Adolescent Adjustment Before and After HIV-Related Parental Death

Mary Jane Rotheram-Borus, Robert Weiss, Susan Alber, and Patricia Lester
University of California, Los Angeles

The impact of HIV-related parental death on 414 adolescents was examined over a period of 6 years. The adjustment of bereaved adolescents was compared over 4 time periods relative to parental death and was also compared with the adjustment of nonbereaved adolescents. Bereaved adolescents had significantly more emotional distress, negative life events, and contact with the criminal justice system than non-bereaved youths; these behaviors did not remain significantly higher after parental death. Depressive symptoms and passive problem solving increased soon after parental death, as compared with non-bereaved adolescents. One year subsequent to parental death, depression and passive problem solving were similar to the levels of nonbereaved peers. Only sexual risk behaviors increased following parental death. These results suggest the importance of early family intervention soon after parental HIV diagnosis, prior to parental death, and sustained over time.

The number of families affected by a parent with HIV (PWH) continues to rise. An estimated 40 million adults are living with HIV (Joint United Nations Program on HIV/AIDS [UNAIDS]/ United Nations Children's Fund [UNICEF]/United States Agency for International Development [USAID], 2002). Most of these adults are parents, and 13 million children have already been orphaned by AIDS (UNAIDS/UNICEF/USAID, 2002). In the United States, about 350,000 children are living with a PWH (Schuster et al., 2000) and another 36,000–65,000 adolescents had a parent die from AIDS (Michaels & Levine, 1992). In this article, our goal is to prospectively examine over 6 years the impact of parental death on the adjustment of adolescents living with a PWH.

Adolescents of PWHs are affected not only by parental death but also by time spent with a chronically ill parent. Parental illness frequently radiates stress throughout the entire family, straining both parents' and children's established coping patterns (Rosenheim & Reicher, 1986). Family structure, cohesiveness, parenting skills, social supports, and stressful events significantly influence family members' responses to the stress of terminal illness (Gonzalez, Steinglass, & Reiss, 1989; Rolland, 1988). Typically, emotional distress is high among families with a person with AIDS (Lamping et al., 1991; Rotheram-Borus, Lightfoot, & Shen, 1999). Parents with HIV may feel overwhelmed and helpless, or may become demanding and argumentative (Cates, Graham, Boeglin, & Tielker, 1990). Thus, similar to children of parents with other illnesses (see Romer, Barkmann, Shulte-Markwort, Thomalla, & Riedesser, 2002, for a review), being a child of a PWH may have a substantial and prolonged developmental impact, both while the parent is living and after parental death.

Adolescence is likely to result in specific types of stressors for children of PWHs. Adolescents have greater developmental resources than younger children; therefore, they are often expected to assume an adult role within the family (Stein, Riedel, & Rotheram-Borus, 1999) and are increasingly expected to care for younger siblings (Rotheram-Borus, Stein, & Lin, 2001). Adolescents must often take responsibility for maintaining daily family routines when parents are ill or hospitalized (Rotheram-Borus, Draimin, Murphy, & Reid, 1997).

Adolescents of PWHs often have parents who injected drugs or who were partners of drug injectors when the children were younger. As the life span of persons with HIV has extended (Eron et al., 1995; Kinloch-de Loes & Perrin, 1995), many PWHs reinitiate substance abuse after years of abstinence (Rotheram-Borus et al., 2003). These parents are modeling negative behaviors for their children at a sensitive developmental period, and the parent's substance use is also likely to result in a more chaotic family life (Garnier & Weisner, 1994; Zayas & Romano, 1994). When PWHs use drugs, the conduct problems and mental health symptoms of their children increase. Therefore, adolescents of PWHs may be at particular risk for alcohol and drug use (Rotheram-Borus, Stein, & Lin, 2001).

Children of PWHs are likely to experience HIV-related stigmatization if the parent's HIV status is publicly known, further increasing their sense of alienation and isolation during a period when peer support is particularly sensitive (Frierson, Lippman, & Johnson, 1987). In addition to these external stressors, youths are also likely to miss developmental opportunities, including the chance to establish autonomy and obtain parental guidance, as their ill parent becomes increasingly disabled (Rosenheim & Reicher, 1986).

Clinicians' reports that parental bereavement is the most stressful life event for children (Dowdney, 2000; Harris, 1991) led us to expect that the impact of parental death among young people would increase over time. There is some evidence, however, that bereaved children are significantly better adjusted a year following parental death (Saldinger, Cain, Kalter, & Lohnes, 1999; Siegel,

Karus, & Raveis, 1996; Silverman & Worden, 1992). In fact, in studies with younger bereaved children, children's adjustment was similar to same-age peers a year later. Yet, because of the developmental challenges of adolescence, we anticipated that emotional distress and high risk behaviors would increase following parental death for adolescents of PWHs.

These hypotheses are based on very limited empirical data. Most of the existing research has been conducted with children from middle class backgrounds with two parents recruited from large, academic medical centers that serve predominantly Caucasian families with cancer (Christ, 2000; Romer et al., 2002; West, Sandler, Pillow, Baca, & Gersten, 1991). These previous studies may be inadequate to understand the impact in families with many preexisting social stressors. Adolescent children of PWHs are raised predominantly in single-parent Latino or African American households. HIV is a more stigmatizing illness than cancer (Herek, 1999), and many of the families live in neighborhoods with high rates of drug dealing and abuse (Centers for Disease Control and Prevention, 2001). Given the differences in socioeconomic status, ethnicity, and type of illness, it may be that the pattern of adjustment of adolescents in families coping with HIV may be quite different from previous literature.

