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Picking Up the Pieces: Caregivers of Adolescents Bereaved by Parental AIDS

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ABSTRACT

This study describes caregivers of adolescents whose parents died of AIDS and examines how caregivers perceive the impact of raising bereaved adolescents. For adolescents bereaved by AIDS, 65 non-parental caregivers were recruited and assessed twice over 6 months. Most caregivers (89%) were female members of the extended family, 49% were married and 29% were employed. Caregivers were older and more likely to be employed than parents with HIV (PWH), but were similar in ethnicity, partnership and financial status, and religiosity. Caregivers had generally been selected by the parent prior to death (66%) and most caregivers (75%) had at least moderate involvement in the care of the youth prior to parental death. Caregiver–youth relationships were stable (91%) over a 6-month period. Caregivers were significantly less emotionally distressed than PWH had been. Caregiver burden was rated as moderate; the number of positive caregiver–youth relationships decreased significantly over 6 months. Family caregiving is a common, ongoing and stable relationship in families coping with AIDS.

KEYWORDS

adolescents, AIDS, caregiver, orphans

Introduction

CAREGIVING, DEFINED AS the parenting of non-biological children, is a practice that has increased dramatically in the past decade among grandmothers, aunts and female family members (Burnette, 1999; Carten & Fennoy, 1997; Fuller-Thomson, Minkler, & Driver, 1997). Almost 5% of youth in the USA (3.2 million) live in households headed by grandparents or other relatives (Fuller-Thomson et al., 1997), usually without the parent living in the same household (Joslin & Brouard, 1995). In a national survey, about 11% of grandparents have primary responsibility of a grandchild for at least 6 months (Fuller-Thomson et al., 1997). African Americans are about twice as likely as whites to provide kinship care, in part because of cultural norms and a history of strong, intergenerational bonds (Burnette, 1999; Fuller-Thomson et al., 1997; Guarnaccia &

Parra, 1996). Parental substance abuse and addiction are the most commonly cited reasons for assuming a caregiver role (Burton, 1992); however, caregiving also arises from parental death, incarceration and mental health problems (Burton, 1996; Carten & Fennoy, 1997; Fuller-Thomson et al., 1997; Minkler & Roe, 1993).

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When a parent is coping with HIV-related illness or dies from HIV, a caregiver is often needed (Levine, Stein, Draimin, & Gamble, 1994). About 125,000 youth have been orphaned by AIDS in the USA (Michaels & Levine, 1992) and about 15,800 are orphaned annually (Liebowitz et al., in press). These children need new custodial guardians. The first goal of this study is to describe non-parental caregivers of adolescents bereaved by AIDS and the types of burdens assumed by caregivers.

The second goal of this article is to examine the characteristics of the caregiver's living situation compared with the living situation when the PWH was alive. Research on children of divorce (Hetherington, Bridges, & Insabella, 1998) suggests that the characteristics of a new living situation are most critical to children's long-term adjustment, rather than the degree of interpersonal loss or interparental conflict. For example, socio-economic status is of particular importance in the long-term adjustment of children of divorce (Clarke-Stewart, Vandell, McCartney, Owen, & Booth, 2000) and may be important for children of PWH. Most PWH are single-parent mothers who lived in neighborhoods with high rates of substance abuse. The families live within subcultures of high alcohol and drug use (Centers for Disease Control and Prevention [CDC], 1998). Caregivers of youth of PWH may or may not be living in similar circumstances. In this study, we examine the characteristics of the family's household and the socio-economic status of the caregivers compared with the situation when the PWH was alive.

In addition, parents' mental health symptoms significantly predict youth's mental health status (Goodman & Gotlib, 1999; Silver, Stein, & Dadds, 1996), and such relationships have been found among families with a PWH (Rotheram-Borus & Stein, 1999). Most of the PWH in this sample had reported clinical levels of depression and anxiety at the time of recruitment (66%; Stein, Reidel, & Rotheram-Borus, 1999). Therefore, in addition to examining the socio-economic status of PWH vs caregivers, we also examined the mental health status of the caregiver in contrast to these characteristics among the parents who had died from HIV. These comparisons allow us to generate hypotheses regarding the child's developmental context when the family setting shifts from the parent with HIV to caregivers. The mental health status of the new caregivers was anticipated to be better than from that of the PWH.

