

PREDICTORS OF PSYCHOLOGICAL DISTRESS AND WELL-BEING IN THE CAREGIVERS OF
CHILDREN WITH OR AT-RISK FOR HIV INFECTION

by

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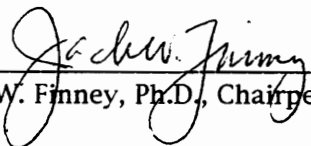
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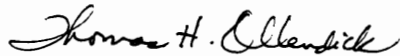
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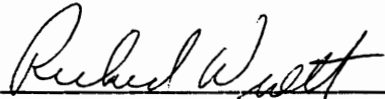
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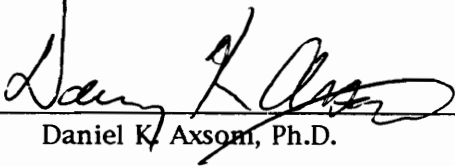
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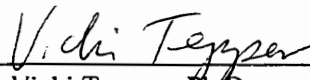
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(ABSTRACT)

Assessed the contribution of demographic, illness, and psychosocial parameters to the psychological adjustment of 64 caregivers of children with or at risk for HIV infection. As a group, caregivers reported a significantly greater level of psychological distress than the general population while the level of well-being reported by caregivers was similar to that of the general population. Illness and demographic parameters failed to significantly predict aspects of caregiver adjustment, together accounting for only six and nine percent of the variance in caregiver psychological distress and well-being, respectively. Psychosocial variables, however, contributed significant increments in the variance of both domains of caregiver adjustment. Specifically, higher levels of caregiver psychological distress were associated with poorer caregiver health status, greater number of coping strategies reported, and higher levels of family conflict. Higher levels of caregiver well-being were associated with perceptions of less impact of negative life events, lower levels of family conflict, and greater perceptions of emotional support. Implications for future research and intervention are discussed.

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Predictors of psychological distress and well-being in the caregivers of
children with or at-risk for HIV infection

Pediatric AIDS/HIV affects a growing number of children and families and presents a major challenge for pediatric health care (Kazak, 1989; Meyers & Weitzman, 1991). The most recent figure estimates that over 5000 cases of pediatric AIDS in children under 13 years of age have been reported in the United States and that the incidence is on the rise (CDC, 1994). Moreover, the number of HIV-infected infants and children in the United States is estimated to be between 10,000 and 20,000 (Boland & Oleske, 1995). Ongoing advances in medical technology, including antiretroviral and prophylactic therapies, have improved the prognosis and life expectancy of children with HIV-infection (Boland & Oleske, 1995; Sherwen & Boland, 1994; Steiner, Boyd-Franklin, & Boland, 1995). As such, pediatric AIDS/HIV is increasingly being conceptualized within a chronic, rather than acute, illness model (Meyers & Weitzman, 1991). As the life expectancy for HIV-infected children increases, quality of life issues assume greater significance and it becomes increasingly important to consider the psychosocial outcomes of these children and their families (Sherwen & Boland, 1994; Taylor-Brown & Kumetat, 1994). Compared to other childhood chronic illnesses, however, the research investigating the psychosocial outcomes associated with pediatric AIDS/HIV has been limited (Sherwen & Boland, 1994). Moreover, the literature that does exist is primarily descriptive in nature, rather than empirical (Bauman & Wiener, 1994; Taylor-Brown & Kumetat, 1994).

With the emergence of any childhood chronic illness, there comes a number of emotional, cognitive, and behavioral challenges which the ill child and his or her family must confront (Sargent & Liebman, 1985). As a result, children with pediatric AIDS/HIV and their families must also respond to a variety of illness-related challenges

and stresses in addition to fulfilling the normative demands of daily life and the tasks of individual and family development. The negotiation of these ongoing challenges is thought to place the psychological adjustment of HIV-infected children and their families at risk.

There is evidence in the literature on childhood chronic illness that, in comparison to their physically health peers, chronically ill children are vulnerable to many psychosocial problems, including elevated behavior problems, increased anxiety and depression, decreased self-concept, decreased social functioning, and noncompliance with medical regimen (see reviews by Eiser, 1990; Johnson, 1985; Lavigne & Faier-Routman, 1992). Pediatric chronic illness affects not only the ill child, but rather challenges all members of the family (Kazak, 1989). In this regard, there is a large body of literature detailing the adverse effects of chronic illness on other family members in addition to those of the chronically ill child (see reviews by Eiser, 1990; Johnson, 1985). Broadly described, the effects of childhood chronic illness on the family include financial stress, influences on the quality and quantity of internal and external family interactions, and considerable strain and distress for parents and healthy siblings. Generally viewed as the primary caretaker of their chronically ill children (Haunstein, 1990; Jessop, Riessman, & Stein, 1988), mothers in particular have been found to experience increased personal strain as well as elevated levels of psychological distress, including anxiety and depression (Breslau, Staruch, & Mortimer, 1982; Kazak, 1987). The fact that mothers carry a greater burden in caring for children with chronic illness dictates particular attention to the impact of chronic illness on maternal health and well-being (Jessop et al., 1988). The maintenance of maternal mental health is especially important since effective maternal caretaking is considered critical for the effective care (Breslau, et al., 1982; Hauenstein, 1990) and positive adjustment (Thompson, Gil, Burbach, Keith, & Kinney, 1993) of children with chronic

illness.

Unfortunately, the psychological impact of pediatric AIDS/HIV on parents remains an understudied area of empirical investigation (Wiener, Theut, Steinberg, Riekert, & Pizzo, 1994). The noncategorical approach, however, assumes that despite the unique qualities of particular conditions (e.g., symptoms, treatment requirements, prognosis), there are factors common to all childhood chronic illnesses (e.g., chronicity, difficult and painful medical procedures) that are more relevant for determining adjustment outcomes (Hobbs, Perrin, & Ireys, 1985; Stein & Jessop, 1982). According to this rationale, as well as the conceptualization of pediatric AIDS/HIV as a chronic illness, it seems reasonable to expect that the primary caregivers of children with AIDS/HIV, like the caregivers of children with other chronic illnesses, are at increased risk for adjustment difficulties and may experience elevated levels of psychological distress.

While the available data is limited, researchers have begun to explore the psychological impact of pediatric AIDS/HIV on parents. For example, Wiener and colleagues (1994) assessed psychological outcomes among 101 parents (21% male, 79% female) of children with HIV infection. When compared to general medical patients, parents of HIV-infected children reported a higher level of both trait and state anxiety and when compared to general medical patients with psychiatric complications, parents of HIV-infected children reported a higher level of state anxiety (as assessed by the Spielberger State-Trait Anxiety Inventory). Two-fifths of the parents reported mild levels of depressive symptomatology, with approximately one-quarter of the parents falling within the moderate-severe range for depression. The depression scores of the parents of HIV-infected children were found to be higher than those among mothers of children with cancer. The study is important as it represents one of the few empirical investigations of the psychological impact of pediatric AIDS/HIV on the parents of

children infected with the disease. As pointed out by the authors, however, the findings should be interpreted with caution given that the composition of the sample (77% Caucasian, 17% African-American, 6% Hispanic) did not accurately reflect the fact that minority children are disproportionately affected by the disease. Thus, replication of these findings with more representative samples is warranted. Despite this qualification, it should be recognized that the above findings are consistent with previous studies which document increased levels of anxiety and depression among parents of children with other chronic illnesses.

Although the psychological symptoms (e.g., depression, anxiety) of the primary caregivers were not measured, a study conducted by Mellins and Erhardt (1994) contributes to our understanding of the impact of pediatric AIDS/HIV on caregivers by recruiting a study sample that more accurately reflects the demographics of the disease and documenting the stressors identified by the caregivers, themselves, that may contribute to poor adjustment. Specifically, an open-ended qualitative interview was used to explore stress and coping among families affected by pediatric AIDS/HIV. The major stressors identified by the caregivers included tasks associated with illness management (e.g., hospitalizations, clinic visits), the stigma associated with HIV infection and the resulting secrecy and ostracism, communicating with health care providers and social service agencies, the pain and stress of AIDS-related losses, and the stress related to poverty, violence, and drug abuse rather than HIV infection. It is such stressors that may lead to difficulties with adjustment for these caregivers. Based on the available data then, there is evidence that the caregivers of children with pediatric AIDS/HIV, like those of children with other chronic illnesses, experience or, at least, are at risk for poor adjustment.

Despite the many features pediatric AIDS/HIV shares with other pediatric chronic illnesses (e.g., chronic nature, demanding medical regimen, unpredictability or

uncertainty about the future), the disease is also characterized by several unique features that distinguish it from other childhood chronic illnesses (Meyers & Weitzman, 1991; Sherwen & Boland, 1994; Steiner et al., 1995; Weiner & Septimus, 1994).

Although the profound impact of pediatric chronic illness on the family system is recognized across all illnesses, pediatric AIDS/HIV is distinguished by the unique way in which it challenges the family (Meyers & Weitzman, 1991; Steiner et al., 1995; Wiener & Septimus, 1994). Specifically, given the association between HIV/AIDS and injection drug use and vertical transmission as the primary mode of infection in children (Task Force on Pediatric AIDS, 1989), there is an increased likelihood that HIV/AIDS may cause concurrent acute and possibly fatal illness in more than one family member (Taylor-Brown & Kumetat, 1994). As such, in contrast to the parents of children with other chronic illnesses (e.g., cancer, diabetes) who are more likely to be both emotionally and physically available, the ability of parents of children with AIDS/HIV to provide quality care to their child may be compromised by their own HIV-infection (Steiner et al., 1995). Additionally, because of poor maternal health or even death from the disease, it is quite common for children with AIDS/HIV to be in the care of other family members (immediate or extended) or foster parents (Meyers & Weitzman, 1991; Sherwen & Boland, 1994; Steiner et al., 1995). In addition to the multigenerational aspects of pediatric AIDS/HIV, other unique stressors facing these children and their families include public fear and ignorance regarding the nature and transmission of HIV, discrimination, isolation, social ostracism, stigma, and the fear of physical and mental disability (Meyers & Weitzman, 1991; Wiener et al., 1994). It has been suggested that these unique aspects of HIV disease may serve to exacerbate many of the general features of childhood chronic illness (Meyers & Weitzman, 1991; Pollock & Thompson, 1995). These unique qualities of pediatric AIDS/HIV further substantiate

the need to document the experience of the caregivers of these children and to compare their experience to that of the caregivers of children with other chronic illnesses.

In general, caretakers of children with chronic illness, including AIDS/HIV, appear to be at risk for increased stress as well as negative psychosocial outcomes. What is notable, however, is the variability in outcomes such that some parents adjust quite well while others demonstrate significant difficulties with adjustment. The variability in outcomes suggests that the presence of a child with a chronic illness alone does not account for the differential adjustment of their caretakers (Wallander & Venters, 1995). As a result, attention in the area of pediatric chronic illness has shifted towards identifying factors contributing to better and worse outcomes rather than simply documenting outcomes. The delineation of factors influencing the adjustment of caregivers to a chronically ill child is critical to the development of interventions to reduce or prevent psychological distress.

In an attempt to explain caregiver adjustment to childhood chronic illness, several multivariate models have been proposed (e.g., Thompson, Gustafson, Hamlett, & Spock, 1992; Wallander, Varni, Babani, DeHaan, Wilcox, & Banis, 1989), which suggest that caregiver adjustment to childhood chronic illness is the result of complex relationships among several factors (i.e., illness-related, caregiver variables, environmental). In particular, Wallander and colleagues (1989, 1992) have proposed a theoretical model that outlines several risk and resistance factors which, through both direct and indirect effects, are thought to result in differential adjustment in caregivers of children with chronic illness. The risk factors are grouped into the following three broad categories: disease/disability parameters (e.g., severity), functional care strain (e.g., activities of daily living), and psychosocial stressors (e.g., life events). Resistance factors are also grouped into categories including, intrapersonal factors (e.g., sense of competence), social-ecological factors (e.g., family functioning), and stress processing

(e.g., coping strategies). Given the lack of a theoretical framework for conducting psychosocial research in the area of pediatric AIDS as well as the overall dearth of research regarding the psychosocial implications of the disease, the research literature from other populations of pediatric chronic illnesses offers a starting point for studying and understanding children and families affected by pediatric HIV infection (Sherwen & Boland, 1994) and for determining the utility of Wallander's model for this population.

**Factors affecting caregiver adjustment: Research from other
pediatric chronic illness populations**

Numerous researchers have investigated the influence of the variables identified in Wallander's model (Wallander et al., 1989) in determining the psychosocial outcomes of mothers/caregivers of children with a variety of different chronic medical conditions.

Risk Factors

According to the model, risk factors are categories of factors that increase the risk of adjustment problems in the caregivers of children with a chronic physical condition. One seemingly obvious risk factor is the severity of the child's illness with the notion being that greater severity leads to poorer outcomes. For the most part, however, objective measures of illness severity have not been found to account for differential adjustment outcomes (e.g., Kronenberger & Thompson, 1992a). Rather, consistent with the notion that cognitive appraisal of events strongly influences coping responses (Lazarus & Launier, 1978), it has been shown that parental appraisal of disease severity may be more important than objective measures of severity in predicting caregiver adjustment (Frydman, 1980). For example, in a study examining the adjustment of mothers of children with cystic fibrosis it was found that mother's who perceived their child's illness to be severe reported greater financial strain, greater limits on the family's opportunity to engage in activities, feelings of personal burden in the caretaking role, worry about the child's future, anticipation of the child's death, and

being less strict in discipline practices (Walker, Ford, & Donald, 1987). Similarly, Jessop and colleagues (1988) found that while a physician rating of burden (i.e., demands placed on the family by the presence of an ill child) was not related to the psychological status of the mother, maternal ratings of the child's functional status was significantly related to the level of depressive symptomatology reported by mothers of children with a variety of physical disorders (e.g., asthma, diabetes, congenital heart disease). In other words, mothers who reported lower levels of functioning of their child in daily activities reported more psychological symptoms. At the same time, the importance of functional status was diminished when examined simultaneously in a regression equation. Instead, maternal symptoms increased with the presence of other stressors such as illness in another family member, perceived impact of child's illness on family, and the physical health of the mother. This apparently limited role of the child's functional status was supported in another study in which the functional status of the child was unrelated to any aspect of maternal adaptation (Wallander, Pitt, & Mellins, 1990). Still other studies have shown that the impact of the child's functional status on caregiver adjustment may be mediated by maternal appraisals of the impact of the child's condition on the family (Lustig, Ireys, Sills, & Walsh, 1996) or result from an interaction with maternal characteristics such as self-efficacy (Silver, Bauman, & Ireys, 1995). In sum, these studies point to the need to consider the role of appraisal in caregiver coping and adjustment and suggest that other factors, besides or in addition to, illness-related variables, may have considerable impact on the psychosocial functioning of these caregivers. The multivariate aspect of Wallander's model (1989; 1992) takes this into account.

Consistent with the notion that illness parameters alone are not sufficient to explain differential adjustment among the caregivers of chronically ill children, psychosocial stress, another risk factor in the Wallander model, has also been shown to

be related to maternal adjustment. As evidence of this, Wallander et al. (1990) found that psychosocial stress (i.e., life events, daily hassles, handicap-related problems) was significantly related to the mental health of mothers of children with physical and sensory disabilities (e.g., cerebral palsy, mental retardation). Specifically, maternal psychosocial stress accounted for 29% of the variance in maternal mental health beyond that attributable to demographics, child disability status, and child functional independence status. The association of psychosocial stress, particularly daily stress, with poor adjustment has also been shown with mothers of children with sickle cell disease (Thompson et al., 1993) and mothers of children with cystic fibrosis (Thompson, Gustafson, Hamlett, & Spock, 1992). As suggested by these findings, the presence of psychosocial stress in addition to the stress associated with the child's illness should not be overlooked when trying to understand the adjustment of caregivers of children with chronic illness.