The present study was conducted with families of PWHs recruited in New York City (NYC) who were followed prospectively over 6 years. These families participated in a randomized controlled intervention trial; therefore, the intervention may have reduced the potential negative impact of bereavement. We have previously demonstrated that the intervention benefited both the PWHs and their adolescent children (Rotheram-Borus et al., 2003; Rotheram-Borus, Lee, Gwadz, & Draimin, 2001; Rotheram-Borus, Lester, Wen, & Shen, 2004; Rotheram-Borus, Stein, & Lin, 2001): Young people reduced problem behaviors, improved emotional distress, had fewer sexual partners, and had less substance use over 2 years; at 4 years, young people had fewer babies and tended to have fewer problem behaviors; at 6 years, young people reported more employment and enrollment in school, fewer received welfare benefits, and less conflict in their romantic relationships. Similarly, parents reported less emotional distress and fewer problem behaviors at 2 years and were less likely to have relapsed into substance abuse at 4 years. The child offspring of the adolescents reported significantly fewer adjustment problems and tended to have better home environments and cognitive functioning at 18 and 36 months.

Although the intervention had clear benefits, there were no intervention benefits to bereaved compared with nonbereaved young people at 2 years (Rotheram-Borus, Stein, & Lin, 2001). However, bereavement resulted in higher rates of problem behaviors and emotional distress at 2 years. Over 6 years, about half of the PWHs died, allowing comparison of the developmental trajectories and emotional distress among bereaved adolescents of PWHs with adolescents of PWHs coping with similar HIV-related stressors whose parents did not die. Given that we had a much longer observation period (6 years, not 2 years) and more adolescents had become bereaved, prospective data were available on behavior patterns prior to and following parental death. We examined adolescents' adjustment patterns during the period more than a year prior to parental death and within the year immediately preceding death and compared these with similar time periods following parental death. We also shifted our analytic strategy to

continuous and discrete regression analyses (autoregressive moving averages); therefore, we were able to include all adolescents in the analyses over time, comparing bereaved and nonbereaved young people over the different time periods. Examination of adolescents' emotional distress and behavior problems over time may suggest optimal timing and types of interventions for adolescents affected by parental illness.

Method

Participants

The NYC Division of AIDS Services (DAS) provides comprehensive case management services to 95% of people with AIDS who qualify for public assistance. For eligibility, PWHs were required to (a) be alive during the recruitment period, (b) have at least one adolescent child between the ages of 11 and 18 years, and (c) have the consent of their case managers. Case managers evaluated the intervention as potentially harmful to 35 potential participants; these participants were not included in the study (5.6% of eligible, $n = 35$ of 619). PWHs were approached by their DAS case managers to allow referral to the research project. After being referred to the DAS, but prior to recruitment, 26% ($n = 155$ of 619) of PWHs who were potential participants died.

Of 429 eligible PWHs, 307 were recruited (71.6%), 65 (15.2%) were untraceable, 46 (10.7%) refused participation, and 11 (2.6%) were severely ill or incarcerated and were not recruited. Thus, the 307 recruited participants reflected 84% ($n = 307$ of 364) of the traceable PWHs. Informed consent and permission to recruit adolescents were obtained from PWHs. Only parents with adolescents in the study and for whom we had a date of death were eligible to participate in the analyses. Therefore, 272 of 307 PWHs were included. Using the same criteria, we found that 414 of 423 potential adolescent participants were eligible for inclusion (average number of adolescents per family = 1.5, $SD = 0.7$, range = 1–5). Informed consent was then obtained from these adolescents. Adolescents were not perinatally infected with HIV; only 1 adolescent reported learning that he or she was HIV positive over the 6 years of the study. If parents died, then caregiver informed consent was obtained and adolescent consent was reobtained.

Survey Procedures

A baseline interview was conducted with each PWH and each adolescent as soon as possible after recruitment and randomization to an intervention or a standard care condition that occurred at the conclusion of the baseline interview. Follow-up interviews were conducted every 3 months for 2 years and then at 6-month intervals until 6 years. The follow-up rates were similar in the intervention and standard care conditions for both parents and adolescents at each assessment. The annual rates of reassessment for years 1–6 were 89%, 92%, 94%, 91%, 85%, and 72% for nonbereaved adolescents and were slightly lower at 77%, 85%, 84%, 79%, 71%, and 63% for bereaved adolescents. As noted above, after parents died, new consent forms were required from caregivers and custodial guardians; there was also typically a time delay in the new recruitment of the bereaved families that was associated with the follow-up rates. Bereaved and nonbereaved adolescents were similar in age, gender, and ethnicity.

Assessments

Parents

As part of the baseline interview, information was collected on background characteristics, including age, gender, socioeconomic status, HIV diagnostic status, and CD4 count. Date of death was recorded by routinely contacting the family and monitoring state records.

Adolescents

Adolescents' age, ethnicity, and gender were recorded at baseline. Youths whose parents died were considered bereaved; youths with a chronically ill PWH were considered nonbereaved. Youths routinely completed the following four measures at each assessment.