Methods

Parents with HIV and caregivers

The caregivers were recruited during the conduct of a longitudinal prospective study of bereaved adolescents. From an initial cohort recruited from 1993 to 1994, 307 parents living with HIV (PWH) and 412 of their adolescent children aged 12–18 years were followed prospectively (Lee & Rotheram-Borus, 2001). Assessed at 3-month intervals for 2 years and at 6-month intervals after that, there was a 92% annual retention rate over 6 years (Rotheram-Borus, Draimin, Murphy, & Reid, 1997). Most PWH were mothers (80%). PWH were primarily from ethnic minority backgrounds (Latino, 45%; African American, 34%; Caucasian, 11%; and 10% were of other ethnicities). A large proportion of PWH had not finished high school (40%), with 25% completing high school and passing the GED, 28% completing part of college and 7% obtaining a college or post-graduate degree.

Over 6 years, 147 parents died (Lee & Rotheram-Borus, 2001), leaving 184 adolescents bereaved by AIDS. Verbal consent was obtained from the youth to contact the caregiver for participation and, where applicable, another surviving parent. Two youth declined to have their caregivers enrolled. We obtained voluntary signed informed consent from caregivers for their participation, as well as for the adolescents to continue

in the study. Following parental death we identified a 'primary caregiver', as someone who met at least three of the following criteria at any point during the first year after parental death: (i) sheltered the youth at least half the week or for large blocks of time beyond a month; (ii) paid for a significant proportion of necessities for survival (food, medical care, clothing); (iii) disciplined the youth; (iv) provided on-going supervision; and (v) had the authority to make decisions for the youth; for example, about where he/she lived. Using these criteria, it was possible for a youth to have more than one primary caregiver if they were not living independently.

Of 184 bereaved youth, 53 lived independently after parental death (28%) and four were in institutional settings (2%). The remaining 127 youth were with 132 caregivers (47%); 105 (79.5%) were recruited, 10% ($n = 13$) refused and 11 are still in the process of being recruited (3 unknown). An additional 22 of these caregivers were uninfected mothers raising their children after the father living with HIV died and 18 were step-parents or a surviving father who assumed caregiving (22%; $n = 40$ parental caregivers). These caregivers were also excluded from the analysis yielding 65 non-parental caregivers.

Caregivers were tracked longitudinally at 6-month intervals; this report focuses on the first recruitment interview and the following interview 6 months later (completed by 91% of caregivers).

Recruitment was scheduled to take place 3–6 months after parental death; however, in many cases it was delayed, often because the caregiver declined to participate in the study during the initial post-death period. The average period between parental death and enrollment was 1.19 years ($SD = 0.92$). In most cases, the caregiver was raising one project youth (78%), although 20 caregivers were raising two or three project youth. Thus, these 65 caregivers were raising 97 youth. When caregivers were raising more than one project youth, only one youth in the family was randomly chosen as the focus of the caregiver's ratings in the present analysis.

Interviews Interviewers were predominantly African American and Latino (62%); nine were bilingual in Spanish, and all received at least 4–6 weeks of training that covered interviewing, ethics, confidentiality, child abuse, emergency crisis protocols, HIV and AIDS, and conducting in-home assessments. About 3% of families were Spanish-speaking only. Prior to assessing participants, interviewers conducted mock interviews, were observed by a supervisor and met established criteria for successful interviewing. Audio-tapes of the assessment interviews were randomly monitored for quality assurance and supervision on an ongoing basis.

Assessments

Caregiver's background Caregivers were interviewed twice in their homes for about 1.5 hours using a structured protocol. The first interview followed parental death, and the second interview followed 6 months later. Demographic and background information, including the relationship of the caregiver to the youth, the caregiver's age, ethnicity, household composition (e.g. who else resides in the household, spouse, other biological children, etc.), financial condition (rated on a scale of 1 to 4; very poor, poor, have the necessities, or comfortable), education, partner status, work history, and public social service benefits were reported.

Custody arrangements The caregiver's report of past and present custody situations, including the original plan made by the parent and the actual custodial arrangement(s)

for the youth after the parent's death were reported. Evaluation of the custody plan included: the length of time the child lived with and/or was cared for by the caregiver, previous involvement in the youth's care, and legality of custodial status.