Resistance Factors

Based on the evidence that not all caregivers exposed to the same risk factors exhibit difficulties with adjustment, the model proposes several categories of resistance variables which are thought to influence the risk-adjustment relationship, through both direct and indirect pathways (Wallander & Varni, 1992; Wallander et al., 1989). Included among the resistance factors identified in the model are social-ecological variables and stress processing variables. While the model also identifies intrapersonal factors as a resistance variable, little research has been conducted investigating the role of intrapersonal variables in determining caregiver adjustment. In the one study that does exist, mothers with more positive views of their self-worth were found to have fewer symptoms of psychological distress (Silver et al., 1995).

With regard to the role of social-ecological factors in determining caregiver adjustment, Wallander and colleagues (1989), in their first test of the model, found that

social-ecological factors accounted for between 57 and 68% of the variance in the mental and social functioning of the mothers of children with physical handicaps. In fact, psychosocial family resources (e.g., better marital satisfaction, larger support group) accounted for a significant increment in the variance in all domains of caregiver adaptation, beyond that accounted for by utilitarian resources (e.g., family income, family size, mother's age, duration of marriage) and child adjustment. Consistent with the findings of Wallander et al. (1989), mothers of children with spina bifida who had more supportive families and marriages reported lower levels of psychological symptoms (Kronenberger & Thompson, 1992b). In this case, marital quality/support and family control together were the strongest predictors of maternal adjustment once demographic and medical variables were accounted for. The need to consider the family environment as a variable influencing caregiver adjustment is further highlighted by the research of Thompson and colleagues who found high levels of family support to be associated with good adjustment among mothers of children with cystic fibrosis (Thompson et al., 1992) and low levels of family support to be associated with poor adjustment among mothers of children with sickle cell disease (Thompson et al., 1993).

Considered an important variable in coping and adjustment in general, social support is also identified in Wallander and colleagues model (1989; 1992) as a resistance factor that is thought to influence caregiver adjustment. Kazak and colleagues have conducted a series of studies investigating the social network characteristics of families with spina bifida, mental retardation, and phenylketonuria (PKU) (Kazak & Marvin, 1984, Kazak, Reber, & Carter 1988). They found that while there were few differences in network size, network density (i.e., members of support network knew each other to a greater extent) was related to greater maternal distress among mothers of children with spina bifida and PKU (Kazak & Wilcox, 1984; Kazak et al., 1988), such that mothers who reported high distress had highly dense friendship networks.

Quittner (1992) found that while mothers of hearing impaired children reported smaller social networks than mothers of healthy children and mothers of children with seizures, they also reported receiving more support than mothers of children with seizure disorders. Another study showed that although mothers of chronically ill children (asthma and diabetes) reported generally receiving a "good amount" of support, they expressed a desire for more support than they were receiving (Pelletier, Godin, Lepage, & Dussault, 1994). What is not clear from the work of Quittner (1992) and Pelletier and colleagues (1994) is whether experiencing high levels of social support is associated with better psychological outcomes among these caregivers. Along these lines, Speechley and Noh (1992) found that among parents experiencing low levels of social support, parents of children surviving cancer were more likely to be distressed than parents of healthy children. Taken together, these findings suggest that, besides network size, other aspects of social support, such as the amount of support, have an important role in determining caregiver adjustment. Perceptions of the quality of support has also been identified as an aspect of social support that warrants consideration in future studies of caregiver adjustment (Quittner, 1992). Clearly, further research is needed to understand the nature of the relationship between social support and caregiver adjustment.

In addition to social-ecological factors, Wallander et al. (1989; 1992) have also identified stress processing variables as resistance factors in the adjustment of caregivers of chronically ill children. In a study investigating the psychological adjustment of mothers of children with myelomeningocele, Kronenberger and Thompson (1992a) found that appraised stress pertaining to the child's medical condition was consistently related to maternal symptoms of depression, anxiety, and global distress. Also of interest in this study is the fact that medical indices of illness severity were unrelated to maternal psychological adjustment and that appraised stress was unrelated

to medical indices of illness severity. Similarly, maternal perceptions of the burden associated with caring for a child with a chronic illness were shown to be predictive of psychiatric symptoms among these caregivers while no relationship was found for maternal or physician ratings of illness severity (Canning, Harris, & Kelleher, 1996). Other researchers have investigated the contribution of maternal perceptions of role restriction/strain, as a form of cognitive appraisal, in predicting the adjustment of caregivers of children with chronic illness. For example, Quittner and associates (1992) demonstrated that after controlling for situation specific parenting stress and marital satisfaction, regression analyses indicated that role strain related to cystic fibrosis was associated with greater depression in mothers. Similarly, Wallander and Venters (1995) found that perceived role restriction (i.e., the extent to which a mother feels unable to pursue her own interests due to responsibilities related to raising a child with a chronic physical condition) reported by mothers of children with chronic physical conditions (i.e.,g spina bifida and cerebral palsy) accounted for a significant increment in variation of maternal adjustment beyond that contributed by an objective measure of the child's disability. As noted in the above section on risk factors, maternal perceptions of severity appear more important than objective measures of illness severity in explaining maternal adjustment. The work of Quittner et al. (1992) and Wallander and Venters (1995), however, go beyond this to suggest that more general measures of maternal stress appraisal may also play an important role in determining caregiver adjustment.

Included among the stress processing variables outlined in the Wallander model (1989; 1992) is coping. Research examining the relationship of coping to adjustment among caregivers of children with chronic illness or disability appears to be in its early stages. The findings of two studies by Thompson and colleagues (1992; 1993) revealed that the use of palliative coping methods, that is, coping methods that serve to regulate

emotional states, was predictive of poorer adjustment of mothers of children with cystic fibrosis and sickle cell disease. Along these lines, Mullins et al. (1991) found that a coping style involving escape-avoidance, along with high levels of family stressors, was significantly associated with poor adaptation in mothers of children with cystic fibrosis. These factors were predictive of maternal adaptation even after controlling for income and disease severity. A relationship between parental use of avoidance coping and poorer parental adaptation, both concurrently and one year later, has also been documented among caregivers (both mothers and fathers) of children with juvenile rheumatic disease (Timko, Stovel, & Moos, 1992). Approach coping, however, was associated with more concurrent social activity and mastery among this same sample of caregivers (Timko et al., 1992). Such findings support the inclusion of coping in the model of caregiver adjustment and point to the need for further research to increase our understanding of the processes through which coping impacts adjustment.

While the studies based on other childhood chronic illness populations seem to support the utility of Wallander's model for explaining caregiver adjustment, the unique aspects of pediatric AIDS/HIV dictate specific testing of the applicability of Wallander's model for understanding adjustment among caregivers of children with HIV infection. The need to evaluate the applicability of Wallander's model for explaining caregiver adjustment to pediatric AIDS is further highlighted by the fact that such models have primarily been derived from white, middle-class samples (Cohen, 1994; Mellins & Ehrhardt, 1994). Mellins and Ehrhardt (1994) note that few studies exist on the experiences of inner-city families coping with chronic illness. Because most families coping with pediatric AIDS are from ethnic minorities and economic disadvantage, pediatric AIDS offers an excellent opportunity to extend this area of research by applying the model to this population.

Although Wallander's model (1989; 1992) was not used as the theoretical basis, there are a few studies in the area of pediatric AIDS/HIV that provide preliminary data regarding factors that may be related to better and worse outcomes among the caregivers of children with HIV infection.

**Pediatric AIDS and Caregiver Adjustment: Available data
regarding factors affecting adjustment**

To date, only one study has examined the role of factors identified in Wallander's model in determining caregiver adjustment. Specifically, Wiener and colleagues (1994) evaluated the relationship between a number of variables, including child's disease status and duration, caregiver relationship to the child (e.g., biological v. adoptive v. foster), parent HIV status, disclosure status, and the psychological adaptation of parents of HIV-infected children. Biological parents reported higher levels of anxiety and depression than did foster or adoptive parents while there was no difference between HIV-infected and noninfected parents. Anxiety level and anticipatory grief were found to increase with the age at which the child was first diagnosed. With regard to disease status, there was little relationship between parent adjustment and the degree of debilitation until the child became extremely debilitated. Although 67% of the children were aware of their diagnosis, there were no significant differences between parents of children who were aware of their diagnosis in this study and those who were not. This study is important in that it represents an initial attempt to delineate factors that are related to adjustment among caregivers of children with HIV infection and thus, provides some clues as to targets for intervention. However, given the nature of the sample in this case (77% Caucasian), there is a need to replicate the findings with a sample that more accurately reflects the epidemiology of the disease (i.e., majority of infected children are minority).

Family functioning, not caregiver adjustment, was the outcome variable in a study investigating the coping patterns of parents of children exposed to HIV (Lesar & Maldonado, 1996). The outcome measure of family impact (i.e., Impact on the Family Scale) did, however, include a subscale tapping caregiver burden which offers some information regarding caregiver adjustment. Participants were caregivers (birth parents, relatives, or foster/adoptive parents) of 48 HIV-exposed children (31 HIV-infected and 17 uninfected via perinatal exposure). Consistent with Wiener et al.'s findings (1994), the results revealed that birth parents experience the most impact (personal strain, familial and social impact) of the child's illness on the family system, with foster and adoptive parents experiencing less impact. However, no differences were found among the groups in terms of the coping strategies endorsed. Additionally, no differences were found in the impact on the family and in coping between parents of infected children and parents of exposed but uninfected children. The relationship between parental coping and the impact of HIV on the family was also examined. Multiple regression analyses revealed that parental coping efforts aimed at maintaining family integration, cooperation, and an optimistic view of the situation were associated with less of an impact on caregiver burden, personal strain, familial and social interactions, and coping with stress related to the child's illness. With specific regard to the adjustment of the caregiver, coping strategies directed towards family integration and understanding the medical situation were significantly related to the perceived burden of caring for an HIV-infected child. This study serves to provide evidence that the coping patterns endorsed by caregivers of HIV-infected children are related to family adjustment, and more specifically, the degree of burden felt by the caregivers of HIV-infected children. This study expands on the work of Weiner and colleagues (1994) by going beyond the realm of demographic and illness parameters to examine the impact of psychosocial variables on family and caregiver adjustment to pediatric AIDS. In

particular, the findings point towards the potential role of coping in determining psychosocial outcomes among parents and families affected by pediatric AIDS/HIV infection. It remains unknown, however, whether the same or different coping patterns are related to *psychological* outcomes among caregivers.

In another study, patterns of coping, along with communication, were investigated among parents of children with HIV infection versus those of children with cancer and healthy children (Hardy, Armstrong, Routh, Albrecht, & Davis, 1994). In terms of coping, mothers of children with both HIV and cancer were found to report significantly more wishful thinking than mothers of healthy children, with mothers of children with HIV infection reporting more than mothers of children with cancer. The authors point out that wishful thinking may be an effective strategy for managing psychological distress in situations in which active, problem-focused strategies are not likely to have an effect, such as when dealing with an illness for which there is no cure (Hardy et al., 1994). However, the present study did not assess maternal adjustment so that the impact of wishful thinking as a coping strategy on caregiver adjustment remains unknown (Hardy et al., 1994). The study also revealed that children with HIV infection were significantly less likely to be told of their illness than were children with cancer although the child's knowledge of the disease was not found to be significantly correlated with reports of parental coping. As with wishful thinking, the impact of disclosure of illness to the child on the psychological adjustment of the caregiver remains unclear and warrants further empirical investigation. Along these lines, Hardy et al. (1994) highlight the need to determine whether coping strategies are helpful, neutral, or harmful in their relationship to caregiver adjustment.

Given that the majority of pediatric cases are acquired through vertical transmission, a study of HIV-infected women and their children (Andrews, Williams, & Neil, 1993) provides additional insight into the experience of mothers of children with

pediatric AIDS/HIV. Qualitative data obtained through interview format revealed increased feelings of anxiety in relation to their children, particularly with regard to issues of placement of children upon the mother's demise and fear for the seropositive child's health and anxiety about long hospitalizations and eventual death. The results also revealed a strong emotional attachment between these women and their children that was marked by a bond of secrecy attributed to the social stigma associated with HIV and AIDS. Mothers expressed a struggle around the issue of disclosure. Again, what is not clear from the above study is how these variables impact maternal psychological adjustment. Moreover, because the HIV status of the children was not reported, it is not known whether the experience of HIV-infected mothers of uninfected children is the same that of HIV-infected mothers of infected children. Finally, because many HIV-infected children are in the care of other persons besides their mother, it will be important to compare adjustment across the different groups of caregivers, including healthy and HIV-infected mothers, relatives, and foster parents.

Clearly additional research aimed at identifying factors related to psychosocial outcomes in this population of caregivers is needed. Research efforts in this regard are particularly important given that the findings have obvious implications (i.e., provide an empirical foundation) for the development of interventions designed to promote adjustment among families affected by AIDS. Yet, despite the explicit call for mental health interventions (e.g., Task Force on Pediatric AIDS, 1989), little research exists identifying factors that might contribute to more positive psychosocial outcomes (Mellins & Ehrhardt, 1994). While the intervention needs may be immediate, there is a need to first broaden the knowledge base in order to make informed decisions regarding service delivery (Task Force on Pediatric AIDS, 1989). As suggested by Thompson et al. (1992), theoretically and conceptually driven studies that attempt to delineate the

processes associated with good and poor adjustment will serve to inform our efforts to foster psychological adjustment.

Proposed Study

Rationale

As with other childhood chronic illness, the primary caregivers of children with pediatric AIDS/HIV are thought to be at risk for deleterious psychological outcomes, which may be exacerbated by the unique features of this particular childhood chronic illness. This, along with the limited amount of data currently available, underscores the need for additional **empirical** investigations documenting the psychological status of the primary caregivers of these children. As pointed out by Wiener et al. (1994), not only is there a paucity of research in this area, but there are few studies that use reliable and valid standardized measures to assess the adaptation of the caregivers of children with AIDS/HIV. Moreover, in an effort to guide the development of psychosocial interventions aimed at promoting coping and adjustment among these caregivers, there is a need to identify factors associated with better and worse adjustment among these caregivers. Thus, the proposed study will provide further documentation of the psychological outcomes among caregivers of children with or at risk for AIDS/HIV and represents a preliminary effort to ascertain factors associated with the adaptation in these caregivers. In this regard, standardized measures were administered to assess the level of psychological distress and well-being among primary caregivers in relation to several illness-related, psychosocial stressor, social-ecological, and stress processing variables.

Hypotheses

Guided by Wallander and colleagues' (1989; 1992) risk and resistance model of adjustment to childhood chronic illness, the proposed study had two primary hypotheses.

1. It was expected that some, but not all, of the caregivers, would demonstrate poor adjustment by meeting the criteria for "caseness" on the Brief Symptom Inventory.
2. It was hypothesized that psychosocial stressors, social-ecological, and stress processing factors would contribute significant increments in the variance of caretaker adjustment (psychological distress and well-being) over and above that accounted for by illness and demographic parameters.