Emotional distress. The Brief Symptom Inventory (BSI) is a 53-item inventory that assesses symptoms of mental distress (Derogatis, 1993). The BSI yields an indicator of overall emotional distress, the Global Severity Index ($\alpha = .96$), and subscales for depression ($\alpha = .80$) and somatization ($\alpha = .78$). Adolescents rated the level of severity for each symptom during the previous week on a scale ranging from 0 (*not at all*) to 4 (*extremely*).

Coping styles. We adapted the Dealing-With-Illness Questionnaire (Namir, Wolcott, Fawzy, & Alumbaugh, 1987) for adolescents using 29 of the original 53 items rated on a Likert scale ranging from 1 (*never*) to 5 (*always*; Murphy, Rotheram-Borus, & Joshi, 1999). Five subscales were considered: Positive Action, Spiritual Hope, Passive Problem Solving, Social Support, and Self-Destructive Escape.

Problem behaviors. Four indices were monitored:

1. Smoking, alcohol, and drug use self-reports were scored as having used (1) or not (0) tobacco, marijuana, alcohol, or hard drugs (e.g., amphetamines–stimulants, inhalants, cocaine, crack, hallucinogens, or heroin).

2. Unprotected sex was documented as whether the adolescent had engaged (1) or not (0) in any casual sex without a condom during the previous 3 months.

3. Contact with the criminal justice system (1) or not (0) in the prior 3 months was recorded, including conviction of a crime, incarceration, or classification as a juvenile offender.

4. School problems were rated as present (1) if youths reported problems in truancy, failing a grade level, or conflicts with teachers. A "0" was assigned if no problems were reported.

Stressful life events. A sum of 10 stressful family events (e.g., increased arguments between parents, mother absent from home) was calculated ($\alpha = .57$) on a measure adapted from Olson et al.'s (1982) study.

Intervention

PWHs and youths in both the control and intervention conditions received case management services from the DAS and had access to mental health counseling and medical care on an ongoing basis. In addition to the care accessible through the DAS, those randomized to the conditions were invited to attend a three-module intervention. An intervention manual (available at http://chipts.ucla.edu) outlined the 31-session intervention, Project TALC (Teens and Adults Learning to Communicate). The first module, Coping with Illness, involved only PWHs; the second module, Planning a Legacy, was attended by PWHs and adolescents (if adolescents were at least 12 years old and knew parental serostatus). Module 3, A New Beginning, was provided to adolescents and new caregivers if the parent died. Across modules, cognitive–behavioral principles were used to (a) improve coping with one's serostatus and ongoing illness-related stressors; (b) help in deciding to whom, when, and how to disclose one's serostatus and to make custody plans; (c) establish positive daily routines that assisted the family in coping with illness; and (d) identify life goals and establish positive communication patterns with caretakers and parents. Each Saturday, two intervention sessions were held, with childcare and transportation provided. Because most PWHs lived longer than expected, PWHs were allowed to attend make-up and booster sessions that covered the same content of the intervention.

Analysis

Before proceeding with more complex model fitting, we first drew exploratory histograms, scatter plots, plots of response profiles, and summary tables. The BSI measures were skewed, so we transformed them by taking the log of BSI plus a constant equal to one over the number of questions before further analysis. We explored the model for BSI Global Severity Index in detail before determining the final model and then used that model for all other outcomes with modest changes for dichotomous outcomes. SAS Proc Mixed (SAS Institute, Cary, North Carolina) was used to analyze continuous longitudinal responses.

The basic analytic design involved categorizing young people as either bereaved or nonbereaved. Adolescents whose parents did not die during the study had all their observations at a single level (nonbereaved). An adolescent whose parent died during the study had each observation fall into one of four pre- or postdeath time categories. For bereaved adolescents, we included four temporal indicators: for more than 1 year prior to bereavement, from 1 year before to the day before bereavement, from the day of bereavement up to 1 year after bereavement, and finally, from more than 1 year postbereavement. A separate indicator identified nonbereaved adolescents; thus, bereavement was a variable with five levels. Comparisons within levels of the bereavement variable were therefore either within-subject comparisons or between-subject comparisons. Thus, comparisons were conducted with five groups: (a) all observations from nonbereaved adolescents, (b) observations from bereaved adolescents more than 1 year before bereavement, (c) observations from bereaved youths 1 year before bereavement up to bereavement, (d) observations from bereaved youths up to 1 year after bereavement, and (e) observations from bereaved youths 1 year or more after bereavement. This five-category variable served as our bereavement covariate. When the F test for this variable was significant, there was an effect on the independent variable due to bereavement.

For each outcome variable, we examined the difference in the general level of responses of the bereaved youths compared with responses of nonbereaved youths. In addition, we examined responses of bereaved youths prior to and following parental death, comparing consecutive time periods among them. We then looked at pre- and postparental death responses within the bereaved group.

An autoregressive moving averages (1, 1) correlation model was used for the continuous longitudinal responses within each adolescent. This was the best fitting correlation model of several available in Proc Mixed. The fitted model states that for the BSI measures, the correlation between consecutive (Lag 1) observations is approximately 0.6 and that observations at Lag k have a correlation of approximately 0.60×0.95^k. Thus there is a slight but significant decrease in correlation between observations with increasing time lag. This correlation model is significantly better than, for example, a random intercept model in which all observations conducted with one adolescent are equally correlated with each other regardless of the time separating the two observations. We included a random family effect to account for correlation of siblings with the same parent. For fixed effects, in addition to the five-level bereavement variable, we included intercept, slope, changes in slope at 18 and 36 months, gender, and a two-parameter season effect (March through June, July through October, and November through February).

