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UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

AIDS ORPHANS: THE PSYCHOLOGICAL ADJUSTMENT OF CHILDREN WITH MULTIPLE FAMILY MEMBERS WITH A TERMINAL ILLNESS

A Dissertation
SUBMITTED TO THE GRADUATE FACULTY
in partial fulfillment of the requirements for the
degree of
Doctor of Philosophy

By
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AIDS ORPHANS: THE PSYCHOLOGICAL ADJUSTMENT OF CHILDREN WITH MULTIPLE FAMILY MEMBERS WITH A TERMINAL ILLNESS

A Dissertation
APPROVED FOR THE DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

BY

Larry E. Toothaker

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Abstract

The rise in the number of Acquired Immune Deficiency Syndrome cases has created a new demographic in society, uninfected children with terminally ill family members. The uninfected children in HIV affected families may be exposed to a series of major psychological risk factors - stigma, secrecy, exposure to acute and chronic illness, death of parents and/or siblings, separations, losses, orphanhood and foster home placements. The purpose of this study was to assess the emotional adjustment of children who have multiple family members diagnosed with an Acquired Immune Deficiency Syndrome(AIDS)/Human Immunodeficiency Virus (HIV). Specifically, descriptive data was collected to determine the degree of relationship among various combinations of the predictor variables (knowledge of parent/sibling illness, previous death experiences, participation in choosing future living situation, social support, and a history of a stable living situation) and each of the dependent measures.

Fifty-two uninfected children of HIV positive women who had a sibling who was followed by the Pediatric AIDS Clinic at a large mid-Atlantic urban pediatric medical center participated in this study. Children ranged from 6 - 16 years of age (M=10.29, SD=3.25). Four separate measures were used; three were completed by the uninfected sibling: The Children's Depression Inventory (CDI), the Revised Children's Manifest Anxiety Scale (RCMAS), and the Kidcope. The remaining measure, the Child Behavior Checklist (CBCL), was completed by the caregiver. Descriptive statistics and multiple regression analyses were performed to test the theoretical model of adjustment created to assess the emotional adjustment of children who have multiple family members diagnosed with HIV/AIDS. As a group, these children were characterized by clinically elevated levels of psychological distress. Specifically, children who have experienced an HIV/AIDS related death in their family, have had their parent's or sibling's diagnosis disclosed to them, have a lack of available social supports and/or lack a stable living environment are at greater risk for developing behavioral and/or emotional problems.

AIDS Orphans: The Psychological Adjustment of Children With Multiple Family Members With a Terminal Illness

Pediatric Acquired Immunodeficiency Syndrome (AIDS) has become the newest chronic illness in childhood according to the Center for Disease Control with more than 12,000 children in the United States currently infected, and more than 1,000 additional children becoming infected each year (Center for Disease Control, 1995; Lipson, 1993; Maieron, Roberts, & Prentice-Dunn, 1996). Human Immunodeficiency Virus (HIV) infected children are often born to minority women who were intravenous drug users, had multiple sexual partners, and lived in large urban areas (Aleman, Kloser, Kreibick, Steiner, & Boyd-Franklin, 1995).

AIDS is the leading cause of death in African-American women (aged 25-44 years) and more than half of the reported AIDS cases in 1994 were among women of color (Abercrombie, 1996; Boland, 1996). The majority of these women were likely to be infected through heterosexual intercourse during their adolescence. In women, heterosexual contact with an infected man and intravenous (IV) drug use are the most common modes of transmission and have caused the rapid increase in the rate of occurrence. (Abercrombie, 1996; Boland, 1996). Despite the potential danger that unprotected heterosexual intercourse poses, many women continue to engage in high risk behaviors.

Having a family is extremely important to many African American women (Boyd-Franklin, 1989). It is typical that extended family networks assist mothers in caring for and raising their children. Specifically, grandmothers often contribute financially and emotionally to their grandchild's development. In many families, the rearing of children skips generations, whereas the biological mother may have been raised by her grandmother, not her mother. According to Boyd-Franklin (1989), grandmothers are often young women (35-48) who were themselves, teen mothers.

