Brief Report: Fathering a Child Living With HIV/AIDS: Psychosocial Adjustment and Parenting Stress

Lori S. Wiener,1 PhD, ACSW, Mary Jo P. Vasquez,1,2 MPhil, and Haven B. Battles,1 PhD
1National Cancer Institute and 2The George Washington University

Objective: To examine the psychosocial stressors experienced by fathers of children diagnosed with HIV/AIDS.

Methods: Thirty-one fathers whose children (ages 6 to 19) were participating in pediatric HIV clinical trials completed self-report measures of parenting stress, psychological distress, and need for psychosocial services.

Results: Over half of this sample experienced significantly elevated levels of both parenting stress and psychological distress compared to standardized norms. Ninety-seven percent of these men reported the need for services including gender-specific support groups, assistance with discipline, disease management, and assistance with planning for the future.

Conclusions: Elevated levels of parenting stress and psychological distress in fathers of children living with HIV suggest the need for additional psychological intervention in this population.

Key words: fathers; HIV/AIDS; children; psychological distress; parenting stress; chronic illness.
treatment, pediatric HIV disease is now considered a chronic illness. This is evidenced by decreasing morbidity and mortality in the pediatric population and a maturation of children living with HIV infection into adolescence. As such, the plight of families affected by HIV/AIDS may be viewed as similar to the experiences faced by families affected by other chronic illnesses. Studies have documented that parents of a child with a chronic illness or disability experience heightened levels of psychological distress as a result of the increased stress associated with their situation (Carter, Urey, & Eid, 1992; Kazak & Barakat, 1997; Sloper, 1996). However, equivocal results have been found between maternal and paternal responses to stress (Cayse, 1994; Kazak, 1987; Kazak & Marvin, 1984; Krauss, 1993; Rodrigue et al., 1996). Of the few existing studies that specifically examined parental responses to an HIV-infected child, findings indicate that these parents experience high levels of psychological distress (Drotar, Agle, Eckl, & Thompson, 1997) and that they remain at high risk for psychiatric morbidity over time (Wiener, Riekert, Theut, Steinberg, & Pizzo, 1995). Only two published reports included fathers in the sample (Melvin & Sherr, 1993; Wiener, Theut, Steinberg, Riekert, & Pizzo, 1994); neither specifically examined the paternal experience.

This study was designed to systematically explore the psychosocial adjustment, parenting stress, and identified needs associated with fathering a child with HIV infection. We hypothesized that fathers of children infected with HIV would report higher levels of psychological distress and parenting stress compared to standardized normative samples. Because extensive normative data for fathers of chronically ill children are not available, parenting stress index scores of fathers in this sample were also compared with data of fathers of children living with asthma (Markson & Fiese, 2000). Additionally, we hypothesized that fathers who had previously lost a spouse or another child to HIV/AIDS would experience higher levels of parenting stress than those who had not experienced such a loss.

**Method**

**Participants**

Participants in this study were part of the clinical research program at the HIV/AIDS Malignancy Branch of the National Cancer Institute. This branch offers treatment to HIV-infected children who meet eligibility criteria for participation in a clinical trial. Biological, foster, and stepfathers, as well as other male caregivers living in the household and caring for a child at least 20 hours per week for a period of at least 1 year, were invited to participate. Out of 149 parents who accompanied their children for clinic visits during this period of time, 35 were fathers (23%) and all 35 (100%) were eligible for and agreed to enroll in the study. None of the 149 children had both parents accompany them to clinic during the study time, although an additional 12% were reported to have a father living in the home. Data were excluded for one father who was unable to attend an appointment at the clinic during the data collection period and three fathers who did not complete all of the assessment measures, resulting in complete data from 31 fathers.

Participants had a mean age of 48.1 (range: 30 to 70 years, $SD = 8.5$). Seventy-one percent of the participants self-identified as Caucasian, 16% as African American, 10% as Hispanic/Latino, and 3% as multiracial. Fifty-two percent were biological fathers, 16% were adoptive fathers, 16% were other male relatives, 6% were foster fathers, and 10% identified themselves as “other.” Of these, 90% of the participants had cared for the child for 2 years or longer. Sixteen percent of the participants had two or more HIV-infected children living at home and 29% were the child’s only caregiver. Ten percent of the participants reported that they were infected with HIV and 6% reported that they did not know their HIV status. The mean educational level was 13.5 years ($SD = 2.9$). Twenty-nine percent of the participants had household annual income less than $30,000, 29% between $30,000 and $49,000 a year, and 41% as $50,000 or more.

Demographic information was also collected on the participants’ children. Ages ranged from 6 to 19 years ($M = 12.3, SD = 4.4$); 59% acquired HIV vertically, 22% acquired HIV via hemophilia-related transfusions, and 19% acquired HIV from non-hemophilia-related transfusions.