Method

Subjects

Participants were recruited from the caregivers of children with or at risk for HIV infection who were being followed through the pediatric AIDS program at the University of Maryland Hospital. The caregiver was defined as the individual (e.g., biological mother, grandparent, foster parent) who was responsible for the primary care of the index child. Because data collection was restricted to a four hour time period of clinic each week, not all eligible caregivers were able to be approached by the researcher regarding the opportunity to participate in the present study. In the end, a total of 85 caregivers were approached to participate; 10 declined and 75 agreed. Of the 75 who agreed to participate, four caregivers were excluded from the final analyses as they were unable to complete the protocol during the clinic visit, two were excluded as they represented outliers due to the index child's age, and five others were excluded as a review of clinic records revealed that the index child was a seroreverter making them ineligible for the present study. The final study sample consisted of 64 caregivers who completed the primary protocol measures. No information regarding the caregivers who declined to participate was available. As a result, any potential differences between the participating and eligible but nonparticipating caregivers and/or between the index children of these caregivers were unable to be explored.

The 64 caregivers included 60 females and 4 males who ranged in age from 17 - 66 years ($M = 41.02$; $SD = 12.23$). Fifty-four (84%) of the caregivers were African-American, with the remainder being Caucasian. Mean grade completed by the caregivers was 11th grade ($SD = 2.00$). Forty-two (66%) of the caregivers were not employed outside the home at the time of the study. The study sample consisted of 33 (52%) biological parents, 23 (36%) relatives, and 8 (12%) nonrelatives who were the caregivers of the

index children. The mean length of the caregiving relationship was 51.33 months ($SD = 34.80$)¹ and ranged from one month to 135 months.

A total of 63 children were represented in the present study as the mother and father of one child both participated in the study. Of these 63 index children, 31 were males (49%) and 32 were females (51%) who ranged in age from one month to 153 months ($M = 64.67$; $SD = 34.27$).² Fifty-seven (91%) of the children were African-American, with the remainder being Caucasian.

Procedure

Caregivers were approached during the index child's regularly scheduled clinic appointment and asked to participate in a project to learn about how families adjust to and cope with having a child with HIV/AIDS. Notes attached to clinic charts reminding clinic physicians to inform the caregivers of the study and flyers about the study posted in the clinic were also used to promote subject recruitment. Caregivers were asked to complete a series of questionnaires (see Appendices) during the clinic visit. The primary researcher or a research assistant was available to administer the questionnaires to caregivers in an interview fashion if the caregiver chose. Time restrictions did not permit the questionnaires to be administered to all participants. Seventy-seven percent ($n = 49$) of the caregivers completed the questionnaires on their own. Prior to testing the primary study hypotheses, differences between caregivers on the study measures were examined as a function of administration method. The analyses revealed no significant differences between the responses of caregivers who completed the measures on their own and those who were administered the measures by the researcher suggesting that the method of administration did not impact caregivers' responses on the questionnaires. Informed consent was obtained from all caregivers who

¹ Figure computed in months due to the young age of some of the children and the brief duration of some of the caregiving relationships.

² Figure computed in months due to the young age of some of the children.

agreed to participate. Upon completion of the questionnaires, caregivers received ten dollars in financial compensation for their participation. Medical information for each index child was obtained from clinic records.

Measures of Predictor Variables

Predictor variables were categorized into 4 components. Several measures representing each component were chosen as independent variables and are summarized below.

Illness Parameters

An objective measure of illness status was based on the index child's infection status as indicated in clinic medical records. Each child's infection status was categorized using the following broad categories of the CDC classification system: indeterminant (14.3%; $n = 9$), asymptomatic (14.3%; $n = 9$), mild (15.9%; $n = 10$), moderate (23.8%; $n = 15$), severe (31.7%; $n = 20$). Information regarding infection status was unavailable for one child. The length of time since diagnosis for the index child was also obtained from clinic medical records. The mean duration of illness for this sample of children was 44.33 months ($SD = 28.89$). A date of diagnosis and thus, duration of illness, was unavailable for 2 children. Given the evidence that perceived illness severity is more strongly related to maternal adjustment than objective measures of illness severity (e.g., Jessop et al., 1988; Walker et al., 1987), a measure of perceived severity was included in the present study to explore its impact on caregiver adjustment. Caregivers were asked to indicate how severe they felt their child's illness was using a five-point likert-type scale ranging from 1 ("Not at all severe") to 5 ("Very severe"). As shown in Table 1, the illness status of the child, as indicated by the CDC classification system, was significantly correlated with the length of time since diagnosis ($r = .71, p < .001$) as well as the caregiver's rating of illness status ($r = .33, p < .01$). The child's illness status was also significantly correlated with the number of

hospitalizations in the past year ($r = .33, p < .01$) and the number of clinic visits in the past year ($r = .64, p < .001$) (see Table 1).³ Given these significant correlations, illness status (based on the CDC classification system) was chosen as the single measure of the child's illness severity to be used in the regression analyses. The use of one variable to represent illness severity will serve to minimize multicollinearity and reduce the ratio of predictors to number of subjects.

Psychosocial Stressors

Life events. The Life Event Questionnaire (LEQ; Norbeck, 1984) is an 82-item instrument which assesses the occurrence of life events during the past year. The measure consists of life events in the areas of health, work, school, residence, love and marriage, family and close friends, parenting, personal and social, financial, crime, legal, and other. For each item the respondent is asked to rate the desirability (i.e., "good" or "bad") and impact (4-point scale: "no effect" to "great effect") of the event. The LEQ yields three possible scores: (a) a total events score (sum of the impact rating for all events that the respondent endorses as having experienced in the past year), (b) a negative events score (sum of impact ratings for all items identified as "bad" by the respondent) and, (c) a positive events score (sum of the impact ratings for all items identified as "good" by the respondent). Test-retest reliabilities for the total, negative, and positive event scores were found to range from .78 to .83 (Norbeck, 1984). In addition, Norbeck (1984) reported a significant relationship between negative events score on the LEQ and measures of psychological symptoms (e.g., Brief Symptom Inventory, State-Trait Anxiety Inventory). For the purposes of the present study four items were added to the LEQ to specifically assess the impact of AIDS-related events

³While the latter two variables were originally conceptualized as psychosocial stressor variables, their significant correlations with illness status and nonsignificant correlations with the other psychosocial stressor variables (see Table 1) supports their inclusion as illness parameters. The number of school days missed in the past year due to illness was also not included in the analyses as nearly 50% of the children ($n = 30$) were not yet of school-age.

(see Appendix E). The negative and AIDS-related event scores were used for the current study. The higher the score the greater the perceived impact of the events.

Caregiver health status. An individual's own health status may also impact his/her level of psychosocial stress. Health status may be a particularly important factor to consider for the caregivers of HIV-infected children who are often HIV-infected themselves or are older age relatives (e.g., grandparents) with age-related health problems. The Symptom List (RAND Health Insurance Survey; Davies, Sherbourne, Peterson, & Ware, 1988) was used to obtain a measure of caregiver health status. The scale, which consists of 26 symptoms, was completed by the caregivers to account for the frequency of symptoms experienced in the past 30 days. A frequency score was used for the current analyses with a higher score indicating greater symptoms and thus, poorer health.

Disclosure status. Disclosure of the illness to the index child and others was assessed with simple 'yes'/'no' questions on the information sheet. Only ten (16%) of the caregivers reported that the index child knew of his/her diagnosis. Fifty-six (88%) of the caregivers reported disclosing the child's illness to someone else while eight (13%) caregivers reported disclosing the child's illness to no one, including the index child. See Table 2 for a breakdown of the groups of people who were reported to know of the index child's diagnosis. Explanations for disclosure and nondisclosure to the child and others are presented in Tables 3 and 4. The limited number of children in this sample who were aware of their diagnosis prevented exploration of the impact of disclosure on caregiver adjustment.

Social-ecological Factors

Family functioning. The Family Environment Scale (FES; Moos & Moos, 1986) is a 90-item, true/false, self-report scale designed to assess social-environmental

characteristics of families. The instrument yields ten subscales (9 items each) that tap the domains of relationships, personal growth, and system maintenance. The FES is a standardized and well-validated measure of family's perceptions of family relationships and structure. Moos and Moos (1981) reported acceptable internal consistencies (ranging from .67 to .78) and test-retest reliabilities (ranging from .68 to .86) for the subscales of the FES. Four FES subscales shown to be relevant to family health issues were used in the present study: FESC (Cohesion; the degree of commitment, help and support family members provide for one another), FESE (Expressiveness; the extent to which family members are encouraged to act openly and to express their feelings directly), FESO (Organization; the degree of importance clear organization and structure play in planning family activities and responsibilities), and FESCO (Conflict; the amount of openly expressed anger, aggression, and conflict among family members). T scores for these four subscales were used.

Social Support. Social support was assessed with the Norbeck Social Support Questionnaire (NSSQ; Norbeck, Lindsey, & Carrieri, 1981), which provides a measure of network size, as well as the function (i.e., affect, affirmation, and aid) and sources of perceived support (e.g., friends, health care professionals). Psychometric testing revealed one-week and seven-month test-retest correlations for NSSQ variables ranging from .85 to .92 and .58 to .78 respectively (Norbeck, Lindsey, & Carrieri, 1983) and internal consistency correlations for the functional items ranging from .89 to .97. Evidence for concurrent validity was supported by moderately high correlations with another measure of social support (i.e., Social Support Questionnaire) (Norbeck et al., 1981) while construct validity was supported by significant correlations between the NSSQ and two measures of other convergent interpersonal constructs (need for inclusion and need for affection) and the lack of a significant correlation between the NSSQ and a

divergent construct (need for control) (Norbeck et al., 1983). The respondent is asked to first generate a list of persons whom he/she feels is important to him/her and to then rate each self-identified member of their network on a five-point scale, ranging from 1 ("not at all") to 5 ("a great deal"), for the extent to which they provide various kinds of support. The scale is changed to 0-4 when scoring so that a '0' reflects no support. The ratings of perceived support on the NSSQ are confounded with network size (i.e., the greater network size, the greater the perceived support). This was corrected by dividing the perceived support ratings by the size of the network. Network size, the level of perceived emotional support, and the level of perceived functional support were used in the current analyses. The higher the number the greater the network size and the greater the level of perceived support. A listing of the sources of support identified by this sample of caregivers is presented in Table 5.

Stress Processing

Perception of Stress. Stress appraisal was assessed using a 10-item, self-report inventory developed by Kronenberger and Thompson (1992a) for another study which investigated the influence of perceived stress on the adjustment of mothers of children with myelomeningocele. Using a scale of 1 ("not at all stressful") to 7 ("extremely stressful"), respondents are asked to indicate their level of stress related to the target child's problems, personal challenges, and social relationships. Factor analyses conducted by Kronenberger and Thompson (1992a) revealed two factors: medical/child stress and social/nonchild stress. Factor scores are derived by taking the mean of the items on the respective factors. Coefficient alphas for the factors and total scale were found to be .85 (for both factors) and .89 respectively (Kronenberger & Thompson, 1992a). The scores on the two factors were used in the present study with higher scores reflecting a greater level of appraised stress.

Caregiver coping. Caregiver coping was measured using an abbreviated version of the COPE (Carver, Scheier, & Weintraub, 1989), a 53-item scale designed to assess coping strategies. The authors report adequate reliability and validity for the full version. The abbreviated version of the COPE consists of 24 items taken from the original scale which are broken down into twelve subscales each reflecting a different coping strategy: self-distraction, active coping, denial, alcohol/drug use, use of emotional support, behavioral disengagement, venting, positive reframing, planning, use of humor, acceptance, and religion. The items were retained in the brief version if they were found to have strong loadings from previous factor and reliability analyses. The psychometric properties of the brief version are currently being evaluated by the authors but have not yet been published. The abbreviated version of the COPE was chosen over the original as it provided a relatively brief assessment of coping that tapped both desirable and undesirable coping strategies. For the present sample, coefficient alphas were found to be .84 for the total measure and to range from .30 to .87 for the subscales. In an effort to reduce the ratio of predictors to number of subjects, only those subscales that were significantly correlated with both measures of caregiver adjustment (i.e., disengagement and venting) and the number of coping strategies endorsed by caregivers, which was also significantly correlated with both measures of caregiver adjustment, were entered into the regression analyses (see Table 6).

Demographic Factors

Several demographic parameters were also obtained, including the index child's age and gender, the caregiver's age and education level, and the nature (e.g., natural parent, grandparent, foster parent) and length of the caregiving relationship. Caregiver race and gender and child race were also collected. However, they were not included in the statistical analyses as the imbalances among the categories within these parameters

(e.g., male/female) would not allow valid analyses. Relationship duration was excluded from the regression analyses due to its significant correlation ($r = .79$, $p < .001$) with the age of the index child. In fact, the age of the index child and the length of the caregiving relationship were equivalent in 61% ($n = 39$) of the cases. Given the small number of non-relative caregivers in the present sample ($n = 8$) and previous research in the area of pediatric AIDS showing that when compared to extended-relative caregivers or adoptive/foster parents, biological parents report greater levels of anxiety and depression (Wiener et al., 1994) and greater impact of the illness on the family (Lesar & Meldonado, 1996), caregivers were categorized as either biological parents or non-biological parents for statistical analyses.

Caregiver Adjustment

Psychological distress. The psychological functioning of the caregivers was assessed using the Brief Symptom Inventory (BSI; Derogatis & Spencer, 1982), a 53-item, self-report instrument designed to reflect a measure of current psychological symptom status. The BSI yields nine clinical scales including depression, anxiety, somatization, obsessive-compulsive, interpersonal sensitivity, hostility, phobic anxiety, paranoid ideation, and psychoticism. Adequate validity and reliability have been demonstrated. Specifically, Derogatis and Spencer (1982) reported internal consistency reliabilities, ranging from a low of .71 on the Psychoticism dimension to a high of .85 on Depression, and test-retest reliabilities, ranging from a low of .68 for Somatization to a high of .91 for Phobic Anxiety. The BSI, and its parent version, the SCL-90 (Derogatis, 1983), have been used extensively in previous research investigating parental/caregiver adjustment to childhood chronic illness (e.g., Kronenberger & Thompson, 1992a & b; Mullins, et al., 1991; Quittner et al., 1992; Thompson et al., 1993). T scores for the Global Severity Index (GSI), an indication of global psychological distress, were used for the analyses.

Psychological well-being. The Mental Health Inventory (MHI) is a 50-item self-report measure of psychological distress and well-being. Previous analyses found the scale to be comprised of two higher order factors (psychological well-being and distress) and five lower order factors (anxiety, depression, emotional ties, loss of behavioral and emotional control, and positive affect) (Veit and Ware, 1983). Thus, the measure yields a single MHI summary, as well as a psychological distress score, a well-being score, and five mental health construct scores. Veit and Ware (1983) report an internal consistency of .96 for the overall Mental Health Index and internal consistencies ranging from .83 to .94 for the underlying factors. Test-retest reliabilities for the Mental Health Index and underlying factors were .64 and from .56 to .63, respectively. Although to a lesser extent than the BSI and the SCL-90, the MHI has also been used in previous research examining the adjustment among caregivers of children with chronic medical conditions (Nagy & Ungerer, 1990; Wallander, et al., 1990). The BSI, to a large extent, emphasizes psychopathology. Thus, in recognition of the shift to conceptualize families of children with chronic illness as "normal" families facing a stressor, the psychological well-being score of the MHI was used in the present study as another indicator of caregiver adjustment.

Results

Means and standard deviations for the life and AIDS-related events, family functioning, social support, perceived stress, coping styles, and psychological distress and well-being variables are listed in Table 7.