In HIV/AIDS affected families, grandmothers often become the primary caregivers for their grandchildren after mothers become unable to care for them. The loss of the young mother is likely to impact the multigenerational model of mothering proposed by Boyd-Franklin (1989). Their absence will create a gap in the "three generation system" which depends upon the extended family to assist with child-rearing, forcing the family to reach beyond immediate family members to assist in times of crisis (Hines & Boyd-Franklin, 1996). Women who are infected with HIV/AIDS often remove themselves from traditional support systems (e.g., church groups, parent groups, friends) that they have relied on to cope with problems and stressors (Boyd-Franklin, 1989). These women often choose to keep their HIV/AIDS diagnosis a secret from family members to avoid the stigma and possible loss of support. African American families may avoid open communication about "toxic issues", despite knowing that each family member is aware of the family secret (Boyd-Franklin, 1989).

Within families with multiple HIV infected members there are also many uninfected children. These children will outlive their infected parents, siblings, extended family members, and neighbors. The issues that confront these orphans of the AIDS epidemic are similar to those of their infected siblings—they too will lose a parent, be asked to maintain the family's "secret" and will live in fear of their parent's and sibling's diagnosis being discovered. The uninfected child may be responsible for "performing physical tasks as well as providing attention and emotional support and supervision for other children and the parent. This role reversal with the parents sets up expectations for the child that may be difficult to achieve, or can be achieved at the cost of one's own development and childhood activities" (Anderson, 1995, p. 62).

Uninfected children in HIV affected families may be exposed to a series of associated major psychological risk factors—stigma, secrecy, exposure to acute and chronic illness, death of parents and/or siblings, separations, losses, orphanhood, and foster home placements. The burden of living with HIV impacts the entire family system, not only the family members that are infected. Uninfected family members living in an HIV affected home are likely to witness profound physical and emotional alterations in infected family members, and experience significant changes in their daily routines as their family member's HIV infection progresses.

As the infected family member's infection progresses, attention is directed toward the ill family member, leaving the uninfected children feeling "isolated, neglected, and worried" (Andiman, 1995, p. 43). Their interactions with peers and involvement in regular activities are limited as the family becomes focused on the ill member. Roles may be reversed as the well children are asked to provide physical care for their sick parent or sibling. The number of clinic appointments, hospitalizations, medications, and treatments increase as the parent or sibling becomes sicker.

HIV affected families struggle to live with a chronic illness and anticipate future losses. For many there is a "paradoxical dilemma" of "how to maintain normality of life to at least some degree while preparing themselves emotionally for the painful inevitability of death" (Boyd-Franklin, Drelich, Schwolsky-Fitch, 1995, p. 179). Anticipating the losses initiates the mourning process after the family member has a prolonged illness, disfigurement, or neurological complications (Worden, 1991). For families affected by HIV/AIDS, observing a once healthy family member "waste away" brings thoughts of their pending death before the family member reaches the final stages of illness.

Anderson (1995) addressed the roller-coaster of emotions that family members will encounter as a sibling or parent's death is preceded by a series of episodic acute illnesses from which they recover, giving the family temporary respite until the following crisis. Many family members begin grieving the loss of the infected parent or child after they observe significant changes in the ill person's emotional or cognitive functioning.

HIV/AIDS differs significantly from other chronic and life threatening illnesses due to the complex psychological and social issues that confront AIDS infected families (Boland, 1990). It is a stigmatized disease that is an "ultimately fatal illness in one or more family members" (Boland, 1996, p. 161). As a result of the association with high risk behaviors, families feel a need for secrecy and a fear of social isolation if the diagnosis in known. Families with HIV/AIDS often struggle with deciding whom they can tell, if anyone, about the child's or parent's condition (Anderson, 1995).