We used this same model for BSI subscales, coping styles, and life events. Adolescent risk behaviors were binary responses; we used a binary response model and the SAS Macro Glimmix, which iteratively calls SAS Proc Mixed to fit the binary response data. Binary data tend to support less-complex models as compared with continuous data, so we used the simpler random adolescent and family effect model and did not include slope change points at 18 and 36 months.

Including parental diagnosis (advanced to AIDS, HIV plus symptomatic, or HIV plus asymptomatic) in the analysis produced no important changes in the effect of bereavement on the youths. Therefore, parental diagnosis is not included in our analyses.

Results

Sample Characteristics

Parents

Among the PWHs, 83% were mothers and 17% were fathers; 35% were African American, 45% were Latina (Dominican and Puerto Rican), 8% were Caucasian, non-Latina, and 12% were of other ethnicities. The mean age was 38 years (SD = 5.7 years). All families were from a lower socioeconomic background or the family would not have been eligible for services from the DAS. Most PWHs were diagnosed with AIDS (38%) or were symptomatic (41%), with about 17% reporting being asymptomatic and 4% unknown. Overall, the mean CD4 count was 192 (SD = 180.7). Only 27% (n = 81) were living with an adult partner at the time of recruitment (30% of these were spouses). More than half of the cohort (53%) had completed high school. Less than 10% had a regular job; almost all participants were receiving one or more government entitlements at study entry. About half (52%) died over the 5-year study period.

Randomization to the intervention or the control group resulted in very similar groups based on sociodemographic characteristics, disease status, emotional distress, substance use, and problem behaviors.

Adolescents

The adolescent children had a mean age of 15 years (SD = 2.1) and were of similar ethnicity to their parents. About 1 in 5 (20%; n = 84) of the adolescents lived with two parents in the household. Of the participants, about half were female adolescents (53%), half experienced a parental death (50%), and parental death was similar across gender (54% female adolescents, 47% male adolescents). At the time of first assessment, only 7% of the adolescents overall reported a BSI score above gender appropriate clinical cutoff scores for global distress (Derogatis, 1993). Randomization resulted in highly similar groups; there were no differences on sociodemographic variables or outcomes (e.g., emotional distress, coping, or problem behaviors).

We examined main intervention effects, as well as two-way interactions of intervention and bereavement. No significant main effects or interaction emerged for the intervention, thus intervention effects are not reported in the remaining analyses.

Emotional Distress, Coping, and Bereavement

Compared with the nonbereaved adolescents, we identified a common pattern for many of the indices of emotional distress and coping in the bereaved adolescents relative to the timing of parental loss. For most subscales on the BSI, including Hostility, $\chi^2(4)$ = 10.1, p = .04, Interpersonal Sensitivity, $\chi^2(4)$ = 11.9, p = .02, Paranoid Ideation, $\chi^2(4)$ = 13.5, p = .01, Psychoticism, $\chi^2(4)$ = 12.6, p = .01, Somatization, $\chi^2(4)$ = 13.2, p = .01, and Global Distress, $\chi^2(4)$ = 12.5, p = .01, adolescents reported significantly higher levels of distress prior to bereavement, with lower levels following bereavement. Compared with the nonbereaved group, the bereaved youths' adjustment was different and worse only prior to parental death but not significantly different after bereavement. We demonstrate this pattern with the overall

scale score for emotional distress and the Somatization subscale score in Figure 1A. Table 1 summarizes the differences among bereaved and nonbereaved adolescents on the BSI scales when the scores are not log transformed.

Two variables did show a temporary increase in the year immediately following parental death before returning to baseline levels 1 year later. These were the BSI subscale for depression, $\chi^2(4)$ = 20.8, p = .0004, and the coping style of passive problem solving, $\chi^2(4)$ = 9.8, p = .04. Overall, depressive symptoms were significantly higher more than 1 year prior to parental death, then they dropped in the year immediately before parental death, increased again the year after bereavement, and then returned to the nonbereaved level 1 year after bereavement (see Figure 1B).

