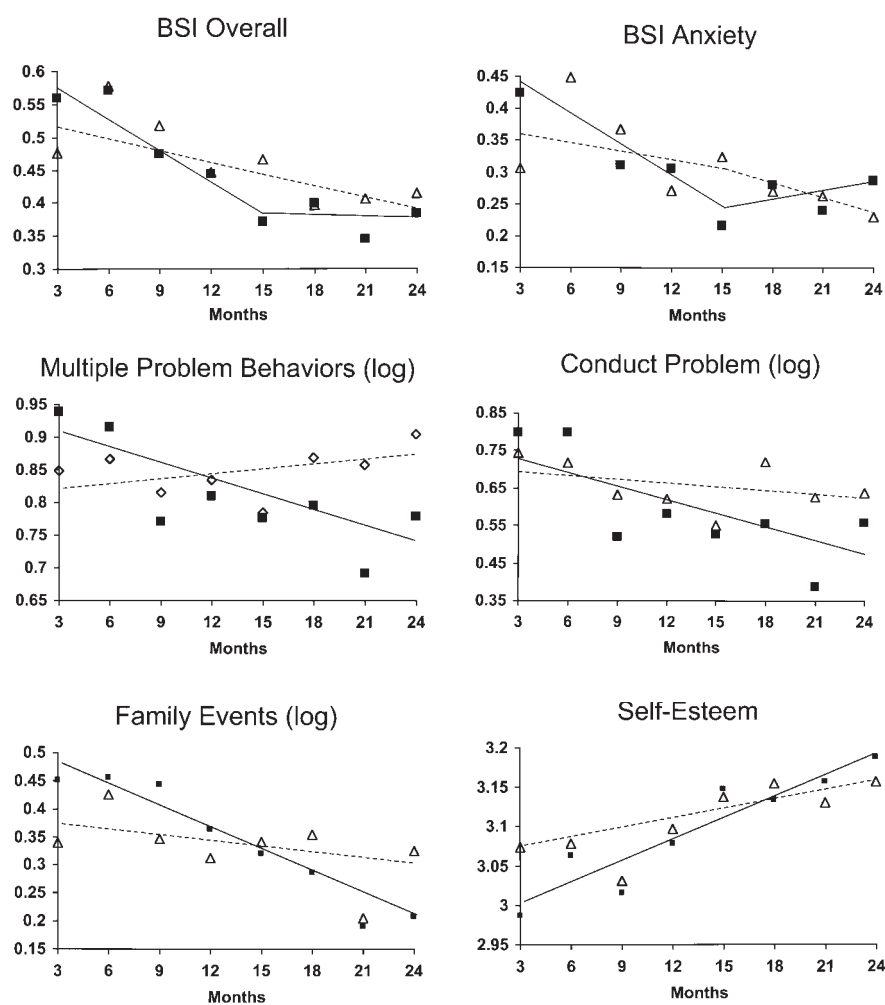
TABLE 3—Estimated Mean Follow-Up Scores Based on Random Coefficient Regression Models: New York City, 1993–1995

	3-Month Follow-Up Estimate		15-Month Follow-Up Estimate			24-Month Follow-Up Estimate		
	Intervention	Standard Care	Intervention	Standard Care	Effect Size <sup>a</sup>	Intervention	Standard Care	Effect Size <sup>a</sup>
<b>Adolescents</b>								
BSI overall	0.572	0.515	0.377	0.442	1.67*	0.373	0.384	0.52
BSI anxiety	0.442	0.362	0.242	0.306	2.57*	0.280	0.232	0.25
Multiple problem behaviors (log)	0.907	0.822	0.808	0.852	4.30**	0.733	0.874	4.35**
Conduct problem (log)	0.728	0.691	0.578	0.647	2.41*	0.465	0.614	2.42*
Family events (log)	0.484	0.375	0.326	0.332	2.67**	0.208	0.299	2.63**
Self-esteem	3.001	3.072	3.111	3.122	1.20*	3.193	3.160	1.18*
<b>Parents with AIDS</b>								
BSI overall	2.017	1.889	1.766	1.929	7.27**	1.600	1.718	1.44
BSI depression	2.138	1.862	1.790	2.006	3.42**	1.622	1.740	3.23
BSI anxiety	1.991	1.871	1.702	1.911	8.23*	1.513	1.690	1.64
Multiple problem behaviors (log)	0.380	0.364	0.293	0.360	20.75*	0.228	0.357	20.71*

Note. BSI = Brief Symptom Inventory.