HIV/AIDS carries a stigma that prevents caregivers from sharing their diagnosis with their children. The diagnosis is often kept a secret to maintain a sense of normalcy in the home (Lesar, Gerber, & Semmel, 1996). Caregivers often worry that the children will be unable to keep the "secret" from teachers, classmates, and other family members (Forsyth, Damour, Nagler, & Adnopoz, 1996; Stuber, 1992). Thus, children frequently are not told of their parent or sibling's diagnosis or if children have been told that a family member has an illness, the information may be inaccurate (e.g., "your sister has sickle cell disease"). In a study that examined the stress in families with HIV infected children, 70% of caregivers reported that they disclosed their HIV diagnosis only to immediate family members. The stigma associated with HIV was described as the most common fear of these caregivers (Lesar, et al., 1996). Because of this fear, parents have reported being treated differently by friends, relatives, child care providers, medical staff, and school personnel after they have disclosed information about their HIV diagnosis (Lesar, et al., 1996). Further, they often feel ashamed and guilty for engaging in high risk behaviors thus, there is a lack of candor within the home. Secrecy then contributes to a loss of social support and a self-imposed isolation that contributes to the parent's feelings of hopelessness, depression, and guilt (Boland, 1990).

Families affected by HIV experience significant psychosocial problems including multiple losses, stigma, shame, guilt, and secrecy. Parents may have difficulty disclosing their child's diagnosis to other family members due to the role that he/she played in transmitting the virus. Although previous research suggests that children benefit from knowing about their illness, many adults fear the social stigma associated with the transmission of the disease. The stigma contributes to the silence that accompanies this disease. As a result of the silence, families often do not get the support needed during a time of loss, upheaval, and despair.

Michaels and Levine (1992) estimated that 45,600 children and adolescents in the United States would be orphaned due to HIV/AIDS by 1996 and the number would increase to 82,000 by the year 2000. Many of the children that survive the death of their infected parent live with other relatives, adoptive parents, or are placed in foster care. Children are often placed outside of their mother's care directly from the newborn nursery because of their mother's inability to provide adequate care due to a host of psychosocial and medical issues: their own HIV-related illness, other health problems, circumstances related to drug-use or other economic and social stresses (Anderson, 1995). A parent's inability to care for their children may be temporary (e.g., during a brief hospitalization for an acute illness) or permanent (e.g., parent is no longer able to care for the child due to severe illness or death).

The psychological effects of a family member's HIV infection on uninfected children remains an understudied area in the empirical literature (Forsyth et al., 1996). One study has been published that specifically focused on the psychological adjustment of uninfected children on HIV-infected parents. Forsyth and colleagues (1996) assessed the psychological impact of HIV on 26 uninfected children in affected families (54% female, 46% male; 70% African American; mean age 9.8 years). When compared to children that were from families without chronic illness, HIV affected children were more withdrawn, depressed and had more problems with attention. Forsyth et al. (1996) demonstrated that uninfected children in an affected family are at risk for developing psychological symptoms as a result of having a parent with an HIV/AIDS diagnosis. Nevertheless, the data should be interpreted with caution given the small sample size, biases in the sample selection (volunteers), and the symptom status of the mothers (7% deceased, 38% symptomatic, 53% asymptomatic). In addition, the children in this study had limited experience with death compared to most HIV affected families (8 of the 26 had lost a relative to

HIV/AIDS) and the majority lived in households where there was only one infected family member (50% had one infected parent, 11% had both parents infected, and 31% also had an infected sibling). Research has failed to address the unique issues and stressors that influence the families' adjustment to a chronic or terminal illness in more than one family member; specifically, the adjustment of the uninfected children living in HIV/AIDS infected families where there are several terminally ill family members.