Caregiver Psychological Adjustment.

Caregiver adjustment was assessed through the utilization of the BSI Global Severity Index (GSI) and the MHI well-being scale. To address the first hypothesis, caregivers were classified as having good or poor adjustment based on the criteria for "caseness" on the BSI as defined by Derogatis and Spencer (1982). According to this criteria, poor adjustment is defined as a t score ≥ 63 (i.e., above the 90th percentile) on the GSI or any two of the nine BSI symptom dimensions. Using this method, 41% ($n = 26$) of the caregivers met the criteria for poor adjustment. Caregivers with poor adjustment ($M = 63.46$; $SD = 6.21$) had significantly higher t scores on the GSI than did caregivers with good adjustment ($M = 45.11$; $SD = 7.19$), $t = -10.59$, $p < .001$. Similarly, caregivers with poor adjustment ($M = 52.97$; $SD = 18.01$) also had significantly lower scores on the MHI well-being scale than did caregivers with good adjustment ($M = 65.86$; $SD = 19.13$), $t = 2.71$, $p = .01$. Thus, as expected there is a group of caregivers among this sample of caregivers of children with HIV infection who seem to be experiencing significant distress. In an attempt to further examine caregiver adjustment, z tests were utilized to compare caregivers' scores on the GSI and the well-being scale with available norms for each measure. Caregivers' scores on the GSI ($M = 52.56$; $SD = 11.32$) were significantly higher than the published nonpatient norms ($M = 50$; $SD = 10$), $z = 2.05$, $p < .01$, suggesting that the caregivers of children with or at risk for HIV infection experience more psychological distress than the normal population. While reaching statistical significance, caregivers' mean score still fell within one standard deviation of the mean

for the general population. This, in combination with the lack of a statistically significant difference between the present sample and the general population on the well-being scale ($z = -1.73$, $p = ns$), provides further evidence that there is a range of adjustment outcomes among these caregivers with some adjusting quite well and others experiencing difficulty.

Association of illness status, psychosocial stressor, social-ecological, and stress processing variables to caregiver psychological adjustment

The zero order correlations between illness status, psychosocial stressor, social-ecological, stress processing, and caregiver adjustment variables are presented in Table 8. It is recognized that as the number of correlations computed increases, so does the chance of a Type I error, such that a correction to the significance level may be warranted. However, given the preliminary nature of the present study, the significance level was maintained at .05 to balance the risk of making a Type II error.

Illness status did not correlate significantly with either caregiver distress or caregiver well-being. Caregiver GSI scores were significantly and positively correlated with perceptions of the impact of negative life events, caregiver health status, family conflict, appraisal of child and nonchild stress, disengagement coping, venting coping, and the number of coping strategies used. In contrast, significant negative correlations were found between caregiver GSI scores and family cohesion, family organization, and perceived emotional support. This suggests that greater levels of psychological distress are associated with the perception of greater impact of negative life events, more health symptoms among caregivers, more family conflict, greater perceptions of child and nonchild-related stress, the use of disengaging and venting coping strategies, and the use of more coping strategies in general, but less family cohesion and organization, and less perceived emotional support.

With regard to psychological well-being, caregiver scores on the well-being scale were significantly and positively correlated with family cohesion, family organization, and perceived emotional support, so that greater levels of family cohesion and organization and greater perceptions of emotional support are associated with higher well-being. As suggested by significant negative correlations, less positive caregiver mental state was associated with higher levels of negative life events, greater family conflict, greater perceptions of nonchild-related stress, the use of disengaging and venting coping strategies as well as the use of more coping strategies in general.

Due to correlations among the predictor variables, however, zero-order correlations do not permit an assessment of the unique contribution of the predictor variables in predicting caregiver adjustment.

Multivariate Analyses

Multiple regression analyses were performed to test the main hypothesis. That is, the extent to which the psychosocial variables of psychosocial stressors, social-ecological factors, and stress processing predict caregiver adjustment above and beyond that accounted for by demographic and illness parameters. Separate analyses were undertaken for each index of adjustment (GSI and well-being scale). Block-wise regression, a conservative forward selection procedure which analyzes variables by component (Pedhazur, 1982), was used to produce the final model for each dependent variable. This method was chosen in an effort to control for Type I error because of the large number of independent variables relative to the sample size. The demographic variables of child gender, child age, caregiver age, caregiver education level, and child-caregiver relationship, were entered first as a block of control variables, followed by illness status, as a second block of control variables. These variables were entered first as they represent fairly stable factors that are not responsive to psychological intervention. According to Wallander et al.'s model, stress, both illness-related and

more generally occurring stress (e.g., change in residence), is thought to be primarily responsible for elevating the risk of development of adjustment difficulties (Wallander & Thompson, 1995). Thus, the block of psychosocial stressors was entered as the third block of predictors after demographic and illness parameters. The remaining two blocks of variables being examined in the present study, social-ecological and stress processing variables, are identified as resistance variables in Wallander et al.'s model (1989; 1992). Because the model does not specify the relative importance of the different resistance variables, the order of entry of the remaining two blocks was determined by comparing the amount of additional variance accounted for by each block when entered as the fourth block. The block that contributed the greatest increment in variance at that step was selected to enter as the fourth block with the remaining block entering as the fifth block of variables for the final analysis. The variables in the first two blocks were force entered to control them statistically while the variables in the remaining three blocks were entered using a stepwise method in which only the variables that added significantly ($p < .05$) to the equation were entered.

Table 9 summarizes the results of the block analysis for GSI as an index of caregiver adjustment. Based on the more conservative estimate provided by adjusted R^2 , the results show that 50% of the variance was predicted. The demographic block accounted for 6% of the variance with none of the variables within the block emerging as significant. Illness status, entered next, failed to add significantly to the predictiveness of the demographic variables with a less than 1% increment in variance. Predictors comprising the psychosocial stressor block accounted for an additional 27% of the variance in caregiver GSI score, which represents a significant increment in variance over demographic and illness parameters alone. Only the psychosocial stressor variable, caregiver health status, was shown to be a significant predictor of caregiver GSI score with a positive relationship (i.e., greater symptom endorsement associated with an

increase in GSI score).⁴ An additional 14% of the variance was accounted for when the block of social-ecological variables was entered into the equation. Among the social-ecological variables, family conflict was positively related to psychological distress suggesting the higher levels of family conflict are associated with greater psychological distress among caregivers. Finally, when stress processing variables were added to the equation, an additional 11% of variance was accounted for. In this block, the number of coping strategies endorsed by caregivers was significantly and positively related to the level of reported psychological distress.

The results of the block regression for caregiver well-being are presented in Table 10. One subject was excluded from this regression analysis as the score on the well-being scale represented an outlier causing it to affect the normality, linearity, and homoscedasticity of the residuals. The overall model accounted for 35% (adjusted R^2) of the variance in caregiver adjustment. Accounting for 8% of the variance, the demographic block failed to significantly predict caregiver adjustment. Illness status also did not emerge as a significant predictor of caregiver well-being resulting in a 1% increase in the amount of variance over that explained by demographic parameters. After controlling for the variance attributable to demographic parameters and illness status, the addition of the psychosocial stressor block significantly predicted an additional 21% of the variance. In particular, the perceived impact of negative life events contributed 14% of the variance and maintained an inverse relationship with caregiver well-being. That is, greater impact of negative life was associated with poorer well-being. The psychosocial stressor variable, caregiver health status, also contributed a significant increment in variance (7%) when initially entered. However, the

⁴Subsequent analyses were conducted to determine whether the ability of caregiver health status to significantly predict GSI score was simply an artifact of its significant correlation with the somatization scale of the BSI ($r = .45$, $p < .001$). The fact that the partial correlation between caregiver health and GSI score when controlling for somatization score ($r = .31$, $p < .02$) remained significant suggests that caregiver health status contributed uniquely to the prediction of caregiver psychological distress.

relationship between caregiver health status and well-being did not maintain its significance when the final block was entered. Predictors comprising the social-ecological block accounted for an additional 17% of the variance. Of the psychosocial variables, perceived emotional support contributed 10% and was positively related to caregiver well-being while family conflict contributed 7% of the variance and was inversely related to caregiver well-being. No stress processing variables met the criteria for entry into the equation.

Discussion

The present study represents an initial attempt at using a conceptually driven multivariate approach to examine the relative contribution of psychosocial factors to the prediction of psychological outcomes among caregivers of children with or at risk for HIV infection. As a group, caregivers of children with or at risk for HIV infection were characterized by elevated, yet subclinical, levels of psychological distress. Moreover, there was a subgroup of caregivers (41%) who appeared to be experiencing extreme distress. At the same time, the results also suggested that these caregivers do not differ from the general population in terms of their level of well-being. Taken together these results suggest that caregivers of children with or at risk for HIV infection constitute a group that is at risk for negative outcomes although poor adjustment is not a certainty. Demographic parameters and illness status of the child failed to predict aspects of caregiver adjustment. Psychological distress was associated with poorer caregiver health status, greater numbers of reported coping strategies, and higher levels of family conflict. Better well-being was found to be associated with perceptions of less impact of negative life events, lower levels of family conflict, and greater perceptions of emotional support.

The present results support previous research documenting increased psychological distress among caregivers of children with chronic illness (e.g., Breslau et al., 1982; Mullins et al., 1991; Quittner et al., 1992; Walker et al., 1987; Wallander et al., 1989). Specifically, 41% of the caregivers in the current sample reported sufficient distress to meet the criteria for poor adjustment on the BSI. Similar rates of poor adjustment among caregivers have been reported across several pediatric chronic illnesses, including sickle cell disease with a rate of 36% (Thompson et al., 1993), cystic fibrosis with a rate of 34% (Thompson et al., 1992), and spina bifida with a rate

of 44% (Kronenberger & Thompson, 1992b). The fact that each of these studies used either the BSI (Derogatis & Spencer, 1982) or its parent version, the SCL-90 (Derogatis, 1983), to assess caregiver adjustment strengthens the comparison across studies. At the same time, conclusions based on the present findings should be made cautiously. Several authors have raised concerns regarding the use of instruments that have yet to be proven valid or reliable for this population (Bauman & Wiener, 1994; Cohen, 1994). Given the preponderance of pediatric AIDS/HIV cases among minority families, measures used in psychosocial research in pediatric AIDS must be sensitive to the sociological environment and perspectives of these families.

In addition to the subset of caregivers who appear to be experiencing elevated psychological distress, this sample of caregivers, as a group, reported levels of psychological distress that were significantly greater than that of the general population. Two issues, however, dictate cautious interpretation of this finding. First, while the level of psychological distress reported by this group of caregivers was significantly elevated from that of the general population, it did not fall in the clinically significant range of psychological distress. Second, the normative sample used for this comparison did not match the current sample of caregivers which consisted predominantly of disadvantaged, African-American females. As a result, the apparent level of psychological distress of this group of caregivers may be a function of differences in the demographics of the two samples rather than caring for a child with HIV infection. It would be more meaningful to compare the level of psychological distress in the present sample to African-American female norms if available.

While the level of psychological distress reported by the caregivers in the present study was significantly greater than the general population, the reported level of psychological well-being was similar to that of the general population. It may be that it is easier for people to acknowledge experiencing symptoms of distress than it is for

them to acknowledge the absence of positive mental states (e.g., having something to look forward to, feeling calm and peaceful). In contrast to the present findings, Nagy and Ungerer (1990) found that mothers of children with cystic fibrosis reported significantly less psychological well-being than the general population although this was not true for fathers in this study. For the most part, however, investigations of the psychological outcomes of caregivers of children with chronic medical conditions, including pediatric AIDS/HIV infection, have focused on global or specific (e.g., anxiety, depression, stress) indices of psychological distress rather than well-being.

As hypothesized, neither demographic parameters or illness status significantly contributed to the models for caregiver adjustment together accounting for only six and eight percent of the variance in psychological distress and well-being, respectively. The failure of demographic and illness parameters to significantly predict adjustment has been documented previously among caregivers of children with cystic fibrosis (Mullins et al., 1991; Thompson et al., 1992), sickle cell disease (Thompson et al., 1993), and physical handicaps (Wallander et al., 1989). Findings with specific regard to the role of demographic and illness factors in pediatric AIDS has been equivocal. For example, two studies documented a relationship between caregiver adjustment and the caregiver's relationship to the ill child such that biological mothers reported significantly greater levels of anxiety and depression (Weiner et al., 1994) and significantly greater impact on the family (Lesar & Maldonado, 1996) than foster or adoptive parents. In contrast, Sherwen and colleagues (1993) reported no statistical differences among biologic, extended-family, or foster caretakers in terms of family adaptability and cohesion, coping, and perceptions of the child's health-related vulnerabilities. Similarly, the nature of the caregiving relationship (e.g., biological parent v. non-biological parent) did not emerge as a significant predictor of caregiver adjustment in the present study. With regard to illness parameters, Weiner et al. (1994) found that anxiety and

anticipatory grief increased with the age at which the child was diagnosed and that negative affectivity increased as the child reached extreme debilitation. In another study, there was no relationship between the child's infection status (i.e., HIV-infected v. HIV-exposed) and the impact of the illness on the family or parental coping (Lesar & Maldonado, 1996). Differences across studies may be the result of differences in measurement strategies used to assess psychological outcomes or differences in sample characteristics across studies. While there have been inconsistent findings regarding a significant relationship between demographic and illness parameters and caregiver adjustment, what has been consistent is the finding that psychosocial variables significantly contribute to the prediction of caregiver adjustment beyond demographic and illness parameters.

Along these lines, rather than demographic or illness parameters, psychosocial factors appear to be more important factors for understanding how caregivers adapt to the task of raising a child with HIV infection. Caregiver health status, in particular, was found to be an extremely robust predictor of psychological distress contributing an additional 26% in variance after controlling for demographic and illness parameters. While the observed relationship between caregiver health status and psychological distress may be inflated somewhat due to shared variance by the measure of caregiver health status and the somatization subscale of the BSI, subsequent analyses (see Footnote 4) supported the notion that caregiver health status uniquely contributed to caregiver psychological distress beyond somatization processes. It is important to note, however, that the cross-sectional nature of the present study prevents an investigation of the direction of the relationship between caregiver health status and psychological distress. As such, it remains unclear whether experiencing greater physical symptoms leads to increased psychological distress or whether the physical symptoms represent a manifestation of distress.

Although caregiver health status contributed significantly to the prediction of well-being when first entered into the regression, the relationship failed to maintain its significance when the remaining psychosocial variables were taken into account. This finding, along with the nonsignificant zero-order correlation between caregiver health status and well-being, suggests that caregiver health status may play more of a role in determining psychological distress than well-being. It may well be that experiencing greater physical symptoms serves to impact psychological distress by enhancing the stress associated with the child's illness that already confronts these caregivers. On the other hand, the absence of physical symptoms may not serve to promote well-being.