Surprisingly, we did not find differences due to bereavement on any dimension that reflected heightened anxiety in the youths,
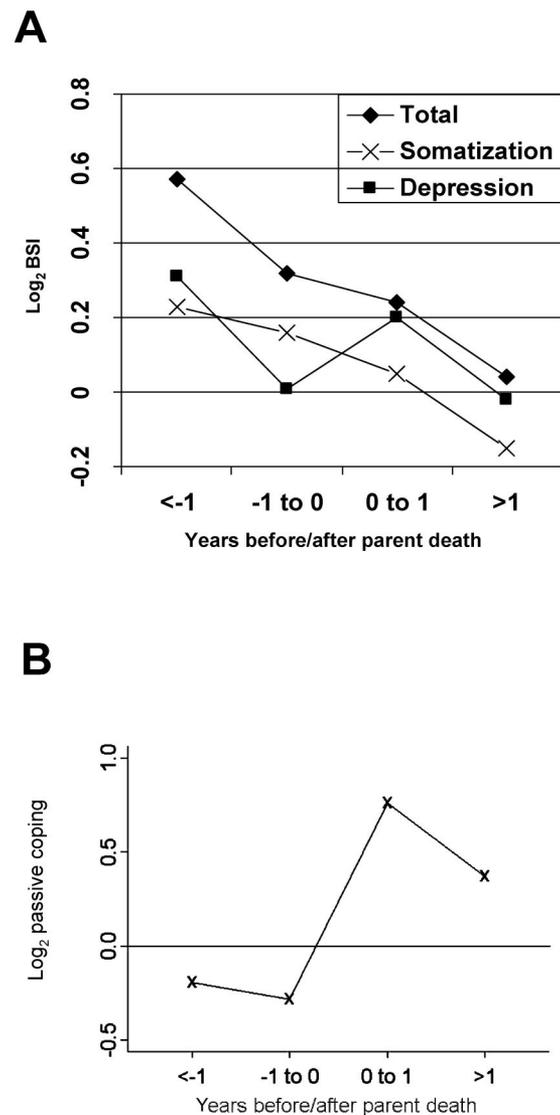

Figure 1. Temporal effects of bereavement compared with the nonbereaved group for (A) emotional distress, somatization, and depression (Log Base 2 Scale) and (B) passive coping (Log Base 2 Scale). BSI = Brief Symptom Inventory.

Table 1
Means (and Standard Deviations) or Percentage of Variables for Bereaved and Nonbereaved Participants and Participants Overall

Response	Bereaved	Nonbereaved	Overall	F	p
Depression	0.465 (0.687)	0.395 (0.638)	0.428 (0.662)	5.20	.0004
Somatization	0.298 (0.513)	0.274 (0.520)	0.285 (0.517)	3.29	.0106
BSI total	0.470 (0.544)	0.421 (0.544)	0.444 (0.544)	3.13	.0139
Passive problem solving	9.200 (3.600)	8.800 (3.600)	9.000 (3.600)	2.45	.0446
Life events	3.600 (3.400)	3.200 (3.300)	3.400 (3.300)	3.89	.0037
Contact CJS (%)	37	39	38	3.95	.0033
Unprotected sex (%)	33	29	31	2.93	.0195

Note. The F statistic and p value for the bereavement variable have 4 numerator degrees of freedom. BSI = Brief Symptom Inventory; CJS = criminal justice system.

including general anxiety, $\chi^2(4) = 2.8$, $p = .60$, obsessive–compulsive, $\chi^2(4) = 7.48$, $p = .11$, or phobic-anxiety, $\chi^2(4) = 4.8$, $p = .30$, symptoms on the BSI.

Adolescent Problem Behaviors and Bereavement

In a pattern similar to the overall emotional distress, bereaved youths were more likely to report contacts with the criminal justice system prior to parental death as compared with levels of non-bereaved youths, whereas after parental death, bereaved and non-bereaved youths were similar, $\chi^2(4) = 15.8$, $p = .003$ (see Figure 2A). Although the percentages of youths with contact with the criminal justice system appear similar on Table 1 for bereaved and nonbereaved youths, when controlling for other factors and time prior to and following parental death, bereaved youths had significantly more contact with the criminal justice system prior to parental death.

Notably, unprotected sex acts by the bereaved youths were significantly higher following parental death, when compared with the time periods prior to parental death, $\chi^2(4) = 11.7$, $p = .02$. However, when compared with nonbereaved adolescents, bereaved adolescents were not significantly different in unprotected sex acts across the study period (see Figure 2B). Surprisingly, no differences were found between the bereaved and nonbereaved adolescents regarding school problems or substance use, and there were no differences between the pre- and postbereavement period within the bereaved group of youths.

Stressful Life Events

Also following the general pattern of emotional distress, bereaved adolescents reported the highest levels of stressful life events in over a year prior to their parent's death, with a decline in stressful events through the time of death and during the bereavement period, $\chi^2(4) = 15.6$, $p = .004$. Stressful life events were similar between the bereaved and nonbereaved group a year following parental death (see Figure 3 and Table 1).