Current theoretical models of coping with a family member's chronic illness can not be used to adequately address the unique psychological issues that coexist with a diagnosis of HIV--the stigma, secrecy, guilt, ostracism, and multiple losses. Proposed models of adjustment to pediatric chronic illness fail to take into account the extraordinary stressors that impact HIV/AIDS-affected families (e.g., poverty, unstable living situations, unemployment, lack of education, substance abuse, and family violence). Previous empirical research has also ignored the extraordinary circumstances which these families encounter besides adjustment to a member's chronic illness.

In the absence of an appropriate theoretical model to address families with an HIV infected child, Lesar, Gerber, and Semmel (1996) developed a family adaptational model. This model combines the concepts used in the stress and coping models with ecological systems theory to illustrate the effects that an HIV infected child's illness has on the family's functioning. The disease is viewed as a "family disease" that threatens the family's existence. Relying upon a combination of family systems theory and an ecological framework, the model suggests that "specific stressors reverberate through a family having both direct and indirect influences upon its members" (Lesar, et al., 1996, p. 225). The model acknowledges that a child with perinatal infection has at least one other family member (the mother) that is also infected with HIV and experiences multiple unrelated stressors in the course of their daily lives (e.g., poverty, unstable living arrangements, and possible substance abuse). In a study to empirically test their model, Lesar and colleagues (1996) examined the relationship between severity and impact of the child's health status, availability of resources and support, and additional or unusual caregiving demands. The combination of the caregiver's HIV status, parenting stress ratings, and the specific burdens involved in providing daily care for a chronically ill child accounted for 62% of the variance in family functioning. Results from this study suggest that the use of the family adaptational model is useful in studying families with children infected with HIV, however, the findings do not adequately speak to the complex relationships between family members with a terminal illness, multiple losses, and the secrecy associated with the diagnosis.

A model was proposed (see Figure 1) in this study that incorporates the stressors related to having multiple family members with a chronic debilitating illness, multiple losses/anticipated losses, and those unique to an HIV diagnosis (e.g., secrecy, stigma, health of caregiver, family stability, future placement).

The proposed model extends beyond previous models that have not addressed uninfected children living in HIV/AIDS affected families. In this model, having a family member infected with HIV is viewed as a potential stressor to which the child and family system endeavor to adjust. It serves as a heuristic tool for conceptualizing how support, stressors, and coping skills relate to child and caregiver adjustment. The model's focus is on the psychological adjustment of children and how it is affected by different stressors, perceptions of the stressors, demographic parameters (age, gender, father presence, number of siblings, and caregiver's relationship), illness parameters (severity and changes in functioning), caregiver adjustment, and available supports.