<sup>a</sup>(change of intervention – change of standard care)/change of standard care.

\* $P < .05$ ; \*\* $P < .01$ .



Note. BSI = Brief Symptom Inventory.

**FIGURE 2—Estimated regression lines and adjusted mean scores for follow-up assessment outcome measures: adolescents in the intervention condition (solid lines, black squares) and standard care condition (broken lines, white triangles), New York City, 1993–1995.**

members and friends,<sup>30</sup> typically owing to fear of stigmatization.

Most of the study parents were Latino or African American substance abusers or ex-abusers who were likely to have experienced discrimination because of their race/ethnicity or lifestyle,<sup>31</sup> as well as their HIV status. In a culture that often creates euphemisms for death and avoids acknowledging personal tragedies,<sup>32</sup> families were frequently overwhelmed with HIV-related issues.

A coping skills intervention is one strategy for preventing negative outcomes among adolescents in families in which there is a parent

with AIDS. The intervention described here significantly improved adjustment among both parents and adolescents, typically with large effects. While problem behaviors increased or remained stable in the families in the standard care condition, there were significant decreases in these behaviors among both the adolescents and the parents in the intervention condition. At 2 years, adolescents in the intervention condition reported 4 times fewer problem behaviors and 2.4 times fewer conduct problems than adolescents in the standard care condition. Increases in self-esteem were shown, and multiple problem

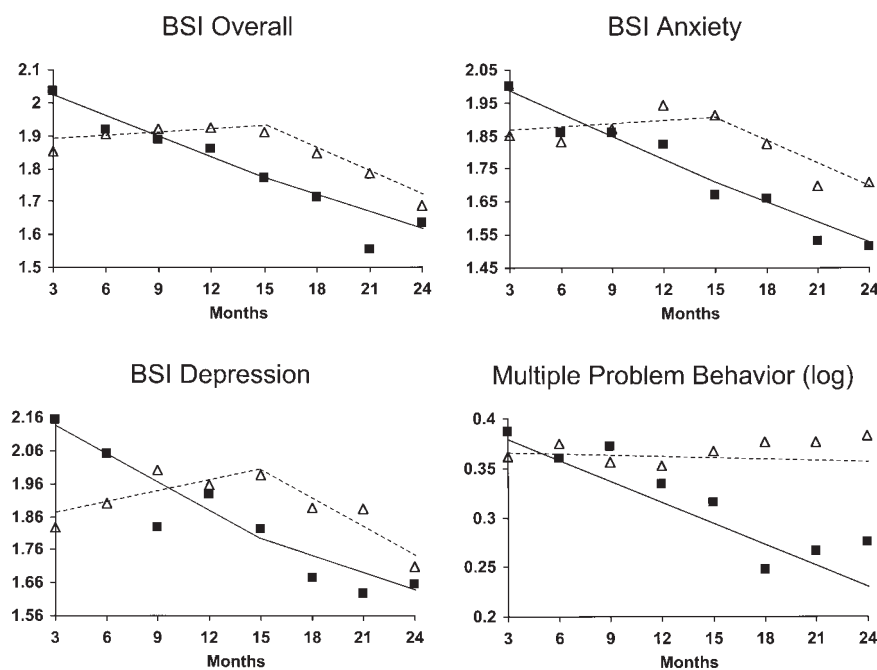
behaviors decreased at a much higher rate among parents in the intervention condition than among parents in the standard care condition. These are important, long-term changes that are likely to reduce the societal costs of AIDS.

Public health officials may emphasize the social costs of having a parent with AIDS, but the quality of life for families must also be considered. In addition to reductions in problem behaviors, emotional distress decreased more quickly among the adolescents and parents in the intervention condition. At 15 months, there was a 3-fold to 8-fold decrease on each measure of emotional distress among parents in the intervention condition relative to those in the standard care condition.

Similar to the findings for emotional distress, family-related life stressors were significantly less prevalent among adolescents in the intervention condition than among those in the standard care condition. These decreases were again substantial and suggest that quality of life improved for those in the intervention condition in comparison with those in the control condition.