To date, only two previous studies have investigated the role of caregiver physical health in predicting psychological adjustment to childhood chronic illness. Lustig et al. (1996) found no relationship between caregivers' perceptions of their physical health and their psychological adjustment to juvenile rheumatoid arthritis. In contrast, caregivers' perceptions of their physical health were found to be predictive of psychiatric symptoms reported by mothers of children with a variety of chronic illnesses in another study by Jessop et al. (1988). Both of the previous studies used one Likert-type item on which caregivers rated their health as 'poor' to 'excellent' while the present study used a symptom checklist to assess caregiver health status. Given the limited and conflicting data, it is difficult to place the present results in a larger context and caution is warranted when interpreting the observed relationship. Moreover, accounting for more than half of the variance in psychological distress that was predicted by the final regression equation, caregiver health status appears to be an extremely influential factor in caregiver distress. In this population of caregivers who are likely to have increased health problems due to their own HIV infection or aging, it is possible that the increased psychological distress is simply a manifestation of their

poor health as opposed to the task of raising a child with HIV infection. The exact nature of this relationship, however, cannot be determined from the present study and warrants further research. For example, comparing the psychological distress of HIV infected women whose children are uninfected to that of HIV infected women whose children are not infected and comparing the psychological distress of older-age caregivers (e.g., grandmothers) who are caring for HIV infected children to that of older-age caregivers caring for healthy children would contribute to our understanding of the relationship between caregiver health and psychological distress.

At the same time, the apparent relationship between health and psychological adjustment has important implications for the caregivers of children with HIV infection, particularly given the possibility that these caregivers may experience increased physical symptoms related to their own HIV infection or aging (in extended-relative caregivers). Moreover, clinical observations suggest that many HIV-infected mothers frequently overlook their own health care. These mothers can be expected to experience increased physical symptoms as they progress through the stages of HIV infection. According to the present results, if their physical health goes unattended, their mental health may, in turn, be negatively impacted. Thus, one component of interventions aimed at promoting adjustment among caregivers should involve efforts to ensure that the health care needs of caregivers are met (e.g, ensuring accessibility to health care through assistance with transportation or presence of clinics in their communities) along with those of the ill child. It appears that such efforts would reduce the impact of one risk factor (i.e., caregiver poor health), thereby promoting better psychological outcomes.

Family conflict emerged as a significant predictor for both indices of caregiver adjustment. That is, family functioning marked by high levels of conflict (family members openly express anger, aggression, and conflict) was associated with greater

psychological distress whereas lower levels of conflict were predictive of better well-being. Similarly, Kronenberger and Thompson (1992b) found that mothers of children with spina bifida with more conflicted and controlling families experienced poorer psychological adjustment. Like caregiver health, high levels of family conflict may function as a risk factor by exacerbating the stress associated with caring for a child with HIV infection and as a result, places the caregiver at risk for increased psychological distress. Other aspects of family functioning, including family support and family control, have also been shown to impact adjustment in caregivers of children with cystic fibrosis (Thompson et al., 1992) and sickle cell disease (Thompson et al., 1993). In the present study, the zero-order correlations between the family functioning variables of cohesion and organization (as assessed by the FES) revealed significant relationships with both indices of caregiver adjustment (see Table 8). However, their failure to emerge as significant predictors in the regression analyses was likely due to their significant correlations with the family conflict subscale of the FES.⁵ Taken together the present and previous findings point to family functioning as a seemingly critical variable for understanding caregiver adjustment. Inconsistencies among studies may reflect differences in the measures used to assess family and caregiver adjustment variables as well as differences in sample composition (e.g., African-American versus Caucasian). It is also possible that different aspects of family functioning have more or less of an impact depending on the specific disease state under investigation. Further research is needed to clarify the mechanisms through which family functioning impacts caregiver adjustment and through which family conflict, in particular, impacts adjustment to pediatric AIDS/HIV infection. The relationship between family

⁵Zero-order correlations among the FES subscales revealed significant negative correlations between both the conflict and cohesion subscales ($r = -.47, p < .000$) and between the conflict and organization subscales ($r = -.56, p < .000$).

functioning and caregiver adjustment has not previously been examined in the pediatric AIDS/HIV infection literature.

Coping represents one of the few psychosocial variables that has been investigated in the pediatric AIDS literature. For example, Lesar and Meldonado (1996) found that coping focusing on family integration and understanding the medical situation was significantly related to the perceived burden of caring for an HIV-infected child. Although the effect on caregiver adjustment was not assessed, Hardy et al. (1994) showed that mothers of children with HIV infection reported significantly more wishful thinking than mothers of healthy children and mothers of children with cancer. The use of palliative coping strategies (i.e., coping methods that serve to regulate emotional states) and a coping style involving escape-avoidance have also been found to be predictive of poorer maternal adjustment to other pediatric chronic illnesses (Mullins et al., 1991; Thompson et al., 1992; 1993; Timko et al., 1992). The present study adds to this previous work by showing a relationship between the number of coping strategies caregivers reported using to deal with the child's illness and increased psychological distress. This operationalization of coping (i.e., number of coping strategies endorsed) represents a variation from the typical operationalization of coping where coping is considered in terms of the function it serves. For example, an individual who endorses an escape-avoidance coping style can be expected to demonstrate behaviors that allow them to evade the particular stressor or situation they are trying to manage. Given the unique conceptualization of coping, caution is recommended when interpreting its relationship with caregiver adjustment demonstrated in the present study. One interpretation could be that the number of coping strategies endorsed represents the range of an individual's coping repertoire. In this case, one might expect that an individual with a large coping repertoire would be better equipped to manage the multitude of stressors that accompany caring for a child with a chronic illness and as a

result, would experience less distress. However, the opposite relationship was found in the present study. Specifically, the greater the number of coping strategies that caregivers reported using to cope with the child's illness, the greater the psychological distress. This positive relationship may reflect the use of multiple coping strategies in an attempt to deal with an increasing level of psychological distress. The lack of a significant finding in this study between specific types of coping strategies and adjustment does not necessarily prohibit a coping skills intervention to assist in promoting caregiver adjustment. At the very least, the present results highlight the need for additional research to better understand the relationship between coping and adjustment in the this population. Additionally, because the measure of coping used in the present study was fairly recently developed, it is not known whether the COPE (Carver et al., 1989) represents a valid instrument for this population. It is possible that the strategies that are most relevant for this population or for coping with pediatric AIDS are not represented on the measure. Moreover, caregivers were simply asked to indicate whether or not they used particular coping strategies but were not asked how successfully they believed themselves to be in implementing these strategies or how effective the strategies were for dealing with the stressors. Self-efficacy and perceived effectiveness of coping may be better predictors of adjustment than the particular strategies themselves.

In addition to family conflict, the perceived impact of negative life events and greater perceptions of emotional support were also shown to predict caregiver well-being. With regard to negative life events, perceptions of less impact of negative events was associated with better well-being. Along these lines, high levels of family life stress were found to be associated with problems in adaptation in mothers of children with cystic fibrosis (Mullins et al., 1991). Other researchers have found that perceived stress related to daily hassles, as opposed to life events, was related to adjustment in

mothers of physically or sensorially handicapped children (Wallander et al., 1990), mothers of children with cystic fibrosis (Thompson et al., 1992), and mothers of children with sickle cell disease (Thompson et al., 1993). Future studies investigating psychological adjustment in pediatric AIDS/HIV infection should consider the role of daily hassles.

The relationship between emotional support and caregiver well-being was a positive one such that greater perceptions of emotional support were found to be predictive of well-being. Family members constituted the most frequently identified source of support by caregivers in the present study (see Table 5) and one of the three most frequently cited sources of support by caregivers of children with HIV infection in another study (Andrews et al., 1993). Thus, despite the failure of family support, as assessed through the FES, to emerge as a predictor of caregiver adjustment, the relationship between perceived emotional support, much of which appears to be provided by family members, and well-being is consistent with the previously mentioned research documenting a relationship between family support and maternal adjustment to other chronic illnesses (Thompson et al., 1992; 1993). Overall then, the present study demonstrates the importance of social relationships, especially those within the family, to the psychological health of caregivers of children with or at risk for HIV infection. Other research in the area of pediatric AIDS demonstrated that parental coping efforts aimed at facilitating family cohesiveness were associated with less of an impact on the family (Lesar & Maldonado, 1996). Interventions designed to foster positive adjustment among these caregivers will likely be made more effective by including components that address family relationships.

The present study represents the first attempt to *empirically* derive a model of the relationships between psychosocial variables and the psychological outcomes of caregivers of children with or at risk for HIV infection. Given the preliminary nature of

this study, generalization from these results remains tenuous. Additionally, several limitations characterized the present study. First, despite the attempt to improve on previous psychosocial research in the area of pediatric AIDS by including a sample that more accurately reflected the demographic characteristics of the disease, the power of the results was limited by the small sample size. Second, while there was an excellent response rate from caregivers who were invited to participate, differences between caregivers who participated and those who were eligible but did not participate were unable to be examined. Third, the current study is limited by its cross-sectional design which prevents the testing of cause and effect relationships and thus, provides an incomplete basis for formulating intervention efforts. Fourth, although a significant proportion of variance in the criterion variables was accounted for by selected variables, a substantial portion of variance remains unexplained. The inclusion of other variables, such as child adjustment, caregiver perceptions of burden, daily hassles, intrapersonal resources (e.g., self-efficacy), could add to the prediction of caregiver psychological distress and well-being scores. Moreover, while the conceptual model is thought to be applicable to any pediatric chronic illness (Wallender et al., 1989), it is possible that the unique aspects of pediatric AIDS (e.g., stigma, secrecy) are not accurately captured by the model and need to be incorporated into future studies. Finally, of note is the fact that four fathers were included in the present sample whereas the majority of previous studies investigating caregiver adjustment have been based on samples consisting exclusively of mothers. The limited number of fathers in the present study did not allow independent assessment of the psychological consequences of pediatric HIV infection separately for mothers and fathers. However, with the exception of one father whose well-being score was more than three standard deviations below the sample mean, fathers did not represent outliers on the variables examined in the present study. Since some differences between the psychological adjustment of mothers and fathers of

children with chronic medical conditions have been documented in the few studies that do exist (e.g., Nagy & Ungerer, 1990; Speechley et al., 1992; Timko et al., 1992), future research should be directed towards identifying the differences between the experience of mothers and fathers of children with chronic conditions. As has been recommended for research on other pediatric chronic illnesses (Glasgow & Anderson, 1995), the psychosocial literature in pediatric AIDS would benefit from theoretically-based studies that incorporate prospective, longitudinal study designs and utilize larger sample sizes to support the analyses of complex multivariate relationships (e.g., structural equation analysis).

This study was the first application of the risk and resistance model proposed by Wallander et al. (1989; 1992) to the area of pediatric AIDS. The emergence of factors from the psychosocial stressor, social-ecological, and stress processing domains to the prediction of caregiver adjustment, highlights the importance of using a multivariate approach and the need to look beyond demographic and illness parameters to understand caregiver adjustment. While the present study does not provide definitive targets for intervention, it does suggest that efforts to promote the physical health, to strengthen the family relationships, and to ensure the provision of emotional support to the caregivers may facilitate positive psychological outcomes among these caregivers.

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Table 1

Zero-order correlations between illness parameters, psychosocial stressors, and caregiver adjustment

Variable	2	3	4	5	6	7	8	9	10
1. GSJA ^a	-.37 ^e	-.17	-.20	-.06	-.05	-.10	.33 ^d	.24	.49 ^f
2. Well-being ^b		.07	.19	-.03	-.13	-.14	-.32 ^d	-.00	-.17
3. Illness status			.71 ^f	.33 ^d	.33 ^d	.64 ^f	.01	-.09	.20
4. Illness duration				.25	.30 ^c	.46 ^f	-.09	-.04	.22
5. Perceived severity					.42 ^e	.40 ^e	.09	.13	.19
6. Hospitalizations						.30 ^c	.23	.17	.12
7. Clinic visits							.00	.03	.28 ^c
8. Life events								.23	.17
9. AIDS events									.18
10. Caregiver health									--

^a Global Severity Index of Brief Symptom Inventory^b Well-being scale of Mental Health Inventory^c $p < .05$ ^d $p < .01$ ^e $p < .005$ ^f $p < .001$

Table 2

Persons having knowledge of child's illness

Category of others	# of caregivers identifying
Family/relatives	50
Friends	18
School personnel	14
Spouse; partner ^a	12
Other children/siblings ^a	11
Agencies/Service Providers (e.g., Health Department, Department of Social Services, doctor)	2
"Everyone that knows me"	1
"Everyone except child's siblings"	1
Specific others not identified	1

Note. Caregivers were able to identify more than one person/group of people.

^a As identified separately from family/relative category.

Table 3

Explanations for disclosing and nondisclosure to index child

Explanation	# of caregivers providing explanation
For nondisclosure:	
Too young to understand; wouldn't understand	31
Fear that others would react negatively to the child	3
Don't know how to tell	1
Not ready	1
Not the right time	1
Child never asked about it	1
Don't want the child to know	1
See no need to tell	1
Personal reasons	1
Child gets very upset and has high blood pressure	1
No explanation offered	9
For disclosure:	
Because child is well informed; like to keep the child well-informed	2
Child has a right to know why ill	1
Felt it best child knew why he/she is ill	1
Child is old enough to know	1
Want the child to know	1
Factors related to illness (e.g., cold, fever, hospital stay)	1
In case of a medical emergency	1
No explanation offered	3

Note. Caregivers were able to provide more than one explanation.

Table 4

Explanations for disclosure and nondisclosure to others

Explanation	# of caregivers providing explanation
For disclosure	
For support/help	8
Protection in case of an emergency	4
As a result of care associated with child's illness (e.g., to explain why need transportation to and from hospital; child hospitalized frequently)	3
Love; have a close relationship; have an understanding family	4
Custody issues	2
Wanted them to know	2
Live in household together	1
Knew because the child's mother passed away from AIDS	1
They have a right to know	1
Because of problems of nosebleeds	1
No reason offered	35
For nondisclosure	
Not ready	1
Don't know how	1
None of their business	1
Personal reasons	1
No explanation offered	5

Note. Caregivers were able to offer more than one explanation.

Table 5

Sources of social support

<u>Source of Support</u>	<u># of caregivers identifying source</u>	<u>%^a</u>
Family member/relatives	57	89
Friends	42	66
Partner/spouse	20	31
Health care providers	10	16
Neighbors	7	11
Work/school associates	5	8
Counselor/therapist	4	6
Priest/minister/rabbi	3	5
Other	1	2

Note. Total percent may be greater than 100% as caregivers were able to endorse more than one source of social support.

^a Data missing for one participant; percents based on valid cases.

Table 6

Zero-order correlations between coping and caregiver adjustment variables

Variable	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. GSJA ^a	-.35 ^e	.31 ^c	-.02	.22	.10	.25 ^c	.26 ^c	.41 ^d	.23	.36 ^e	-.01	.03	.07	.48 ^f
2. Well-being ^b		-.15	-.16	-.19	-.04	.07	-.31 ^c	-.28 ^c	-.09	-.19	.16	.01	.13	-.27 ^c
3. Self-distraction			.25	.33 ^d	.08	.46 ^f	.12	.35 ^d	.47 ^f	.60 ^f	-.01	.21	.14	.55 ^f
4. Active coping				.05	-.25 ^c	.37 ^e	.02	.08	.43 ^f	.46 ^f	-.04	.45 ^f	.19	.24
5. Denial					.16	.32 ^c	.36 ^e	.32 ^c	.32 ^c	.41 ^e	-.22	.10	.18	.50 ^f
6. Alcohol/drug use						-.14	.11	.28 ^c	-.02	-.01	-.04	-.22	-.03	.28 ^c
7. Emotional support							.08	.20	.52 ^f	.52 ^f	.14	.34 ^d	.09	.51 ^f
8. Disengagement								.32 ^c	.14	.18	.06	-.14	-.09	.48 ^f
9. Venting									.38 ^e	.51 ^f	-.03	.11	.10	.50 ^f
10. Reframing										.70 ^f	-.08	.53 ^f	.44 ^f	.52 ^f
11. Planning											-.08	.43 ^e	.35 ^e	.65 ^f
12. Humor												.01	-.21	.16
13. Acceptance													.36 ^e	.22
14. Religion														.18
15. # of strategies														..