Emotional distress The caregiver also reported his or her emotional distress on the Brief Symptom Inventory (BSI; Derogatis, 1993), a 53-item symptom inventory with a global scale score and nine subscales of: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychotism (Cronbach's α range: .70-.93).

Caregiver concerns The Burden Scale (now called the Caregiver Strain Questionnaire; England & Roberts, 1996; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997) examined the perceived impact the youth's functioning had on the caregiver in the previous 3-month period. Caregiver's rated three items on youth's physical health and three items on emotional health on a 5-point Likert scale (0 = 'not at all'; 4 = 'a lot') and a mean score was calculated for each. Caregivers also rated their own distress over youth's functioning on three items. Caregiver's rated the positive relationships on nine true/false statements regarding their family's living situation. Items that indicated a negative family relationship were reversed to be interpreted as positive relationships. The sum of these nine items indicated a score for positive family relationships (scale range 0-9). Examples of positive family relationships are: 'There is plenty of time and attention in our family'; 'Family members help and support each other'; and 'There is a feeling of togetherness in our family'. Caregiver's rated the emotional impact of their new role and a mean score calculated on 7 items scored on a 5-point Likert scale (0 = 'never true'; 4 = 'often true'; e.g. 'It is painful to see what (the youth) is going through'; α = .85).

Assessments of PWH

At the time of recruitment into the study, PWH reported their age, ethnicity, household composition, financial condition, education, partner status and work history. PWH's emotional distress was also assessed in the BSI (global, Cronbach's α = .97; depression, Cronbach's α = .85; anxiety, Cronbach's α = .84).

Custody plans PWH reported their discussions with potential guardians about custody, contacts with social service agencies, wills and legal arrangements, and legal standby custody agreements for each child.

Data analysis

Comparison of non-parental caregivers with PWH matched on family were conducted using chi-squared analysis or *t*-test statistics. *T*-test statistics were used in comparing PWH's levels of emotional distress to caregivers' levels at recruitment and 6 months later. Similarly, *t*-test statistics were used in comparing caregivers' perceptions of adolescents at the time of recruitment and 6 months later.

Results

Comparisons of caregivers and PWH

Table 1 summarizes the socio-demographic characteristics of the caregivers and the PWH. Caregivers were similar to PWH in most socio-demographic characteristics. Most were primarily female (89%), and from Latino (37%) or African American (55%) ethnic background. However, caregivers were significantly more likely to be African American

than were PWH ($\chi^2 = 35.44$, d.f. = 2, $p = .0001$). The caregivers were typically related to the youth: 35% were grandparents or great grandparents; 26% were other relatives (e.g. aunts); 20% were siblings; and 18% were non-relatives. On average, the caregivers were 44.9 years old ($SD = 14.6$), and ranged in age from 20 to 81 years. This is about 8 years older than the youth's PWH and the range in ages among caregivers is much larger. The youth were aged 16.3 years ($SD = 1.55$). Among the 65 non-parental caregivers, 10 caregivers (15.4%) were also raising other (non-project) adolescents. Almost all caregivers (85%) had raised or were also raising their own children, so that the mean number of children in the household was 2.6 ($SD = 1.17$). Most caregivers had graduated from high school (60%), and most had worked in their lifetimes (80%). Currently, 29% were working and 23% were retired. In contrast, only about 8% of PWH had been working while parenting their adolescent children, yet educational background was similar to caregivers. Almost all caregivers received some form of government aid (91%). Caregivers were asked to report their household financial situations: 38% said they were poor or struggling; 29% said they 'have the necessities'; and 32% said they were comfortable. The ratings were very similar to that of the parents. Almost half (49%) reported no change in their financial situation since starting to take care of the adolescent, and 37% reported that their financial situation had become more difficult. Only about 18% reported problems with the youth's government benefits (social security, Medicare).

About half (49%) had romantic partners and most partners (59%) were working (a pattern very similar to the PWH). Finally, most of caregivers reported being somewhat or very religious. Again, most PWH also reported being very religious.