While the intervention substantially improved outcomes among parents with AIDS and their adolescent children, the outcomes for families in the control condition also improved over time, in contrast to existing theories regarding the long-term impact of chronic illness and bereavement.<sup>33</sup> Emotional distress of parents and youths in both the intervention and control conditions improved over time. For example, while emotional distress was significantly less prevalent in the intervention group at 15 months, the conditions were similar in regard to emotional distress at 24 months.

There are at least 3 reasons for this improvement. First, antiretroviral therapies were introduced about 2 years into the study. A profound change occurred when families expected the parent with AIDS to die in about a year and these expectations were not realized. As one participant stated, "I made it for the cure." Such perceptions are likely to decrease both parents' and adolescents' emotional distress. Second, adolescents and parents may have learned to adapt to the illness; over time, conversations about the parent's HIV status decreased.<sup>30</sup> Finally,



Note. BSI = Brief Symptom Inventory.

**FIGURE 3—Estimated regression lines and adjusted mean scores for follow-up assessment outcome measures: parents in the intervention condition (solid lines) and standard care condition (broken lines), New York City, 1993–1995.**

participation in the study itself may have been a positive intervention for the families, even if they took part only in the standard care condition. An interviewer visited the family every 3 months and repeatedly asked about disclosure, custody, and risk behaviors. Every major HIV prevention trial<sup>34,35</sup> has shown control group improvements that have been sustained over time. Repeated assessments may be responsible for these changes, even without intervention.<sup>7</sup> Future studies involving families coping with HIV may help clarify whether improvements over time are typical or related to the medical breakthroughs in disease management.

The intervention was aimed at helping families with issues relating to disclosure and custody plans, yet families in the intervention and standard care conditions were similar in these areas. As noted earlier, completion of repeated interviews regarding disclosure and custody plans represents a significant intervention in itself, and families in both conditions experienced these assessments. How-

ever, disclosing and making custody plans may be inevitable over time among parents with AIDS. Most parents had disclosed their HIV status to their adolescent children before the initiation of the study (75%); therefore, there was little opportunity for change. Even though the program did not either endorse or discourage disclosure, all but 8 of the parents in the study had disclosed their serostatus to their adolescents within 2 years. About two thirds of the parents in both conditions had taken steps to formalize custody plans within 2 years.

Given the positive results, it is important to consider the strengths and limitations of the study's design. The sample was one strength. About one third of parents with AIDS in the United States reside in New York City (New York City Human Resources Agency, Division of AIDS Services, unpublished data, 1993),<sup>36</sup> the study's site. New York City is unique nationally in centralizing referrals to the Division of AIDS Services, which allowed us to recruit a sample reflecting a representative

population of parents with AIDS (84% recruitment rate for traceable participants). The sociodemographic characteristics of the sample were similar to those reported to the Centers for Disease Control and Prevention for women with AIDS,<sup>36</sup> again suggesting a representative sample.

Randomization to the intervention and control conditions was successful, in that there were no significant differences at the time of recruitment in regard to any sociodemographic or outcome measures for the parents or the adolescents. In addition, the follow-up rates were very good over time for both the parents and their adolescents, and a conservative analytic strategy was adopted via the intention-to-treat analysis.

There has been little research on the children of parents with long-term chronic diseases, particularly adolescent children.<sup>37</sup> Existing studies of bereaved youths often recruit participants at large university medical centers, resulting in samples of middle-class, Anglo children with 2 parents.<sup>33</sup> Our study sample was unique in that the parents with AIDS were predominantly African American and Latino single parents. Low-income parents coping with HIV provide another picture of coping with life-threatening illness.

However, fathers and Spanish-speaking mothers typically did not attend the intervention groups, even after specialized recruitment strategies had been instituted. In the future, alternative intervention modalities must be designed for families from these 2 subgroups.

Over 2 years, 44% of the parents with AIDS died.<sup>38</sup> Deaths were distributed throughout the follow-up period, and rates were similar across intervention conditions. After the parent's death, a third intervention module was delivered to the bereaved adolescents and their caregivers. The results of that module are being evaluated. ■

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This article was accepted August 31, 2000.