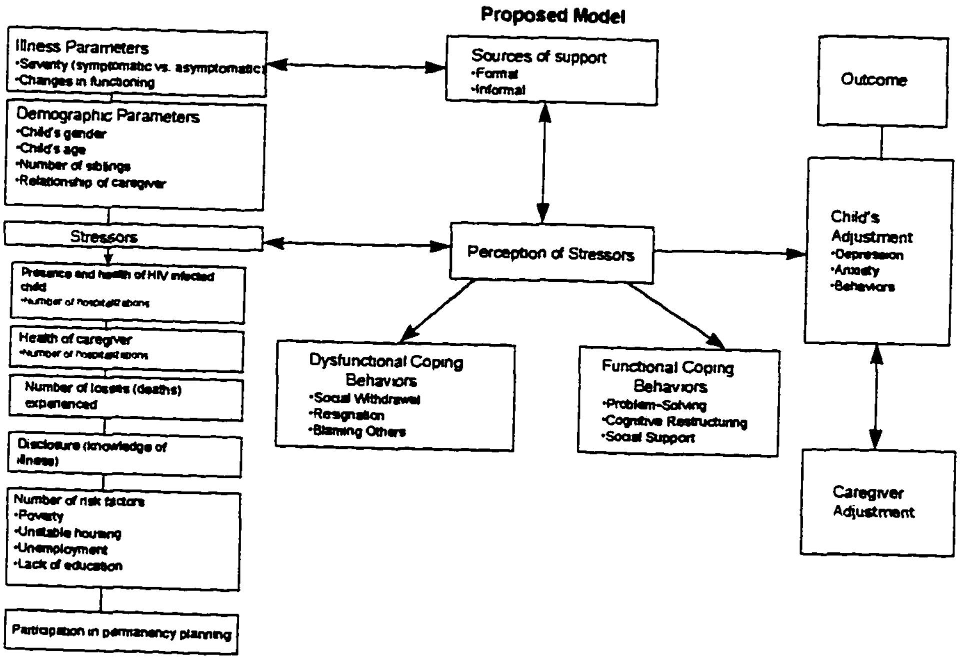

Figure 1. Model of psychological adjustment in children with multiple family members infected with HIV/AIDS.

Coping with general life stresses and chronic illness occurs within a social context (Compas, Worsham, & Ey, 1992). Families are resources that provide the support and information that help children cope with difficult situations. Parents can serve as models who influence the coping strategies that individual family members choose to utilize. However, families often can impede coping processes and affect the coping efforts of family members in a negative way. Family functioning is often measured in terms of their cohesion, expressiveness, organization, independence, and control (Moos & Moos, 1981). The family's level of functioning directly impacts the child's psychological adjustment (Thompson & Gustafson, 1996). The literature supports a relationship between children's adjustment and parental stress and distress (Banez & Compas, 1990).

A family member with a chronic illness significantly impacts other individuals within the family due to distress caused by numerous disruptions in the family which includes; frequent separations from caregivers, disruption of daily routines, lack of information about the illness, focus of the family on the ill member, repeated hospitalizations, exposure to numerous painful procedures, and fear of death (Sargent, et al., 1995). Children differ from adults in their understanding and reactions to illness based upon their developmental level. Their views regarding the concepts of health and illness develop through a series of systematic stages which parallel those described by Piaget (Eiser & Eiser, 1987; Eiser, Eiser, & Lang, 1989; Harbeck & Peterson, 1992).

Children with a parent diagnosed with a terminal illness are faced with significant psychosocial stresses. The parent's illness disrupts the entire family system, forcing other family members to make changes to their daily routine to assist with their health care needs (Baker, Nieswiadomy, & Arnold, 1988; Brooks, 1991). A parent's illness specifically causes major stress on the family because of the numerous functions that he/she performs by being a partner in a marital relationship, parent, manager of the household, employee, and friend (Johnston, Martin, Martin, & Gumaer, 1992). The nature and extent of changes within the family's structure are dependent upon the length and severity of the parent's illness. Currently, few studies have assessed the long term impact of parental physical illness on children even though it is believed to be a cause of psychiatric illness in children (Gallo, Breitmayer, Knafl, & Zoeller, 1992; Glass, 1985; Johnston et al., 1992; Roy, 1991).

Children who have a sibling in the hospital often experience many of the same stressors as children who are hospitalized for their own illness. Stressful situations that have been identified in hospitalized children include separation from parents, loss of self-control, and confusion over medical procedures. According to Pidgeon (1981), these aspects of hospitalization create a series of real, imagined, or potential threats for the child. The nature of the threat depends upon the child's age and level of development, previous experiences with such threats, amount and type of relevant information they possess, and the amount and type of support they receive (Eiser, 1990). Hospitalization provides many stressors which may intensify a sibling's reactions such as unfamiliarity with hospital environment and personnel, separation from caregiver, disruption of typical routines, loss of control over daily events, and misconceptions about the purpose of their brother or sister's hospitalization (Peterson, 1989; Siegel & Hudson, 1992).