**Procedure**

The protocol and consent form were approved by the Office of Human Subjects Research. The principal investigator recruited participants, described the investigation, obtained informed consent, and
scheduled the interview with one of the authors (LW or MJV) during their child’s clinic visit. Participants completed the self-administered measures listed below.

**Measures**

**Parenting Stress Index (PSI; Abidin, 1995).** The PSI is a 121-item self-report measure that assesses the degree of parental distress and difficulty along three major domains: child characteristics, parent characteristics, and situational/demographic life stress. The parent and child domain subscale scores and the composite PSI score were used as outcome measures for this investigation. Lower scores indicate less parenting stress. The PSI is a widely used measure of parenting stress and demonstrates high levels of validity and reliability (Loyd & Abidin, 1985). Internal consistency coefficients range from .87 to .91. Normative father data used for statistical comparisons are from the PSI manual (100 fathers of children ages 4 to 6 years) (Abidin, 1995). Internal consistency measured by Cronbach’s alpha for this sample was .94.

**Brief Symptom Inventory (BSI; Derogatis, 1993).** The BSI is a 53-item paper and pencil self-report inventory assessing psychological distress. The BSI includes nine individual symptom scales and three global indices of distress. The Global Severity Index was used in this study as a general report of psychological distress. Lower scores indicate less distress. Normative male data used for statistical comparisons are from the BSI manual (344 adult nonpatient males). The test-retest coefficient for the GSI is .90, and the construct and predictive validity of the BSI are reported to be high (Derogatis & Melisaratos, 1983). Internal consistency measured by Cronbach’s alpha for this sample was .95.

**Fathers’ Questionnaire.** A self-administered questionnaire developed by the investigators included a checklist of service needs such as different types of counseling services and support groups. Fathers were asked to check off each service that they would use, if available. Of the services listed, only clinic-based parent support groups were available to all participants at the time of the study. To assess the need for more specific services, fathers were also asked to rate on a scale from 1 (no assistance needed) to 5 (a lot of assistance needed) the areas in which they needed assistance. This section included areas such as parenting, planning for the future, disclosing the diagnosis, and health insurance. The questionnaire took approximately 20 minutes to complete.

**Results**

Preliminary analyses were conducted to rule out the possibility that differences in PSI and BSI scores could be the result of demographic variables. Pearson product-moment correlations were run between the father’s age and PSI and BSI scores. An independent samples \( t \) test was conducted to determine if there were any differences on the PSI and BSI for fathers who were HIV-infected and those who were not. ANOVAs were conducted to determine if there were any significant differences on PSI or BSI scores by child’s HIV transmission mode, race/ethnicity, education level, or income level. We found no significant differences for any comparisons.

**Parenting Stress**

To test the hypothesis that fathers in this sample experienced higher levels of parenting stress than the normative fathers sample (Abidin, 1995) on the PSI, we performed a one-sample \( t \) test comparing the scores obtained by this group of fathers to the mean score of the normative group of fathers on the PSI. Results indicate that fathers in this sample experienced significantly more parenting stress than the normative group on the child subscale (\( t = 2.98, p < .01 \)). Fathers in this sample also experienced more parenting stress than the normative fathers group on the total subscale (\( t = 2.54, p < .05 \)). There was no statistically significant difference between groups on the parent subscale. Fathers from this study were compared to fathers of children with asthma (Markson & Fiese, 2000) using a one-sample \( t \) test and no significant differences were found on the child, parent, or total PSI scores. Data from this sample of fathers, the normative sample, and the asthma sample are reported in Table I.

**Psychological Distress**

To test the hypothesis that fathers of children living with HIV/AIDS experienced higher levels of affective distress than the adult nonpatient male normative group (Derogatis, 1993), we conducted a
one-sample *t* test comparing these sample scores to the normative sample mean. The results indicated that the fathers in this sample experienced significantly more psychological distress than the males in the normative group (*t* = 2.91, *p* < .01). Data for both samples are reported in Table II.

**Losses**

We found no statistically significant differences on outcome measures between fathers who had experienced a loss of a spouse/partner or other child and those who had not.

**Service Needs**

Nearly all (97%) of the fathers in this study identified services they felt they would utilize if available. Specifically, 79% of the fathers indicated they needed and wanted help planning for the future, 56% indicated the need for additional information on medical or insurance services, 48% identified the need for information on disease management, 42% indicated the need for assistance or support in their relationships with significant others, 38% of the fathers in this sample identified the need for assistance in disciplining their child, and 34% sought assistance in disclosing the diagnosis to others. In addition, 37% requested a support group for fathers and 26% of the participants indicated that they would take advantage of an Internet chat room or on-line support group for fathers if one were available to them.