Caregiving history Almost all caregivers had sole responsibility for youth; only 8% were raising the youth with another adult sharing the responsibility. Caregivers generally did not begin their role with the death of the parent or the most recent serious illness episode. Most caregivers (75%) had previously assumed significant responsibility for the youth while the PWH was alive. Some caregivers (14%) had always raised the youth, sometimes in conjunction with the biological parent. Full-time (permanent) caregiving generally started close to the time of death for youth whose parents were deceased (78%). At the time of the recruitment interview, the caregiver had been raising the adolescent full-time for an average of 1.54 years ($SD = 2.43$), typically 4–5 months prior to parental death.

Many caregivers (66%) reported that the PWH selected them to raise the youth, similar to the reports of PWH. Caregivers reported having legal custody of youth under age 18 about half the time, including foster care arrangements (58%), but only 29% of the permanency plans had been formalized by a judge, indicating that the proportion of caregivers with legal custody of youth in their care was likely to be lower than reported. At 6 months after recruitment, almost all (89%) of caregivers were still taking care of the adolescent. Youth who left the caregiver's household generally lived independently.

Mental health status Table 2 summarizes the caregivers' reports of emotional distress at the time of recruitment and then 6 months later, as well as the PWH's rating of their emotional distress at the time of recruitment. Comparisons of these scale scores indicate that the caregivers report significantly less emotional distress than the parents on each subscale (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism). When comparing the caregivers' reports of emotional distress at recruitment to their own emotional distress reported 6 months later, the levels of emotional distress are similar across all BSI scales and overall.

Table 1. Comparison of non-parental caregivers with parent characteristics matched on family at baseline

	Parents	Caregivers	Overall
	(n = 65)	(n = 65)	(n = 130)
<i>Socio-demographic Characteristics</i>			
Female (%)	91	89	90
Mean age (SD)	36.2 (4.40)	44.9 (14.6)	40.5 (13.2)
Ethnicity (%)			
Latino	40	37	41
Black	45	55	45
White and others	14	8	15
Educational levels (%)			
Less than high school	43	40	42
High school	34	25	29
More than high school	23	35	29
Partner relationship (%)	46	49	48
Employed (%)	8	29	21
Financial situation (%)			
Struggling to survive or barely paying the bills	51	38	45
Have the necessities	22	29	26
Comfortable	27	32	29
Religiosity (%)			
Very or somewhat	93	92	93
Not at all	7	8	8

Table 2. Comparison of parents' levels of emotional distress with caregivers' levels at recruitment and caregivers' ratings 6 months later

	Parents at Baseline	Caregivers at Baseline	Caregivers 6 months later
	(n = 65)	(n = 65)	(n = 59)
<i>Emotional Distress (BSI)</i>			
<i>Brief Symptom Inventory (SD)</i>			
Overall BSI	2.02 (0.76)*	0.51 (0.43)	0.52 (0.49)
Somatization	2.28 (0.86)*	0.42 (0.49)	0.48 (0.65)
Obsessive-compulsive	2.23 (1.07)*	0.60 (0.64)	0.62 (0.62)
Interpersonal sensitivity	1.92 (0.92)*	0.49 (0.48)	0.59 (0.63)
Depression	1.99 (0.90)*	0.54 (0.62)	0.53 (0.75)
Anxiety	1.93 (0.99)*	0.55 (0.61)	0.44 (0.59)
Hostility	1.91 (0.79)*	0.50 (0.68)	0.45 (0.56)
Phobic anxiety	1.81 (0.98)*	0.27 (0.44)	0.27 (0.44)
Paranoid ideation	1.99 (0.83)*	0.83 (0.85)	0.86 (0.84)
Psychoticism	1.70 (0.79)*	0.35 (0.44)	0.39 (0.45)

Note. All the levels of emotional distress differed significantly among parents and caregivers at baseline. Levels of emotional distress among caregivers at baseline and 6 months later did not differ significantly.

* $p < .05$.