## Contributors

M.J. Rotheram-Borus directly supervised the implementation of the intervention, provided critical feedback on the procedures followed, and wrote the first draft of the paper. M.B. Lee conducted and supervised the data analysis, analyzed the data and wrote the results section, and edited the draft of the paper. M. Gwadz supervised data collection, initiated assessments and procedures to improve the study, and contributed to the editing of the paper. B. Draimin was involved in the initial design and data collection and contributed to the editing of the paper.

## Acknowledgments

This paper was completed with the support of National Institute of Mental Health grant 1ROI MH49958-04.

We thank the parents, caregivers, and adolescents who participated in this study, as well as those who assisted in the study, including Julie LeHane, the staff of The Family Center/Medical and Health Research Association and Housing Works, and our interviewers and group leaders. We also thank Coleen Cantwell, Tri Cisek, Betty Crenshaw, Jen Elliott, Hsin-Hsin Foo, Laura Franzke, Nionne James, Kris Langabeer, Noelle Leonard, Patrice Lewis, Marguerita Lightfoot, David Litke, Tanko Mohammed, Marian Riedel, Laura Rosen, Nim Tottenham, Julian Wang, and Karen Wyche.

## References

1. Michaels D, Levine C. Estimates of the number of motherless youth orphaned by AIDS in the United States. *JAMA*. 1992;268:3456–3461.
2. Leibowitz A, Schuster M, Bhattacharya J, Rotheram-Borus M. AIDS orphans in the United States: new estimates from nationally representative data. Paper presented at: Annual Meeting of the Population Association of America; March 2000; Los Angeles, Calif.
3. Gwadz M, De Vogli R, Rotheram-Borus MJ, et al. Behavioral practices regarding combination therapies for HIV/AIDS. *J Sex Educ Ther*. 1999;24:81–88.
4. Herek GM, Capitanio JP. Public reactions to AIDS in the United States: a second decade of stigma. *Am J Public Health*. 1993;83:574–577.
5. Armistead L, Forehand R. For whom the bell tolls: parenting decisions and challenges faced by mothers who are HIV seropositive. *Clin Psychol Sci Pract*. 1995;2:239–250.
6. Rotheram-Borus MJ, Murphy DA, Miller S, Draimin BH. (1997). An intervention for adolescents whose parents are living with AIDS. *Clin Child Psychol Psychiatry*. 1997;2:201–219.
7. Worsham NL, Compas BE, Ey S. Children's coping with parental illness. In: Wolchik SA, Sandler IN, eds. *Handbook of Children's Coping: Linking Theory and Intervention*. New York, NY: Plenum Press; 1997: 195–213.
8. Hilton B, Elfert H. Children's experiences with mothers' early breast cancer. *Cancer Pract*. 1996;4: 96–104.
9. *Report of the Global HIV/AIDS Epidemic: June 2000*. Geneva, Switzerland: World Health Organization; 2000:123–137.
10. World Health Organization. The World Health Report, 1999: making a difference. Available at: <http://www.who.org/whr/1999/en.report.htm>. Accessed August 1, 2000.
11. West SG, Sandler I, Pillow DR, Baca L, Gersten JC. The use of structural equation modeling in generative research: toward the design of a preventive intervention for bereaved children. *Am J Community Psychol*. 1991;19:459–480.
12. *NIH Consensus Development Conference on Interventions to Prevent HIV Risk Behaviors: Programs and Abstracts*. Bethesda, Md: National Institutes of Health; 1997.
13. Bandura A. Social cognitive theory and exercise of control over HIV infection. In: DiClemente R, Peterson JL, eds. *Preventing AIDS: Theories and Methods of Behavioral Interventions*. New York, NY: Plenum Press; 1994:25–59.
14. Kelly JA. *Changing HIV Risk Behavior: Practical Strategies*. New York, NY: Guilford Press; 1995.
15. Rotheram-Borus MJ, Lightfoot MA. Helping adolescents cope with parental AIDS and its aftermath: a prevention program for families. In: Pequegnat W, Szapocznik J, eds. *Working With Families in the Era of HIV/AIDS*. Thousand Oaks, Calif: Sage Publications; 2000:189–211.