Discussion

This prospective study documents the emotional adjustment, coping, problem behaviors, and life events of bereaved adolescents of PWHs relative to those continuing to live with a PWH over time. There are many advantages to the study design. In the United
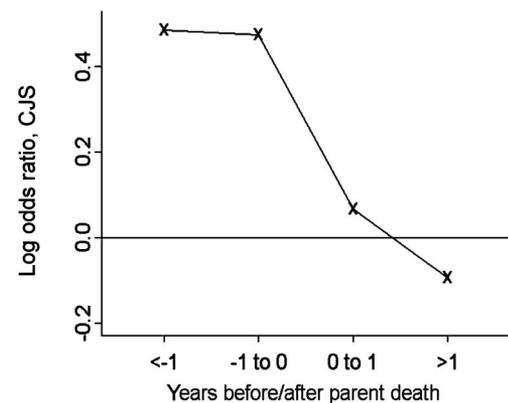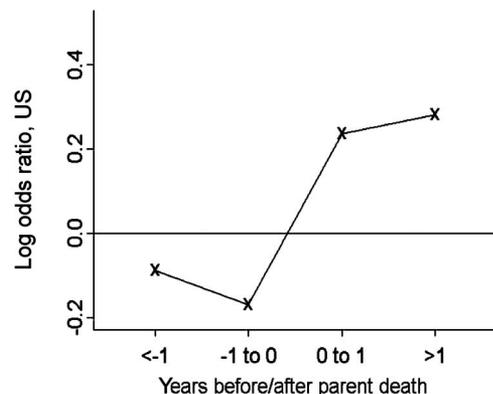
Figure 2. Temporal effects of bereavement compared with the non-bereaved group for (A) contact with the criminal justice system (CJS; Log Odds Ratio [OR] Scale) and (B) unprotected sex acts (US; Log OR Scale).
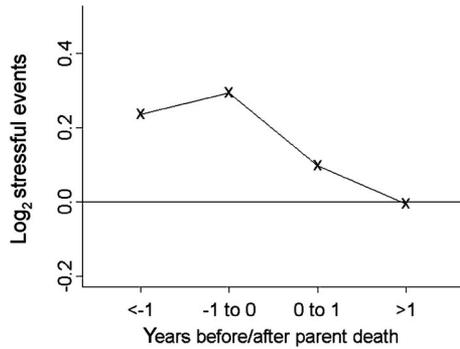
Figure 3. Temporal effects of bereavement compared with the non-bereaved group for the stressful events response.

States, about one third of parents living with HIV reside in NYC (Schuster et al., 2000). NYC is unique because it has a centralized referral source for families living with an AIDS diagnosis, providing the opportunity for a representative sample of PWHs. Thus, we were able to recruit 72% of PWHs from this central referral source during the specified period (84% if untraceable participants are excluded). We followed the adolescents for up to 6 years, maintaining high follow-up rates over time. Furthermore, this study is one of only a few prospective investigations of the impact of parental bereavement on children's adjustment in the past 25 years (Sandler et al., 2003; Stein et al., 1999) and the first prospective study of adolescent adjustment in the face of parental HIV diagnosis.

Most existing research on how chronic parental illness and death affect children comes from the investigation of primarily middle class samples of younger children (Christ, 2000; Romer et al., 2002; West et al., 1991). Parents with HIV in the United States are predominantly African American or Latino (Centers for Disease Control and Prevention, 2001; Schuster et al., 2000). Thus, these data substantially expand our understanding of adolescent adjustment in the context of parental HIV illness and death. Despite the multiple risk factors identified for these youths earlier, symptoms of emotional distress in the cohort were not elevated compared with nonclinical adolescents, with less than 10% of the youths of PWHs meeting criteria for clinical caseness. However, we did find important and unanticipated differences in emotional distress between the bereaved and nonbereaved groups over time.

Contrary to our expectations, the overall emotional and behavioral impact of parental death on the bereaved adolescents was not dramatic compared with nonbereaved adolescents. In this study, adolescents of PWHs experienced their highest levels of emotional distress more than a year prior to the death of their parents. Although we expected that living with a PWH would include feelings of heightened anticipatory anxiety, the impact appeared in reports of symptoms other than anxiety. The BSI subscales describe a pattern of distress marked by isolation and fearfulness of others, irritability and angry impulses, in addition to a range of depressive symptoms and somatic complaints. During the same period, adolescents reported a high level of stressful events in their lives, perhaps related to their parents' HIV diagnoses.

Surprisingly, in the year immediately prior to the parent's death, the adolescents' emotional distress declined. Perhaps as the child

and family became more focused on the necessary tasks of care-taking and planning for the future, the adolescents became more externally focused on the concrete tasks of daily life and reported fewer symptoms. Furthermore, many families with HIV experience increases in social services, medical care, and family support in the immediate time before death, which may serve to protect the adolescent during this period. Many of the parents in this study had preexisting custody plans for their children in the event of disabling illness and death, which enabled the new caretaker to assume responsibility for the child. In many cases, the new caretaker provided a more stable household with more resources than the child's home with the PWH. These explanations are supported by the decline in stressful life events reported by the adolescents, which parallels the decline in overall distress and behavioral problems during this same period.

Although most indicators of distress in the adolescents suggested a peak at least 1 year prior to death and then a linear decline over the year following death and beyond, depressive symptoms followed a different course. The BSI Depression subscale includes symptoms of low mood, anhedonia, hopelessness, and suicidal thoughts. These, as well as an increase in passive problem solving, appeared most sensitive to the acute loss of the parent, as they rose in the time interval following death and then returned to normal levels a year following parental death.

Surprisingly, externalizing behaviors such as substance abuse, school problems, and peer conflicts were not associated with parental death. Our ability to detect fluctuations over time may have been limited by the low base rates reported by the adolescents of PWHs. Perhaps the infrequent risk behaviors reflect youths' abilities to rise to the responsibilities of living with a chronically ill parent. The exception to this is the adolescents' contact with the criminal justice system. Similar to prior emotional distress and negative life events, contact with the criminal justice system was more common in the period prior to parental death and decreased after parental death. Only unprotected sexual behavior showed a steep increase in the immediate period after the parent's death, and high rates of sexual risk were sustained over the subsequent year following death and beyond. We interpret this not as an increase in impulsive, externalizing behavior in the group but as a reflection of the adolescents' developmentally linked needs to establish intimacy in romantic relationships (Erikson, 1950).