^a Global Severity Index of Brief Symptom Inventory

^b Well-being scale of Mental Health Inventory

^c $p < .05$

^d $p < .01$

^e $p < .005$

^f $p < .001$

Table 7

Descriptive statistics for psychosocial stressor, social-ecological, stress processing, and maternal adjustment variables

Variable	<i>M</i>	<i>SD</i>
Predictor		
Life Events Questionnaire		
Negative events	11.92	13.19
AIDS-related events	2.75	4.02
Symptom Checklist (caregiver health)	3.41	3.31
FES		
Cohesion	52.66	12.81
Organization	52.34	11.04
Expressiveness	48.95	11.54
Conflict	47.80	11.34
Social Support Questionnaire		
Network size (63)	7.35	5.71
Perceived emotional aid (62)	13.48	2.70
Perceived functional aid (61)	6.19	2.07
Stress Questionnaire		
Child/medical stress	3.17	1.62
Nonmedical/social stress	2.97	1.51
COPE (63)		
Self-distraction	4.57	2.27
Active coping	5.79	1.92
Denial	3.95	2.16
Alcohol/drug use	2.43	1.25
Emotional support	5.17	2.04
Disengagement	2.76	1.36
Venting	4.02	1.83
Reframing	5.57	2.14
Planning	5.57	2.24
Humor	2.51	1.16
Acceptance	6.32	1.90
Religion	6.03	2.25
Number of strategies	7.94	2.42
Criterion		
BSI	52.56	11.32
Well-being scale	60.63	19.61

Note. Number in parantheses indicates the n used for the analyses. No number in parantheses indicates complete N=64 available. Lower n's due to missing data.

Table 8

Zero-order correlations between illness status, psychosocial stressor, social-ecological, stress processing and caregiver adjustment variables.

Variable	Caregiver Adjustment	
	GSI ^a	Well-being ^b
Illness Parameters		
Illness status	-.17	.07
Psychosocial Stressor		
Life Events	.33 ^d	-.32 ^d
AIDS Events	.24	-.00
Caregiver Health Status	.49 ^f	-.17
Social-Ecological		
FES-Cohesion	-.30 ^c	.39 ^e
FES-Expressiveness	-.09	.20
FES-Organization	-.36 ^e	.30 ^c
FES-Conflict	.43 ^f	-.34 ^d
Network Size	.18	-.05
Emotional Support	-.26 ^c	.43 ^e
Tangible Aid/Support	-.12	.16
Stress Processing		
Child/Medical Stress	.33 ^d	-.14
Social/Nonchild Stress	.50 ^f	-.27 ^c
Disengagement	.26 ^c	-.31 ^c
Venting	.41 ^e	-.28 ^c
Number of Coping Strategies	.48 ^f	-.27 ^c

^a Global Severity Index from the Brief Symptom Inventory

^b Well-being scale from the Mental Health Inventory

^c $p < .05$

^d $p < .01$

^e $p < .005$

^f $p < .001$

Table 9

Hierarchical Multiple Regression Analysis for the Prediction of GSI

	<i>b</i> ^a	R ^{2b}	R ² change	F ^{cd}
Block 1				
Child gender	.02			
Child age	-.07			
Caregiver age	-.16			
Caregiver education	.17			
Relationship	-.22	.06	.06	.66
Block 2				
Illness status	-.02	.06	.00	.35
Block 3				
Caregiver health status	.45 ^f	.33	.27	20.28 ^f
Block 4				
FES - conflict	.34 ^e	.47	.14	14.34 ^f
Block 5				
Number of coping strategies	.33 ^e	.58	.11	11.90 ^e

^a Standardized regression coefficients for final model.

^b Adjusted R² for the entire model = .50.

^c F for entire model = 7.53, p < .0001.

^d F test on change in R²

^e p < .005

^f p < .001

Table 10

Hierarchical Multiple Regression Analysis for the Prediction of Well-being

	<i>b</i> ^a	R ^{2b}	R ² change	F ^{cd}
Block 1				
Child gender	-.06			
Child age	.21			
Caregiver age	-.14			
Caregiver education	-.16			
Relationship	-.10	.08	.08	.94
Block 2				
Illness status	.02	.09	.01	.26
Block 3				
Impact negative life events	-.26 ^e	.23	.14	9.65 ^g
Caregiver health status	-.21	.30	.07	4.58 ^e
Block 4				
Perceived emotional support	.31 ^e	.40	.10	8.54 ^f
FES - conflict	-.27 ^e	.47	.07	5.82 ^e

^a Standardized regression coefficients for final model.

^b Adjusted R² for the entire model = .35.

^c F for entire model = 4.17, *p* < .001.

^d F test on change in R²

^e *p* < .05

^f *p* < .01

^g *p* < .005

Title of Research: "Predictors of Psychological Distress and Well-Being in Caregivers of Children with HIV Infection"

Investigator: Kathryn M. Miller, M.S. 706-3083
Prasanna Nair, M.D. 328-2533
Vicki Tepper, Ph.D. 706-3542
Ligia Peralta, M.D. 328-6495
John Farley, M.D. 706-8220

Purpose of Study

You are being asked to participate in a project to help us learn about your experiences taking care of a child with HIV infection. We are interested in learning what things help parents/caregivers cope and what things make it more difficult to deal with having a child with HIV infection. Learning about things that help or make it difficult will help us develop programs to help families adjust positively to having a child with a chronic illness.

Procedures

If you choose to participate in the project, you will be asked to complete several questionnaires that ask about your health, your child's health, your experiences as a parent/caregiver, support from family and others, and things you do to cope. The questionnaires take about an 1 to 1 1/2 hour(s) to complete. You will complete the questionnaires during your child's regularly scheduled clinic visit. You will only have to complete them one time. We will also be looking in your child's medical chart to obtain some basic information.

Benefit/Risk

We hope that what we learn from this project will help all parents/caregivers who have children with HIV infection. The information we learn from this project will also be shared with you if you are interested. It is possible that you may experience mild discomfort related to the questions asked as part of the project. If during your participation in the project it seems that you need help or there is serious concern for your health and safety, we will assist you in obtaining treatment.

Confidentiality

All information from this project will be kept strictly confidential. Neither you nor your child will be identified in any report. The forms you fill out for the project will not have you or your child's name, only a project number will appear. The information will be used only for the purpose of this project. The forms will be kept in a locked cabinet. They will be destroyed 5 years after the project and data analysis are finished.

Right to Withdraw

Participation in this project is completely voluntary. You have the right to refuse to answer questions, and you may stop your participation at any time. If you decide not to participate, this will have no effect on any services you or your child receive now or may receive in the future at the University of Maryland Medical System or at the University of Maryland at Baltimore.

Compensation

You will receive \$10.00 for completing the questionnaires. There are no costs to you for participating in this project.

University Statement

During your participation in the research, if you suffer physical injury, the University of Maryland at Baltimore will provide acute medical treatment and provide subsequent referrals to appropriate health care facilities. However, the UMAB/UMMS cannot provide any financial compensation due to injury suffered during this project. Information regarding this research can be obtained from Human Volunteers Research Committee, (UMAB), Bressler Research Building, Room 14-002, 655 West Baltimore Street, Baltimore, MD 21201, (410) 706-5037.

Permission

I have read and understand the above information. I have had an opportunity to ask questions and have had them all answered. I agree to participate in the project under the conditions stated. I understand that I may withdraw at any time without penalty.

Caregiver's Signature

Date

Caregiver's Name and Relationship

Witness' Signature

Date

INFORMATION SHEET

Name: _____ Date of birth: _____

Child's name: _____ Child's gender: M F

Your relationship to child: _____ Child's date of birth: _____

How long has _____ been in your care (please indicate number of months or years)? _____

Please list all other persons who also live in the home with you and the child:

<u>Name</u>	<u>Relationship to child</u>	<u>Age</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

What is your highest level of education? _____ How many years of school did you have? _____

- a. less than high school b. some high school (grade completed? ___) c. completed high school
 d. some college or trade school e. graduated from college f. graduate or advanced education

Do you work outside of the home? YES NO If yes, what is your job? _____

How severe is your child's illness right now? 1 2 3 4 5
 Not at all Somewhat Very
 Severe Severe Severe

How many days of school has _____ missed in the past year due to his/her illness?

- a. less than 5 days b. 5 - 10 days c. 10 - 15 days d. more than 15 days

Does your child know about his/her HIV stams? YES NO

Why or why not? _____

Does anyone else know about your child's HIV stams? YES NO

If yes, who knows? _____
 (spouse/partner, other children, _____
 relatives, friends, extended _____
 family, school personnel) _____

Why or why not? _____

Please indicate whether you have had any of the following symptoms during the past 30 days. Please respond to all of the items.

During the past 30 days, did you have...

- | | | | |
|-----|--|-----|----|
| 1. | A cough, without fever, which lasted 3 weeks. | YES | NO |
| 2. | A sore throat or cold, with fever, lasting more than 3 days. | YES | NO |
| 3. | A weight loss of more than 10 pounds (unless you were dieting). | YES | NO |
| 4. | An upset stomach, for less than 24 hours. | YES | NO |
| 5. | Stiffness, pain or swelling of joints, lasting more than 2 weeks. | YES | NO |
| 6. | Backaches or sciatica. | YES | NO |
| 7. | Trouble falling asleep at night. | YES | NO |
| 8. | Getting up exhausted in the mornings, even with the usual amount of sleep. | YES | NO |
| 9. | A skin rash, or breaking out on any part of the body. | YES | NO |
| 10. | Shortness of breath with light exercise or work. | YES | NO |
| 11. | Chest pain when exercising. | YES | NO |
| 12. | Your nose stopped up, or sneezing or allergies for 2 weeks or more. | YES | NO |
| 13. | Swollen ankles when you wake up. | YES | NO |
| 14. | Headaches almost every day. | YES | NO |
| 15. | A cough, without fever, which lasted less than a week. | YES | NO |
| 16. | Loss of consciousness, fainting, or passing out. | YES | NO |
| 17. | Acid indigestion or heartburn after many meals. | YES | NO |
| 18. | A sprained ankle, but you could still walk. | YES | NO |
| 19. | A toothache. | YES | NO |
| 20. | Stomach "flu" or virus (gastroenteritis) with vomiting or diarrhea. | YES | NO |
| 21. | Bleeding (other than nose bleeds or periods) not caused by accident or injury. | YES | NO |
| 22. | An eye infection. | YES | NO |
| 23. | Feeling nervous or anxious most of the time. | YES | NO |
| 24. | Feeling depressed or sad most of the time. | YES | NO |
| 25. | Difficulty controlling urine, or bladder kidney problems. | YES | NO |
| 26. | Irregular periods, or bleeding between periods. | YES | NO |

Life Events

I am going to read a number of events which may bring about changes in the lives of those who experience them.

1) Listen to the event, and decide whether or not it has occurred in your life within the past year.

2) If the event has occurred within the past year:

a) Tell me whether it was "GOOD" or "BAD". (Some events have both good and bad elements. Tell me which one best applies.)

b) Then tell me whether the event had **NO EFFECT, SOME EFFECT, MODERATE EFFECT,** or a **GREATEFFECT**

EVENT	TYPE OF EVENT		EFFECT OF EVENT ON YOUR LIFE			
	(1)	(2)	(1)	(2)	(3)	(4)
1. Engagement	Good	Bad	no effect	some effect	moderate effect	great effect
2. Getting married	Good	Bad	no effect	some effect	moderate effect	great effect
3. Detention in jail or other institution (you or anyone close to you)	Good	Bad	no effect	some effect	moderate effect	great effect
4. Trouble with police (you or anyone close to you)	Good	Bad	no effect	some effect	moderate effect	great effect
5. Alcohol or drug problems	Good	Bad	no effect	some effect	moderate effect	great effect
6. Legal Problems (other than detention in jail or trouble with police)	Good	Bad	no effect	some effect	moderate effect	great effect
7. Death of close family member						
a) parent(s)	Good	Bad	no effect	some effect	moderate effect	great effect
b) child	Good	Bad	no effect	some effect	moderate effect	great effect
c) another child	Good	Bad	no effect	some effect	moderate effect	great effect
d) brother or sister	Good	Bad	no effect	some effect	moderate effect	great effect
e) husband/male partner	Good	Bad	no effect	some effect	moderate effect	great effect
f) grandparent(s)	Good	Bad	no effect	some effect	moderate effect	great effect
g) other (please specify relationship)	Good	Bad	no effect	some effect	moderate effect	great effect
8. Death of a close friend	Good	Bad	no effect	some effect	moderate effect	great effect

EVENT	TYPE OF EVENT		EFFECT OF EVENT ON YOUR LIFE			
	(1)	(2)	(1)	(2)	(3)	(4)
9. Serious illness or injury of close family member						
a) parent(s)	Good	Bad	no effect	some effect	moderate effect	great effect
b) child	Good	Bad	no effect	some effect	moderate effect	great effect
c) another child	Good	Bad	no effect	some effect	moderate effect	great effect
d) brother or sister	Good	Bad	no effect	some effect	moderate effect	great effect
e) husband/male partner	Good	Bad	no effect	some effect	moderate effect	great effect
f) grandparent(s)	Good	Bad	no effect	some effect	moderate effect	great effect
g) other (please specify relationship)	Good	Bad	no effect	some effect	moderate effect	great effect
10. Serious illness or injury of close friend	Good	Bad	no effect	some effect	moderate effect	great effect
11. Major personal illness or injury	Good	Bad	no effect	some effect	moderate effect	great effect
12. Outstanding personal achievement	Good	Bad	no effect	some effect	moderate effect	great effect
13. New job for you	Good	Bad	no effect	some effect	moderate effect	great effect
14. Change your work responsibility (major change in working conditions, working hours, promotions, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
15. Losing your job	Good	Bad	no effect	some effect	moderate effect	great effect
16. Trouble with your employer (in danger of losing your job, being suspended, demoted, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
17. Change in husband or partner's work (loss of job, beginning new job retirement, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
18. Sexual difficulties	Good	Bad	no effect	some effect	moderate effect	great effect

EVENT	TYPE OF EVENT		EFFECT OF EVENT ON YOUR LIFE			
	(1)	(2)	(1)	(2)	(3)	(4)
19. Major change in sleeping habits (much more or much less sleep)	Good	Bad	no effect	some effect	moderate effect	great effect
20. Major change in eating habits (much more or much less food intake)	Good	Bad	no effect	some effect	moderate effect	great effect
21. Trouble with in-laws (or boyfriend's relatives)	Good	Bad	no effect	some effect	moderate effect	great effect
22. Major change in closeness of family members (increase or decrease in closeness)	Good	Bad	no effect	some effect	moderate effect	great effect
23. Major change in number of arguments with husband, partner, or boyfriend (much more or much less)	Good	Bad	no effect	some effect	moderate effect	great effect
24. Separation from husband or male partner (due to conflict)	Good	Bad	no effect	some effect	moderate effect	great effect
25. Separation from husband or male partner (due to work, travel, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
26. Breaking up with boyfriend or girlfriend	Good	Bad	no effect	some effect	moderate effect	great effect
27. Reconciliation with boyfriend or girlfriend	Good	Bad	no effect	some effect	moderate effect	great effect
28. Divorce	Good	Bad	no effect	some effect	moderate effect	great effect
29. Reconciliation with husband after divorce	Good	Bad	no effect	some effect	moderate effect	great effect
30. Major change in financial status						
a) income decreased substantially	Good	Bad	no effect	some effect	moderate effect	great effect
b) income increased substantially	Good	Bad	no effect	some effect	moderate effect	great effect
31. Borrowing more than \$10,000 (buying house, business, medical bills, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
32. Borrowing less than \$10,000 (buying car, T.V., school loan, medical bills, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
33. Not having enough money to take care of your child properly	Good	Bad	no effect	some effect	moderate effect	great effect
34. Foreclosure on mortgage or loan	Good	Bad	no effect	some effect	moderate effect	great effect

EVENT	TYPE OF EVENT		EFFECT OF EVENT ON YOUR LIFE			
	(1)	(2)	(1)	(2)	(3)	(4)
35. Change of residence	Good	Bad	no effect	some effect	moderate effect	great effect
36. Major change in living conditions of family (building new home, remodeling, deterioration of home, neighborhood, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
37. Major change in church activities (increase or decrease in attendance)	Good	Bad	no effect	some effect	moderate effect	great effect
38. Major change in usual type and/or amount of recreation	Good	Bad	no effect	some effect	moderate effect	great effect
39. Major change in social activities (parties, movies, visiting, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
40. Leaving home for the first time	Good	Bad	no effect	some effect	moderate effect	great effect
41. Gaining a new family member (through birth, adoption, relative moving in, etc.)	Good	Bad	no effect	some effect	moderate effect	great effect
42. Son or daughter leaving home	Good	Bad	no effect	some effect	moderate effect	great effect
43. Completion of your schooling	Good	Bad	no effect	some effect	moderate effect	great effect
44. Dropping out of school	Good	Bad	no effect	some effect	moderate effect	great effect
45. Having problems in school						
a) with schoolwork	Good	Bad	no effect	some effect	moderate effect	great effect
b) with teachers	Good	Bad	no effect	some effect	moderate effect	great effect
46. Entering a new school	Good	Bad	no effect	some effect	moderate effect	great effect

AIDS-related Life Events

I am going to read several more items. As with items previously mentioned, these events may bring about changes in the lives of those who experience them.