The brothers and sisters of children with chronic illnesses have reported feeling resentful, angry, anxious, depressed, jealous, guilty, and afraid (Fanos & Wiener, 1994; Sargent et al., 1995). Long-term effects of a sibling's illness and death have been found in adults who lost a sibling to cystic fibrosis (Fanos & Wiener, 1994). They described feeling guilty about surviving and having not been ill. After they reached new developmental milestones that their sibling did not achieve, they began to revisit their feelings of guilt and often began to worry that they themselves would die at an early age.

Research findings have consistently indicated that the family crises of childhood illnesses (e.g., cancer, diabetes) can have a profound impact on a sibling's psychosocial functioning (Menke, 1987; Sargent, et al., 1995). Several studies have reported that these siblings experience adjustment problems, emotional symptoms of distress, and behavioral symptoms of distress (Bendor, 1990; Carpenter & Sahler, 1991; Walker, 1988). Unsuccessful adaptation of siblings may be associated with: (1) insufficient or infrequent parental communication about their brother or sister's illness, (2) limited participation in their sibling's treatment or care, (3) feelings of physical and emotional isolation from their parents, and (4) insufficient resources to provide them with emotional, social, and peer support. In a study that examined the responses of 254 siblings of children with cancer, Sargent and colleagues (1995) found significant age differences in adjustment. Healthy siblings reported feeling most distressed about the lack of attention they received, the number of family separations and disruptions, their sibling's medical treatments and possible death. Nevertheless, these siblings reported being closer to their siblings and feeling more compassionate towards their families. Older children were viewed as having greater patience and awareness of the needs of their ill siblings. The literature on childhood chronic illness suggests that young children are more likely to have difficulty adjusting to the disruptions in their lives and have fewer resources available to assist them with coping (Sargent et al., 1995).

A child's response to death is influenced by their previous experiences with death, availability of support, parent or caretaker's demeanor, the nature of the person's death, and his/her developmental age (Wolfelt, 1996). Their ability to understand the concept of death is dependent upon the their level of cognitive, emotional, and social development (Worden, 1996). The death of a parent is a psychological trauma which threatens the child's social and emotional development. According to Furman (as cited in Siegel, Mesagno, & Christ, 1990) "no other event is comparable in psychological significance because the death of a parent deprives children of so much opportunity to love and be loved and confronts them with a formidable adaptive task" (p. 168). It is not a single, discrete event, but rather a life transition compiled of a series of changes that take place prior to and following this significant loss . The loss often precipitates many stressful changes such as alterations in the family's daily routines, financial status, residence, and the caretaker's ability to provide emotional and physical support (Reynolds, Miller, Jelalian, & Spirito, 1995; Siegel, Mesagno, & Christ, 1990; Worden, 1996).

Children who lose a parent are at risk for developing emotional disturbances. These children may manifest symptoms in childhood and adulthood which could include: sadness; anxiety; confusion; eating, sleeping, and toileting problems; somatic complaints; disruptive behaviors; social and emotional withdrawal; suicide attempts; loss of interest in favorite pastimes; decreased attention span; learning problems; decreased effectiveness in school; and expressions of guilt over past experiences (Brent, 1983; Furman, 1983; Gelcer, 1983; Koocher & Gudas, 1992; Worden 1996).

A parent's death will have both short and long term effects on a child. Furman (1974) described bereavement as a threefold task--to cope with the immediate impact of the circumstances, to mourn, and to resume one's emotional life. The degree of success depends upon the intrafamilial communication and the shared expression of feelings. A child's adjustment is "related to the surviving parent's ability to offer physical and emotional comfort; provide an environment in which the child feels able to express distressing or conflicting thoughts, feelings, and fantasies about the loss; and maintain stability and consistency in the child's environment" (Reynolds, et al., 1995, p. 157). Children who do not have a supportive and caring environment that strives to minimize the number of changes and open the lines of communication are at risk for poor psychological adjustment.