16. Wortley P, Chu SY, Diaz T, et al. HIV testing patterns: where, why and when were persons with AIDS tested for HIV? *AIDS*. 1995;9:487–492.
17. Rotheram-Borus MJ, Draimin BH, Murphy DA, Reid HM. The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS*. 1997;11:1159–1164.
18. Levine C. The new orphans and grieving in the time of AIDS. In: Dane BO, Levine C, eds. *AIDS and the New Orphans*. Westport, Conn: Auburn House; 1994:1–11.
19. Clark DC, Pynoos RS, Goebel AE. Mechanisms and processes of adolescent bereavement. In: Haggerty RJ, Sherrod LR, eds. *Stress, Risk, and Resilience in Children and Adolescents: Processes, Mechanisms, and Interventions*. New York, NY: Cambridge University Press; 1996:100–146.
20. Lutzke JR, Ayers TS, Sandler IN, Barr A. Risks and interventions for the parentally bereaved child. In: Wolchik SA, Sandler IN, eds. *Handbook of Children's Coping: Linking Theory and Intervention*. New York, NY: Plenum Press; 1997:215–243.
21. Derogatis LR. *Brief Symptom Inventory: Administration, Scoring, and Procedures Manual*. Minneapolis, Minn: National Computer Systems; 1993.
22. Jessor R. Problem behavior theory, psychosocial development, and adolescent problem drinking. *Br J Addict*. 1987;82:331–342.
23. Rosenberg M. *Society and the Adolescent Self-Image*. Princeton, NJ: Princeton University Press; 1965.
24. Namir S, Wolcott DL, Fawzy FI, Alumbaugh MJ. Coping with AIDS: psychological and health implications. *J Appl Soc Psychol*. 1987;17:309–328.
25. Rotheram-Borus MJ, Lee MB, Murphy DA, et al. Efficacy of a preventive intervention for youths living with HIV. *Am J Public Health*. 2001;91:400–405.
26. Rotheram-Borus MJ, Leonard NR. Training facilitators to deliver HIV manual-based interventions to families. In: Pequegnat W, Szapocznik J, eds. *Working With Families in the Era of HIV/AIDS*. Thousand Oaks, Calif: Sage Publications; 2000:45–67.
27. Diggle PJ, Liang KY, Zeger SL. *Analysis of Longitudinal Data*. Oxford, England: Clarendon Press; 1996.
28. Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale, NJ: Lawrence Erlbaum Associates; 1988.
29. Cicchetti D, Toth SL. Developmental psychopathology and disorders of affect. In: Cicchetti D, Cohen DJ, eds. *Developmental Psychopathology*. New York, NY: John Wiley & Sons Inc; 1995:369–420.
30. Lee MB, Rotheram-Borus MJ, Ramos B. Disclosure of serostatus over time among parents living with HIV. Paper presented at: National Conference on Women and HIV; August 1999; Los Angeles, Calif.
31. Zayas LH, Romano K. Adolescents and parental death from AIDS. In: Dane BO, Levine C, eds. *AIDS and the New Orphans*. Westport, Conn: Auburn House; 1994:59–76.
32. Gellman B. Death watch: the belated global response to AIDS in Africa. *Washington Post*. July 5, 2000:A1.
33. Sandler II, West SG, Baca L, et al. Linking empirically based theory and evaluation: the family bereavement program. *Am J Community Psychol*. 1992;20: 491–521.
34. NIMH Multisite HIV Prevention Trial Group. Methodological overview of a multisite HIV prevention trial for populations at risk for HIV. *AIDS*. 1997;11: 1–13.
35. Kamb ML, Fishbein M, Douglas JM, et al. Efficacy of risk-reduction counseling to prevent HIV and sexually transmitted diseases: a randomized controlled trial. *JAMA*. 1998;280:1161–1167.
36. *HIV/AIDS Surveillance Report: US HIV and AIDS Cases Reported Through December 1994*. Atlanta, Ga: Centers for Disease Control and Prevention; 1994.
37. Romer G, Barkmann M, Schulte-Markwort G, et al. Children of somatically ill parents: a methodologic review. *J Clin Child Psychol Psychiatry*. In press.
38. Lee M, Rotheram-Borus MJ. Challenges associated with increased survival among parents living with AIDS. *Am J Public Health*. 2001;91:1303–1309.