**Discussion**

This was the first investigation designed to specifically examine the paternal response to caring for a child infected with HIV. The results demonstrated that fathers of children living with HIV are at risk for experiencing elevated levels of psychological distress. Additionally, our results indicate that these fathers experience clinically significant increases in parenting stress compared to normative fathers. Our findings also suggest that their degree of parenting stress is similar to that for fathers of children with other chronic illnesses, such as asthma.

The mean score of fathers in this sample demonstrated elevated levels of psychological distress in comparison to norms on the BSI. Of importance is the fact that fully one third of our sample exceeded the operational definition of “caseness” (raw score of .58 or more) set forth in the BSI manual (Derogatis, 1993) and thus should be considered for psychological consultation. It is also noteworthy that 20% of this sample scored above the cut-off score for total stress, which Abidin (1995) states as indicating the need for referral or psychological consultation. These findings highlight the magnitude of distress these fathers experience in their personal lives. HIV/AIDS presents numerous unique and complex social issues to families. These include the difficulty in disclosing the child’s diagnosis to others, coping with the fact that no cure exists, and dealing with complex medical treatments. Many of these men have already grieved for a loved one lost to AIDS and are without savings, employment, income, insurance, extended family support, and/or confidence in their parenting skills. Together, these issues interact and may create heightened levels of stress and tension that would lend further support to our findings and the need for psychological consultation.

We believe that fathers in need of psychological services would indeed take advantage of them, if offered. Considering the fact that 29% of the participants actually attended a group that was available to all parents during the year prior to this investigation, it is likely that many of the men who re-

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<th>Table II. Means of Global Severity Index Scores for Fathers of Children With HIV/AIDS and Male Comparison Groups on the BSI</th>
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quested a support group or an on-line support group specifically for fathers would use these services, if available. This speaks to the need for gender-sensitive psychosocial support services to assist these men with relationship and financial issues along with parenting and disclosure concerns in conjunction with quality medical care.

Although 45% of the fathers in this sample have lost a spouse or child to AIDS, these fathers did not exhibit increased parenting stress or psychological distress compared to fathers who had not experienced such a loss. This finding contradicts our hypothesis and may be due to the small sample size, other confounding variables, or the fact that the loss itself was used as the independent variable rather than the intensity of grief.

Interpretation of these data must be viewed cautiously, due to the small sample and the lack of a control group. In fact, the small sample size may have led us to believe that there were no differences between groups, such as those who had lost a child or spouse to AIDS from those who had not, when such differences may in fact exist. Power calculations revealed that the BSI analysis had .91 power to detect our effect size of .74; the PSI child domain analysis had .76 power to detect our effect size of .59; the PSI parent domain analysis had .51 power to detect our effect size of .45 and the PSI total stress analysis had power of .80 to detect our effect size of .62. Power for the loss analysis was very low, ranging from .07 to .19 to detect small effect sizes. Thus, our sample size was adequate to detect a large effect size, but somewhat small to detect medium or small effect sizes (such as the case with the PSI parent domain and the loss analyses).

This study was intended to assess fathers caring for children with HIV/AIDS at one discrete point in time. As such, the data were able to identify a high-risk group relative to a normative sample and to identify the perceived service needs of the group. This sample is not representative of the disproportionate impact of HIV/AIDS on people of color and may reflect the overrepresentation of resourceful families who were able to involve their child in clinical trials. The latter, however, allowed us to evaluate fathers’ experiences of caring for a child with HIV/AIDS apart from some of the powerful confounding stresses generally associated with HIV/AIDS, such as poverty, substance use, and lack of adequate medical care. Additionally, there is a need for longitudinal designs in order to investigate the changes in psychosocial functioning of families affected by HIV over longer periods of time.

Despite the limitations, these results have direct applicability for health care providers and investigators. The paternal role in the HIV epidemic may be increasing. Many men will continue to care for their child(ren) when the mother is not emotionally or physically able to do so. The men in this sample were not only willing but also frequently quite thankful for the opportunity to participate in the study, share their experiences, and document their needs. In addition to finding ways to reduce stress, these fathers expressed the need for assistance in parenting training, obtaining medical information, accessing social support services, and planning for the future. A critical next step is to develop models of care that respect the strengths of these men as well as their gender-specific needs and concerns.

In conclusion, the findings suggest that fathers caring for children living with HIV/AIDS experience heightened psychological distress and suffer from stress in their parenting roles. Clearly, these findings support the need for mental health professionals to be cognizant of the paternal adjustment process and to make timely interventions. We hope that the data presented here will serve to stimulate larger investigations that will in turn clarify and expand these preliminary findings.

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