Surprisingly, anxiety symptoms did not shift as a function of bereavement. Unfortunately, BSI anxiety scales do not identify symptoms of posttraumatic stress, which may have been a better indicator of anxiety for adolescents experiencing the untimely death of a parent to HIV. Posttraumatic stress models have been proposed for understanding the experience of parental bereavement, as they may account for the persisting sense of vulnerability and helplessness that these children feel (McCloskey & Walker, 2000). In addition, increased rates of posttraumatic stress have been found among children of PWHs (manuscript in preparation) and other parentally bereaved children (Gibbs, 1989; Romer et al., 2002). Traumatic stress research has also contributed central concepts of the importance of traumatic reminders for the clinical presentation and treatment of traumatized and bereaved children (Pynoos, Nader, & March, 1991; Pynoos, Steinberg, & Wraith, 1995), which are important considerations of developmental adaptation over time. Despite decreasing emotional distress found on the BSI in the year following bereavement, these adolescents may

have ongoing vulnerability to reminders of loss as they age into adulthood.

Most of the parents acquired HIV heterosexually in the context of their primary romantic relationships. The central developmental task of young adulthood is to establish intimacy (Erikson, 1950), thus, perceptive adolescents may struggle with accomplishing this developmental task. Similarly, focusing on their family during adolescence may have prohibited adolescents from exploring career options and making vocational plans. Longitudinal research is needed on the adaptation of these adolescents as they age into adulthood.

In this study, we provide important information on the critical periods of vulnerability and distress for adolescents facing parental death. Although it is not surprising that adolescents reported acute depressive symptoms for a year following parental death, the reports of high distress more than a year prior to parental death indicates the importance of early identification and preventive interventions for families affected by HIV. When a parent is diagnosed with HIV, the entire family needs support and information about the impact of HIV illness. Developmentally sensitive interventions must be designed to promote parenting skills, family communication, and positive coping for both parents and children. Previous reports on this trial's outcomes (Rotheram-Borus, Murphy, et al., 2001; Rotheram-Borus et al., 2003) suggest that parental bonds and adaptive coping styles (e.g., positive action, social support, and spiritual coping styles) are associated with the intervention's benefits. Interventions that improve coping skills and address HIV-related challenges may help decrease the increases in problem behaviors, particularly contact with the criminal justice system, in the period prior to parental death.

References

Cates, J. A., Graham, L. L., Boeglin, D., & Tielker, S. (1990). The effect of AIDS on the family system. *Families in Society, 71,* 195–201.

Centers for Disease Control and Prevention. (2001). *HIV/AIDS update: A glance at the HIV epidemic.* Retrieved March 14, 2003, from http://www.cdc.gov/nchstp/od/news/At-a-Glance.pdf

Christ, G. H. (2000). Impact of development on children's mourning. *Cancer Practice, 8,* 72–81.

Derogatis, L. R. (1993). *Brief Symptom Inventory: Administration, scoring, and procedures manual.* Minneapolis, MN: National Computer Systems.

Dowdney, L. (2000). Childhood bereavement following parental death. *Journal of Childhood Psychology and Psychiatry, 41,* 819–830.

Erikson, E. H. (1950). *Childhood and society.* New York: Norton.

Eron, J. J., Benoit, S. L., Jemsek, J., MacArthur, R. D., Santana, J., Quinn, J. B., et al. (1995). Treatment with lamivudine, zidovudine, or both in HIV-positive patients with 200 to 500 CD4+ cells per cubic millimeter. *New England Journal of Medicine, 333,* 1662–1669.

Frierson, R., Lippman, S., & Johnson, J. (1987). AIDS: Psychological stresses on the family. *Psychosomatics, 28,* 65–68.

Garnier, H., & Weisner, T. S. (1994, February). *A longitudinal study on the effects of family lifestyle, values, and drug use on adolescents' achievement.* Paper presented at the meeting of the Society for Research on Adolescence, San Diego, CA.

Gibbs, M. S. (1989). Factors in the victim that mediate between disaster and psychopathology: A review. *Journal of Traumatic Stress, 2,* 489–514.

Gonzalez, S., Steinglass, P., & Reiss, D. (1989). Putting the illness in its place: Discussion groups for families with chronic medical illnesses. *Family Progress, 28,* 69–87.

Harris, E. S. (1991). Adolescent bereavement following the death of a parent: An exploratory study. *Child Psychiatry and Human Development, 21,* 267–281.

Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist, 42,* 1106–1116.

Joint United Nations Program on HIV/AIDS (UNAIDS)/United Nations Children's Fund (UNICEF)/United States Agency for International Development (USAID). (2002, July). Children on the brink 2002: A joint report on orphan estimates and program strategies. Retrieved July 15, 2003, from http://www.unaids.org/barcelona/presskit/childrenonthebrink.html

Kinloch-de Loes, S., & Perrin, L. (1995). Therapeutic interventions in primary HIV infection. *Journal of Acquired Immune Deficiency Syndromes, 10,* S69–S76.

Lamping, D. L., Gilmore, N., Ryan, B., Sewitch, M., Grover, S. A., Williams, J. L., et al. (1991, June). *HIV-related mental health distress in persons with HIV infection, caregivers, and family members/significant others: Results of a cross-Canada survey.* Paper presented at the VII International Conference on AIDS, Florence, Italy.