1.) Listen to the event and decide whether or not it has occurred in your life within the past year.

2.) If the event has occurred within the past year:

a.) Tell me whether it was "GOOD" or "BAD" (Some events have both good and bad elements. Tell me which one best applies.

b.) Then tell me whether the effect had NO EFFECT, SOME EFFECT, MODERATE EFFECT, or a GREAT EFFECT

EVENT	TYPE OF EVENT		EFFECT OF EVENT ON YOUR LIFE			
	(1)	(2)	(1)	(2)	(3)	(4)
1. Death of a close family member due to AIDS. relationship: _____	Good	Bad	no effect	some effect	moderate effect	great effect
2. Death of a close friend related to AIDS	Good	Bad	no effect	some effect	moderate effect	great effect
3. AIDS-related illness in a close family member. relationship: _____	Good	Bad	no effect	some effect	moderate effect	great effect
4. AIDS-related illness in a close friend.	Good	Bad	no effect	some effect	moderate effect	great effect

SOCIAL SUPPORT QUESTIONNAIRE

**PLEASE READ ALL DIRECTIONS
ON THIS PAGE BEFORE STARTING.**

Please list each significant person in your life on the right. Consider all the persons who provide personal support for you or who are important to you.

PERSONAL NETWORK

Number _____
Date _____

Use only first names or initials, and then indicate the relationship, as in the following example:

Example:

First Name or Initials	Relationship
1. MARY T.	FRIEND
2. BOB	BROTHER
3. M. T.	MOTHER
4. SAM	FRIEND
5. MRS. R.	NEIGHBOR
etc.	

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

- spouse or partner
- family members or relatives
- friends
- work or school associates
- neighbors
- health care providers
- counselor or therapist
- minister/priest/rabbi
- other

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life.

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

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University of California, San Francisco
Revised 1982

First Name or Initials

Relationship

1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____
5. _____	_____	_____
6. _____	_____	_____
7. _____	_____	_____
8. _____	_____	_____
9. _____	_____	_____
10. _____	_____	_____
11. _____	_____	_____
12. _____	_____	_____
13. _____	_____	_____
14. _____	_____	_____
15. _____	_____	_____
16. _____	_____	_____
17. _____	_____	_____
18. _____	_____	_____
19. _____	_____	_____
20. _____	_____	_____
21. _____	_____	_____
22. _____	_____	_____
23. _____	_____	_____
24. _____	_____	_____

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You listed, please answer the following questions
 the number that applies.

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 1:

How much does this person make
 you feel liked or loved?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 2:

How much does this person
 make you feel respected
 or admired?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 3:

How much can you confide
 in this person?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 4:

How much does this person
 agree with or support your
 actions or thoughts?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

117-01

GO ON TO NEXT PAGE

118-101

119-101

GO ON TO NEXT PAGE

118-101

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 5:

If you needed to borrow \$10, a ride to the doctor, or some other immediate help, how much could this person usually help?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

Question 6:

If you were confined to bed for several weeks, how much could this person help you?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

Question 7:
How long have you known this person?

- 1 = less than 6 months
- 2 = 6 to 12 months
- 3 = 1 to 2 years
- 4 = 2 to 5 years
- 5 = more than 5 years

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

Question 8:
How frequently do you usually have contact with this person? (Phone calls, visits, or letters)

- 5 = daily
- 4 = weekly
- 3 = monthly
- 2 = a few times a year
- 1 = once a year or less

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

GO ON TO NEXT PAGE

PLEASE BE SURE YOU HAVE RATED EACH PERSON ON EVERY QUESTION GO ON TO THE LAST PAGE.

Family Environment Scale - Form R

Instructions: There are 90 statements in this test. They are statements about families. You are to decide which statements are true of your family and which are false. Make all your marks on the answer sheet. If you think the statement is true or mostly true of your family, place an "X" next to the "T" (for True) in the box that corresponds with that item. If you think the statement is false or mostly false of your family, place an "X" next to the "F" (for False) in the box that corresponds with that item.

You may feel that some statements are true for some family members and false for others. Answer true if the statement is true for most members. Mark false if the statement is false for most members. If the members are evenly divided, decide what is the strong overall impression and answer accordingly.

Remember, we would like to know what your family seems like to you. So do not try to figure out how other members see your family, but do give us your general impression of your family for each statement.

	True	False
1. Family members really help and support one another.	_____	_____
2. Family members often keep their feelings to themselves.	_____	_____
3. We fight a lot in our family.	_____	_____
4. Activities in our family are pretty carefully planned.	_____	_____
5. We often seem to be killing time at home.	_____	_____
6. We say anything we want to around home.	_____	_____
7. Family members rarely become openly angry.	_____	_____
8. We are generally very neat and orderly.	_____	_____
9. We put a lot of energy into what we do at home.	_____	_____
10. It's hard to "blow off steam" at home without upsetting somebody.	_____	_____
11. Family members sometimes get so angry they throw things.	_____	_____
12. It's often hard to find things when you need them in our household.	_____	_____
13. There is a feeling of togetherness in our family.	_____	_____
14. We tell each other about our personal problems.	_____	_____
15. Family members hardly ever lose their tempers.	_____	_____
16. Being on time is very important in our family.	_____	_____
17. We rarely volunteer when something has to be done at home.	_____	_____
18. If we feel like doing something on the spur of the moment, we often just pick up and go.	_____	_____
19. Family members often criticize each other.	_____	_____
20. People change their minds often in our family.	_____	_____
21. Family members really back each other up.	_____	_____
22. Someone usually gets upset if you complain in our family.	_____	_____
23. Family members sometimes hit each other.	_____	_____

- 24. Family members make sure their rooms are neat. _____
- 25. There is very little group spirit in our family. _____
- 26. Money and paying bills are openly talked about in our family. _____
- 27. If there's a disagreement in our family, we try to smooth things over and keep the peace. _____
- 28. Each person's duties are clearly defined in our family. _____
- 29. We really get along well with each other. _____
- 30. We are usually very careful about what we say to each other. _____
- 31. Family members often try to one-up or outdo each other. _____
- 32. Money is not handled very carefully in our family. _____
- 33. There is plenty of time and attention for everyone in our family. _____
- 34. There are a lot of spontaneous discussions in our family. _____
- 35. In our family, we believe you don't ever get anywhere by raising your voice. _____
- 36. Dishes are usually done immediately after eating. _____

Stress Questionnaire

Many caretakers of children with chronic illness experience different levels of stress in different parts of their lives. Please indicate how stressful you find each of the following tasks, using the following scale.

- | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|-------------------------|---|---|-----------------------|---|---|------------------------|
| Not at all
Stressful | | | Somewhat
Stressful | | | Extremely
Stressful |
| _____ 1. | | | | | | |
| | | | | | | |
| _____ 2. | | | | | | |
| | | | | | | |
| _____ 3. | | | | | | |
| | | | | | | |
| _____ 4. | | | | | | |
| | | | | | | |
| _____ 5. | | | | | | |
| | | | | | | |
| _____ 6. | | | | | | |
| | | | | | | |
| _____ 7. | | | | | | |
| | | | | | | |
| _____ 8. | | | | | | |
| | | | | | | |
| _____ 9. | | | | | | |
| | | | | | | |
| _____ 10. | | | | | | |

We are interested in how people respond when they confront difficult or stressful events related to their child's illness. There are lots of ways to try to deal with stress or problems. These questions ask what you have been doing to cope with ___'s illness. Think about what you *usually* do when you are under a lot of stress related to ___'s illness.

Each item says something about a particular way of coping. I want to know *to what extent* you've been doing what the item says. How *much* or how *frequently*. Don't answer on the basis of whether it is working or not—just whether or not you're doing it. Try to rate each item separately from the others. Make your answers as true FOR YOU as you can. Please answer *every* item. Use these response choices.

- 1 = I usually don't do this at all
- 2 = I usually do this a little bit
- 3 = I usually do this a medium amount
- 4 = I usually do this a lot

- | | |
|---|---|
| <p>_____ 1. I've been turning to work or other activities to take my mind off things.</p> <p>_____ 2. I've been concentrating my efforts on doing something about the situation I am in.</p> <p>_____ 3. I've been saying to myself "this isn't real".</p> <p>_____ 4. I've been using alcohol or other drugs to make myself feel better.</p> <p>_____ 5. I've been getting emotional support from others.</p> <p>_____ 6. I've been giving up trying to deal with it.</p> <p>_____ 7. I've been taking action to try to make the situation better.</p> <p>_____ 8. I've been refusing to believe that it has happened.</p> <p>_____ 9. I've been saying things to let my unpleasant feelings escape.</p> <p>_____ 10. I've been using alcohol or other drugs to help me get through it.</p> <p>_____ 11. I've been trying to see it in a different light, to make it seem more positive.</p> <p>_____ 12. I've been trying to come up with a strategy about what to do.</p> <p>_____ 13. I've been getting comfort and understanding from someone.</p> <p>_____ 14. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping.</p> | <p>_____ 15. I've been learning to live with it.</p> <p>_____ 16. I've been thinking hard about what steps to take.</p> <p>_____ 17. I've been praying or meditating.</p> <p>_____ 18. I've been making fun of the situation.</p> <p>_____ 19. I've been trying to find comfort in my religion or spiritual beliefs.</p> <p>_____ 20. I've been expressing my negative feelings.</p> <p>_____ 21. I've been accepting the reality of the fact that it has happened.</p> <p>_____ 22. I've been making jokes about it.</p> <p>_____ 23. I've been looking for something good in what is happening.</p> <p>_____ 24. I've been giving up the attempt to cope.</p> |
|---|---|

INSTRUCTIONS:

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask about them.

SEX

MALE

FEMALE

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR _____ SEP _____ DIV _____ WID _____ SING _____

DATE			ID. NUMBER	AGE
MO	DAY	YEAR		

EXAMPLE	NOT AT ALL	A LITTLE BT	MODERATELY	QUITE A BT	EXTREMELY
HOW MUCH WERE YOU DISTRESSED BY:					
1. Bodyaches	0	1	2	3	4

VISIT NUMBER: _____

HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BT	MODERATELY	QUITE A BT	EXTREMELY	
1. Nervousness or shakiness inside	1	0	1	2	3	4
2. Faintness or dizziness	2	0	1	2	3	4
3. The idea that someone else can control your thoughts	3	0	1	2	3	4
4. Feeling others are to blame for most of your troubles	4	0	1	2	3	4
5. Trouble remembering things	5	0	1	2	3	4
6. Feeling easily annoyed or irritated	6	0	1	2	3	4
7. Pains in heart or chest	7	0	1	2	3	4
8. Feeling afraid in open spaces or on the streets	8	0	1	2	3	4
9. Thoughts of ending your life	9	0	1	2	3	4
10. Feeling that most people cannot be trusted	10	0	1	2	3	4
11. Poor appetite	11	0	1	2	3	4
12. Suddenly scared for no reason	12	0	1	2	3	4
13. Temper outbursts that you could not control	13	0	1	2	3	4
14. Feeling lonely even when you are with people	14	0	1	2	3	4
15. Feeling blocked in getting things done	15	0	1	2	3	4
16. Feeling lonely	16	0	1	2	3	4
17. Feeling blue	17	0	1	2	3	4
18. Feeling no interest in things	18	0	1	2	3	4
19. Feeling fearful	19	0	1	2	3	4
20. Your feelings being easily hurt	20	0	1	2	3	4
21. Feeling that people are unfriendly or dislike you	21	0	1	2	3	4
22. Feeling inferior to others	22	0	1	2	3	4
23. Nausea or upset stomach	23	0	1	2	3	4
24. Feeling that you are watched or talked about by others	24	0	1	2	3	4
25. Trouble falling asleep	25	0	1	2	3	4
26. Having to check and double check what you do	26	0	1	2	3	4
27. Difficulty making decisions	27	0	1	2	3	4
28. Feeling afraid to travel on buses, subways, or trains	28	0	1	2	3	4
29. Trouble getting your breath	29	0	1	2	3	4
30. Hot or cold spells	30	0	1	2	3	4
31. Having to avoid certain things, places, or activities because they frighten you	31	0	1	2	3	4
32. Your mind going blank	32	0	1	2	3	4
33. Numbness or tingling in parts of your body	33	0	1	2	3	4
34. The idea that you should be punished for your sins	34	0	1	2	3	4
35. Feeling hopeless about the future	35	0	1	2	3	4

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Trouble concentrating	36	0	1	2	3	4
37. Feeling weak in parts of your body	37	0	1	2	3	4
38. Feeling tense or keyed up	38	0	1	2	3	4
39. Thoughts of death or dying	39	0	1	2	3	4
40. Having urges to beat, injure, or harm someone	40	0	1	2	3	4
41. Having urges to break or smash things	41	0	1	2	3	4
42. Feeling very self-conscious with others	42	0	1	2	3	4
43. Feeling uneasy in crowds, such as shopping or at a movie	43	0	1	2	3	4
44. Never feeling close to another person	44	0	1	2	3	4
45. Spells of terror or panic	45	0	1	2	3	4
46. Getting into frequent arguments	46	0	1	2	3	4
47. Feeling nervous when you are left alone	47	0	1	2	3	4
48. Others not giving you proper credit for your achievements	48	0	1	2	3	4
49. Feeling so restless you couldn't sit still	49	0	1	2	3	4
50. Feelings of worthlessness	50	0	1	2	3	4
51. Feeling that people will take advantage of you if you let them	51	0	1	2	3	4
52. Feelings of guilt	52	0	1	2	3	4
53. The idea that something is wrong with your mind	53	0	1	2	3	4

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These next questions are about how you feel, and how things have been with you mostly within the past month.