Caregiving over time Caregivers report little burden of caregiving due to youth's emotional state ($M = 0.17$ – 1.44 on a scale range of 0–4), and youth's physical health ($M = 0.06$ – 0.77 on a scale range of 0–4). The burden of caregiving generally tends to be stable over the 6-month period (i.e. was not significantly different; $p > .05$). Caregivers reported a moderate emotional impact from assuming their new role with youth ($M = 1.38$ – 3.29 ;

range 0–4) and this was similar at 6 months. The number of positive family relationships declined significantly over the 6 months from a mean of 7.06 (SD = 1.58) positive events at the time of recruitment in contrast to 5.69 (SD = 2.11) events reported 6 months later. ($t = -5.14, p < .0001$).

Conclusion

This article describes the caregivers of HIV bereaved youth and how caregivers adjust to parenting non-biological adolescent children. The original sample of PWH represented families with parental AIDS in New York City, an epicenter with 30% of the AIDS orphans in the USA (Michaels & Levine, 1992). The socio-demographic characteristics of the PWH's in our original study are consistent with the CDC's profile of cases of heterosexual transmission of HIV (CDC, 1998), and reflect 77% of a consecutive series of PWH referred to the DAS in New York City. The caregiver sample reflects about 71% of the potential non-parental caregivers for bereaved youth, suggesting that this is a sample characteristic of caregivers of HIV-bereaved adolescents.

The caregivers' relationships were closely monitored after parental death and very complex relationships evolved. Among 184 bereaved youth, parental death led 22% of youth to live with a surviving parent, 50% lived with non-parental caregivers, 28% lived independently and 2% lived in institutional settings. Although the focus of this article is on caregiving, the pathways of bereaved youth to new living situations suggest the importance of studying bereaved youth: one in four is living independently at a young age. The situations of these youth after parental death have not been described previously.

The non-parental caregivers presented in this report are similar to clinical reports and custody patterns of caregiving associated with other diseases (Collins, Stommel, Wang, & Given, 1994; Guarnaccia & Parra, 1996). Most caregivers are women, and related to the PWH. Further, these female relatives are involved with the care of adolescents long before a parent dies. Thus, the caregivers who assume parenting roles are for the most part 'not new'. Similar to other studies (e.g. Burnette, 1999; Fuller-Thomson et al., 1997), African American and Latino women are involved in the care of their family members, particularly African American women. Further, PWH are involved in the selection of their children's caregivers. Most youth go to live with a caregiver prior to or at the time of parental death, and this arrangement tends to endure for at least 1–2 years after parental death. While we report that 91% of the caregiving relationships are stable over 6 months, these caregivers had typically assumed their roles 1–2 years earlier. Therefore, the stability of the caregiving relationship is longer than examined in this study.

The living situations with caregivers appear highly similar to the situation when the PWH was alive. Caregivers' financial status is similar to or better than the financial status of PWH and the children's lives do not appear to decrease significantly in financial status or stability, as do the lives of children of divorce. Caregivers have romantic partners, are highly religious, receive public assistance, and are of similar ethnicity to PWH. Caregivers are older and more likely to be employed. Many caregivers have other children and a partner in the household, but this partner is not 'responsible' for the HIV-bereaved children. The caregivers' levels of emotional distress are similar to adults in the general population, while PWH reported rates similar to adult psychiatric out-patients (Derogatis, 1993). In contrast to the children of divorce whose family upheavals thrust the youth into poverty (Hetherington et al., 1998), bereaved youth are entering more stable settings with their caregiver. It will be key to monitor the youth's outcomes over time, in response to these stable environments.

Caregivers report adjusting well to parenting the bereaved youth. As noted earlier, caregivers have symptoms of emotional distress similar to the general population. Furthermore, caregivers' levels of anxiety decreased significantly over the 6-month period. The caregivers' perceptions of the youth and of their own adjustment are relatively positive, not only at the first assessment following the PWH's death, but also over the next 6 months. Caregiver burden is moderate as new stress has been assumed. However, caregivers report that the youth have a significantly smaller impact on the caregiver's life and appear to be in less emotional distress at the second assessment 6 months later. The number of positive family events does decrease significantly from 7 to 5 over 6 months, indicating that stress continues. Overall, however, caregivers are not reporting significant negative reactions to their caregiving roles. In part, the positive aspects of adjustment may due to caregiver's long-standing involvement in the lives of the youth. The long-term adjustment of caregivers to bereaved adolescents and adolescents' reactions to these patterns is the focus of ongoing research.

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