McCloskey, L. A., & Walker, M. (2000). Posttraumatic stress in children exposed to family violence and single-event trauma. *Journal of the American Academy of Child Adolescent Psychiatry, 39,* 108–115.

Michaels, D., & Levine, C. (1992). Estimates of the number of motherless youth orphaned by AIDS in the United States. *Journal of the American Medical Association, 268,* 3456–3461.

Murphy, D. A., Rotheram-Borus, M. J., & Joshi, V. (1999). Tuberculosis testing, knowledge, and medication adherence among HIV-infected adolescents and adults. *AIDS Care, 12,* 59–63.

Namir, S., Wolcott, D. L., Fawzy, F. I., & Alumbaugh, M. J. (1987). Coping with AIDS: Psychological and health implications. *Journal of Applied Social Psychology, 17,* 309–328.

Olson, D., McCubbins, H., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1982). *Family inventories: Inventories used in a national survey of families across the family life cycle.* St. Paul, MN: University of Minnesota.

Pynoos, R. S., Nader, K., & March, J. (1991). Posttraumatic stress disorder. In J. Weiner (Ed.), *Textbook of child and adolescent psychiatry* (pp. 339–348). Washington, DC: American Psychiatric Publishing.

Pynoos, R. S., Steinberg, A. M., & Wraith, R. (1995). A developmental model of childhood traumatic stress. In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology: Risk, disorder, and adaptation* (Vol. 2, pp. 72–95). New York: Wiley.

Rolland, J. S. (1988). Chronic illness and the family life cycle. In B. Carter & M. McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy* (2nd ed., pp. 433–456). New York: Gardner Press.

Romer, G., Barkmann, C., Shulte-Markwort, M., Thomalla, G., & Riedesser, P. (2002). Children of somatically ill parents: A methodological review. *Journal of Clinical Child Psychology and Psychiatry, 7,* 17–38.

Rosenheim, E., & Reicher, R. (1986). Children in anticipatory grief: The lonely predicament. *Journal of Clinical Child Psychology and Psychiatry, 15,* 115–119.

Rotheram-Borus, M. J., Draimin, B. H., Murphy, D. A., & Reid, H. M. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS, 11,* 1159–1164.

Rotheram-Borus, M. J., Lee, M. B., Gwadz, M., & Draimin, B. (2001). An intervention for parents with AIDS and their adolescent children. *American Journal of Public Health, 91,* 1294–1302.

Rotheram-Borus, M. J., Lee, M. B., Leonard, N., Lin, Y. Y., Franzke, L., & Lightfoot, M. A. (2003). Four-year behavioral outcomes of an intervention for parents living with HIV and their adolescent children. *AIDS, 17,* 1217–1225.

Rotheram-Borus, M. J., Lester, P., Wen, P., & Shen, Q. (2004). Custody plans among parents living with HIV. *Archives of Pediatrics & Adolescent Medicine, 158,* 327–332.

Rotheram-Borus, M. J., Lightfoot, M., & Shen, H. (1999). Levels of emotional distress among parents living with AIDS and their adolescent children. *AIDS and Behavior, 4,* 367–372.

Rotheram-Borus, M. J., Murphy, D. A., Wight, R. G., Lee, M. B., Lightfoot, M. A., Swendeman, D., et al. (2001). Improving the quality of life among young people living with HIV. *Evaluation Program Planning, 24,* 227–237.

Rotheram-Borus, M. J., Stein, J. A., & Lin, Y. Y. (2001). Impact of parent death and an intervention on the adjustment of adolescents whose parents have HIV/AIDS. *Journal of Consulting and Clinical Psychology, 69,* 763–773.

Saldinger, A., Cain, A., Kalter, N., & Lohnes, K. (1999). Anticipating parental death in families with young children. *American Journal of Orthopsychiatry, 69,* 39–48.

Sandler, I. N., Ayers, T. S., Wolchik, S. A., Tein, J. Y., Kwok, O. M., Haine, R. A., et al. (2003). The family bereavement program: Efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. *Journal of Consulting and Clinical Psychology, 71,* 587–600.

Schuster, M. A., Kanouse, D. E., Morton, S. C., Bozzette, S. A., Miu, A., & Scott, G. B. (2000). HIV-infected parents and their children in the United States. *American Journal of Public Health, 90,* 1074–1081.

Siegel, K., Karus, D., & Raveis, V. (1996). Adjustment of children facing the death of a parent due to cancer. *Journal of the American Academy of Child and Adolescent Psychiatry, 35,* 442–450.

Silverman, P. R., & Worden, J. W. (1992). Children's reactions in the early months after death of a parent. *American Journal of Orthopsychiatry, 62,* 93–104.

Stein, J. A., Riedel, M., & Rotheram-Borus, M. J. (1999). Parentification and its impact among adolescent children of parents with AIDS. *Family Process, 38,* 193–208.

West, S. G., Sandler, I., Pillow, D. R., Baca, L., & Gersten, J. C. (1991). The use of structural equation modeling in generative research: Toward the design of a preventive intervention for bereaved children. *American Journal of Community Psychology, 19,* 459–480.

Zayas, L. H., & Romano, K. (1994). Adolescents and parental death from AIDS. In B. O. Dane & C. Levine (Eds.), *AIDS and the new orphans: Coping with death* (pp. 59–76). Westport, CT: Auburn House.