For each question, please circle a number for the one answer that comes closest to the way you have been feeling.

1. How happy, satisfied, or pleased have you been with your personal life during the past month?

- Extremely happy, could not have been more satisfied or pleased.....1
- Very happy most of the time.....2
- Generally satisfied, pleased.....3
- Sometimes fairly satisfied, sometimes fairly happy.....4
- Generally dissatisfied, unhappy.....5
- Very dissatisfied, unhappy most of the time.....6

2. How much of the time have you felt lonely during the past month?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

3. How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

4. During the past month, how much of the time have you felt that the future looks hopeful and promising?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

5. How much of the time, during the past month, has your daily life been full of things that were interesting to you?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

6. How much of the time, during the past month, did you feel relaxed and free of tension?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

7. During the past month, how much of the time have you generally enjoyed the things you do?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

8. During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory?

- No, not at all.....1
- Maybe a little.....2
- Yes, but not enough to be concerned or worried about it.....3
- Yes, and I have been a little concerned.....4
- Yes, and I am quite concerned.....5
- Yes, and I am very much concerned about it.....6

9. Did you feel depressed during the past month?

- Yes, to the point that I did not care about anything for days at a time.....1
- Yes, very depressed almost every day.....2
- Yes, quite depressed almost every day.....3
- Yes, I am a little depressed now and then.....4

10. During the past month, how much of the time have you felt loved and wanted?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

11. How much of the time, during the past month, have you been a very nervous person?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

12. When you got up in the morning, this past month, about how often did you expect to have an interesting day?
- Always.....1
 Very often.....2
 Fairly often.....3
 Sometimes.....4
 Almost never.....5
 Never.....6
13. During the past month, how much of the time have you felt tense or "high-strung"?
- All of the time.....1
 Most of the time.....2
 A good bit of the time.....3
 Some of the time.....4
 A little of the time.....5
 None of the time.....6
14. During the past month, have you been in firm control of your behavior, thoughts, emotions, feelings?
- Yes, very definitely.....1
 Yes, for the most part.....2
 Yes, I guess so.....3
 No, not too well.....4
 No, and I am somewhat disturbed.....5
 No, and I am very disturbed.....6
15. During the past month, how often did your hands shake when you tried to do something?
- Always.....1
 Very often.....2
 Fairly often.....3
 Sometimes.....4
 Almost never.....5
 Never.....6
16. During the past month, how often did you feel that you had nothing to look forward to?
- Always.....1
 Very often.....2
 Fairly often.....3
 Sometimes.....4
 Almost never.....5
 Never.....6
17. How much of the time, during the past month, have you felt calm and peaceful?
- All of the time.....1
 Most of the time.....2
 A good bit of the time.....3
 Some of the time.....4
 A little of the time.....5
 None of the time.....6

18. How much of the time, during the past month, have you felt emotionally stable?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

19. How much of the time, during the past month, have you felt downhearted and blue?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

20. How often have you felt like crying, during the past month?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

21. During the past month, how often did you feel that others would be better off if you were dead?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

22. How much of the time, during the past month, were you able to relax without difficulty?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

23. During the past month, how much of the time did you feel that your love relationships, loving and being loved, were full and complete?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

24. How often, during the past month, did you feel that nothing turned out for you the way that you wanted it to?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

25. How much of the time have you been bothered by nervousness, or your "nerves", during the past month?

- Extremely so, to the point where I could not take care of things.....1
- Very much bothered.....2
- Bothered quite a bit by nerves.....3
- Bothered some, enough to notice.....4
- Bothered just a little by nerves.....5
- Not bothered at all by this.....6

26. During the past month, how much of the time has living been a wonderful adventure for you?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

27. How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

28. During the past month, did you ever think about taking your own life?

- Yes, very often.....1
- Yes, fairly often.....2
- Yes, a couple of times.....3
- Yes, at one time.....4
- No, never.....5

29. During the past month, how much of the time have you felt restless, fidgety, or impatient?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

30. During the past month, how much of the time have you been moody or brooded about things?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

31. How much of the time, during the past month, have you felt cheerful, light-hearted?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

32. During the past month, how often did you get rattled, upset, or flustered?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

33. During the past month, have you been anxious or worried?

- Yes, extremely so, to the point of being sick or almost sick.....1
- Yes, very much so.....2
- Yes, quite a bit.....3
- Yes, some, enough to bother me.....4
- Yes, a little bit.....5
- No, not at all.....6

34. During the past month, how much of the time were you a happy person?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

35. How often during the past month did you find yourself having difficulty trying to calm down?

- Always.....1
- Very often.....2
- Fairly often.....3
- Sometimes.....4
- Almost never.....5
- Never.....6

36. During the past month, how much of the time have you been in low or very low spirits?

- All of the time.....1
- Most of the time.....2
- A good bit of the time.....3
- Some of the time.....4
- A little of the time.....5
- None of the time.....6

37. How often, during the past month, have you been waking up feeling fresh and rested?

- Always, every day.....1
- Almost every day.....2
- Most days.....3
- Some days, but usually not.....4
- Hardly ever.....5
- Never wake up feeling rested.....6

38. During the past month, have you been under or felt you were under any strain, stress, or pressure?

- Yes, almost more than I could stand or bear.....1
- Yes, quite a bit of pressure.....2
- Yes, some, more than usual.....3
- Yes, some, but about normal.....4
- Yes, a little bit.....5
- No, not at all.....6

CURRICULUM VITA
Kathryn M. Miller

PERSONAL INFORMATION

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Date of Birth: July 6, 1969
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EDUCATION

Virginia Polytechnic Institute and State University, Blacksburg, VA.
• Candidate, Clinical Psychology Doctoral Program, degree expected December, 1996
• M.S., Clinical Psychology, 1993

University of Richmond, Richmond, VA.
• B.A. (Magna Cum Laude), Psychology, 1991

RESEARCH EXPERIENCE

9/96-Present Post-doctoral Fellowship, Nemours Children's Clinic.
Supervisor: Tim Wysocki, Ph.D.

- participation in data analysis, interpretation, and co-authorship on current NIH grant "Behavior Therapy for Families of Diabetic Adolescents"; in particular, responsible for overseeing the scoring of over 9000 minutes of audiotaped family discussions being used as one of the outcome measures for the study
- participation in the evaluation of the effectiveness of a videotape on pediatric anesthesia for increasing knowledge and decreasing anxiety among parents of children undergoing their first surgeries; participation includes data collection, analysis, and interpretation, and assistance with preparation for publication and presentation of findings
- participation in preparatory activities for NIH grant "Intensive Therapy for IDDM in Youth: Outcome Prediction"
- assistance with review of journal articles

12/96: Dissertation: *Predictors of Psychological Distress and Well-Being among the Primary Caregivers of Children with Pediatric AIDS/HIV.* Chair: Jack W. Finney, Ph.D.

8/94: Preliminary Examination: *The Role of Family Functioning in Children's Adjustment to Chronic Illness: A Systems Approach.* Chair: Jack W. Finney, Ph.D.

12/93: Masters Thesis: *A Test of Protection-Motivation Theory for Promoting Injury Control.* Chair: Jack W. Finney, Ph.D.

8/91-5/95: Research Assistant: Department of Psychology, Va Tech.
• assisted with subject recruitment, data collection, and administration of structured interviews for research projects being conducted by faculty and graduate students

9/90-4/91: Research Assistant: Department of Psychology, University of Richmond. Supervisor: Andrew F. Newcomb, Ph.D.
• assisted with data management and analysis for research project investigating the effects of methylphenidate on ADHD children's peer relations.

1/90-4/90: Class Research: Department of Psychology, University of Richmond. Instructor: Andrew F. Newcomb, Ph.D.
• developed and carried out a meta-analysis examining three components of ADHD children's peer relations: the incidence of appropriate, negative and nonsocial behaviors; the effect of the method of assessment (direct observation v. ratings); and the role of psychostimulant medication.

CLINICAL EXPERIENCE

9/96-Present Post-doctoral Fellowship, Nemours Children's Clinic.
Supervisor: Tim Wysocki, Ph.D.
• clinical activities will include provision of 6-8 hours per week of billable clinical service consisting of general pediatric psychology cases and participation in weekly supervision
• training will also consist of attendance at the bi-weekly Psychology Continuing Education conference (with at least two presentations given by the fellow) as well as Pediatric Grand Rounds, Clinical Case Conference

7/95-6/96 Pediatric Psychology Internship, University of Maryland School of Medicine. Supervisors: E. Wayne Holden, Ph.D., Vicki Tepper, Ph.D., Jeffrey Barnett, Psy.D., Laura Nabors, Ph.D., Steve Band, Ph.D., and Murray Kappelman, M.D., Maureen Black, Ph.D., Deborah Young-Hyman, Ph.D.

Core experiences included:

- served as a consultant (evaluation, disposition, and follow-up) through the Behavioral Pediatrics/Child Psychiatry Consultation and Liaison Service to the Pediatric Emergency Room, inpatient units, outpatient clinics, and Shock Trauma Center on cases presenting with a wide range of child and adolescent psychopathology and psychosocial issues
- conducted psychological assessments as part of a multidisciplinary team through the Comprehensive Evaluation Unit
- provided individual and family therapy through the outpatient Behavioral Pediatric Clinic to children with various behavior problems

- conducted psychological assessments, and providing individual, group, and family treatment, and consultation services for children in the physical rehabilitation program at Mount Washington Pediatric Hospital (a private, extended care facility)
- internship training also included participation in assessment, intervention, multicultural/ethnic issues, and professional issues seminars, participation in Consultation Liaison Service and Comprehensive Evaluation Unit rounds, and provision of training seminars to medical students and pediatric residents

Elective experiences include:

- performed psychosocial assessments and follow-up of children and adolescents and their families through the Pediatric Diabetes Center
- co-developed and co-led a coping- and skills-oriented peer support group for adolescents with diabetes
- led a therapeutic play group for children with HIV/AIDS
- served as a consultant to a primary care team through the Pediatric Ambulatory Clinic
- performed developmental and cognitive assessments of preschool and early school age children identified as having high lead levels

Research activities include:

- evaluated the effectiveness of a group intervention for promoting adaptive coping among adolescents with diabetes
- assessed the psychological distress and well-being among the primary caregivers of children with HIV/AIDS; investigating factors related to better and worse outcomes

8/91-5/95: Child Clinical Practicum: Psychological Services Center and Study Center, Va Tech. Supervisors: Thomas H. Ollendick, Ph.D., Jack W. Finney, Ph.D., Robert S. Stephens, Ph.D., George A. Clum, Ph.D., Richard M. Eisler, Ph.D., Ellie T. Sturgis, Ph.D., and Russell T. Jones, Ph.D.

- completed over 1100 hours of Clinical Practicum training and served as a graduate clinician for two summers
- training included assessment and treatment of adult, child, and family clientele, completion of psychological evaluations, facilitation of a children's social skills group, and participation in weekly practicum team meetings and weekly individual supervision
- fourth-year practicum experience included supervision of a second year graduate student

5/93-8/93: Children, Clinical Externship - Virginia Treatment Center for Richmond, VA. Supervisors: Donald Oswald, Ph.D., Molly Brunk, Ph.D., and Debbie Webb Blackburn, Ph.D.

- completed a 480 hour Clinical Externship on children's unit of acute inpatient psychiatric hospital for children
- duties included case management as well as individual and family therapy for a total of eight inpatient cases, assessment and treatment of three outpatient cases, and participation in interdisciplinary treatment team meetings and weekly individual supervision
- attended family clinic and training seminars (e.g., play therapy, MMPI-A, group therapy, music therapy)

8/92-5/93: **School Counselor: Montgomery County Public Schools, Christiansburg Middle School, Christiansburg, VA.**
Supervisor: Thomas H. Ollendick, Ph.D.

- responsibilities included providing weekly individual counseling for emotionally disturbed students as specified on IEP's and attendance to bi-weekly group supervision meetings and monthly staff meetings

TEACHING EXPERIENCE

8/94-5/95: **Graduate Teaching Assistant: Department of Psychology, Va Tech.** Teaching Mentor: Jack W. Finney, Ph.D.

- 8/94-5/95: served as the primary course instructor for an undergraduate course in Social Psychology
- 8/93-5/94: served as the primary instructor for an undergraduate lab in Social Psychology which involved guiding students in designing and conducting social psychological research projects
- 8/91-5/93: served as an instructor for lab sessions of undergraduate Introductory Psychology course which involved facilitating class discussions of assigned readings
- 8/91-12/92: assisted with an upper-level undergraduate course in Social Psychology and an undergraduate course in Abnormal Psychology; duties included grading course exams and papers, guest lecturing, and providing individual assistance to students

PUBLICATIONS

Finney, J.W., Miller, K.M., & Adler, S.P. (1993). Preventing child-to-parent transmission of cytomegalovirus by changing protective and risk behaviors. *Journal of Applied Behavior Analysis*, 26, 471-472.

Miller, K.M., & Finney, J.W. A test of Protection-Motivation Theory for promoting injury control. *Manuscript in preparation.*

Finney, J.W., & Miller, K.M. The Influence of Parental Illness on Children. In W.K. Silverman and T.H. Ollendick (Eds.), *Developmental Issues in the Clinical Treatment of Children and Adolescents*. Needham Heights, MA: Allyn & Bacon. *Chapter in preparation.*

PRESENTATIONS

Miller, K.M., & Rawlins, C. A. (1996, April). *Evaluation of a peer support group to promote coping in adolescents with diabetes*. Poster session presented at the North Coast Regional meeting of the Society of Pediatric Psychology in Toronto, Canada.

Febbraro, G.A.R., Clum, G.A., Curtin, L., Miller, K.M. (1994, November). *A critical examination of claustrophobia: Do subtypes exist?* Poster session presented at the 28th Annual Conference of the Association for the Advancement of Behavior Therapy in San Diego, CA.

Miller, K.M., & Finney, J.W. (1994, April). *A test of Protection-Motivation Theory for promoting injury control*. Poster session presented at the 10th Annual Graduate Research Symposium at Va Tech in Blacksburg, VA.

Miller, K.M., & Finney, J.W. (1994, April). *A test of Protection-Motivation Theory for promoting bicycle safety*. Paper presented at the North Coast Regional meeting of the Society of Pediatric Psychology in Cincinnati, OH.

Finney, J.W., Miller, K.M., & Adler, S.P. (1993, April). *Preventing child-to-parent transmission of cytomegalovirus*. Poster session presented at the Florida Conference on Child Health Psychology in Gainesville, FL.

Newcomb, A., Strandburg, K., & Miller, K. (1991, April). *A meta - analysis of ADHD children's peer relations*. Paper presented at Biennial Meetings of the Society for Research in Child Development in Seattle, WA.

HONORS/AWARDS

- Phi Beta Kappa National Honor Society
- Psi Chi National Honor Society in Psychology

- Phi Eta Sigma Freshman Honor Society
- Virginia Tech Graduate Student Assembly Travel Award (1993)
- Virginia Tech Graduate Student Assembly Graduate Research Award (1995)
- American Psychological Association Dissertation Research Award (1995)

PROFESSIONAL AFFILIATIONS

- American Psychological Association, Student Affiliate
- Association for Advancement of Behavior Therapy
- Society for Pediatric Psychology

Kathryn M. Miller