Sibling loss differs significantly from that of parental loss due to the impact that the loss has on the parents and the lack of support that is available to be given to bereaved siblings. Often the focus is on the bereaved parent who needs for the surviving child to "be strong" (Reynolds et al., 1995). According to Worden (1996), the caregivers grief may interfere with their ability to parent or be emotionally available to their surviving children. Surviving children are likely to experience the parents' mourning and withdrawal as an additional loss (Brent, 1983). This loss is often amplified for children of single parents who do not have another person that can help with parenting/nurturing.

Losing a parent, sibling or other family member to AIDS is likely to complicate the mourning process (Boyd-Franklin, Drelich, & Schwolsky-Fitch, 1995). The task of mourning a family member who suffers an AIDS related death is confounded by the number of losses within one family, the social stigma associated with AIDS, and the challenges to the family's stability. Often family members have not had enough time to mourn one loss before another occurs (Boyd-Franklin, et al., 1995).

The "illness and cause of death are often kept secret" because of the stigma and discrimination associated with AIDS (Siegel & Gorey, 1994, p. S67).

Family members are likely to be ashamed and afraid of the repercussions that are a result of disclosure. Due to the risk behaviors associated with HIV transmission, extended family members may feel anger and resentment towards the parents for burdening them with their care and that of their children. These families often live under a veil of silence, refusing to acknowledge the illness and their need for support. Siegel and Gorey (1994) spoke of the overload experienced by families when they lose several friends and relatives within a short period of time.

Mourning a parent may be difficult for a child who has lost a parent infected with HIV due to the lack of factual information surrounding the cause of death. As a result, children may not be given the opportunity to openly express their feelings about the loss or modify misconceptions about their understanding of the illness or cause of death. Previous research indicates that children benefit from receiving developmentally appropriate information, being included in decision-making, having their feelings and thoughts validated, and remaining involved in age-related activities (Adams-Greenly & Moynihan, 1983). Families who strive to achieve some sort of family organization that mirrors the child's previous experience are likely to enhance the child's sense of control. Despite the efforts that families make to avoid further disruptions, children may be placed in foster care, moved between temporary placements, or separated from significant others due to the lack of custody planning and/or available support (Siegel & Gorey, 1994).

The empirical and theoretical literature on the effects of HIV infection on the psychosocial adjustment of the uninfected children in an HIV/AIDS infected family is virtually nonexistent. In an effort to promote the development of culturally sensitive and appropriate psychosocial interventions to assist families affected by HIV, factors that are associated with better or worse adjustment among uninfected children (AIDS Orphans) need to be identified.

The purpose of this study was to assess the emotional adjustment of children who have multiple family members diagnosed with a terminal illness, HIV/AIDS. Specifically, this study provides further documentation of the psychological outcomes among children in HIV/AIDS affected families who are at risk for adverse psychological consequences.

Guided by the proposed model of adjustment in children having multiple family members with a terminal illness, the current study examined the relationship between selected stressors and resources to specific outcome indices of the uninfected children's adjustment (i.e., Child Behavior Checklist, Children's Depression Inventory, and the Revised Children's Manifest Anxiety Scale). Situation specific stressors associated with living in a family where multiple family members are terminally ill were selected (i.e., knowledge of parent's HIV/AIDS diagnosis, knowledge of sibling's HIV/AIDS diagnosis, knowledge of future custody arrangements, participation in custody arrangements and previous experience with an HIV/AIDS related death). As resources, the availability of social support and a stable living environment were hypothesized to have direct and positive effects on children's adjustment. In addition, children's coping behaviors were assessed to identify whether they accounted for independent and significant increments in the variance within child adjustment over and above that accounted for by demographic and illness parameters.

METHOD

Participants

The sample consisted of 52 uninfected children ages 6-16 who have multiple HIV infected family and their care providers (defined as the individual who is responsible for the primary care of the children in the family such as the biological mother, grandparent, or foster parent). Participants were recruited from families who are followed by the Pediatric AIDS program at Maryland's Hospital for Children, at the University of Maryland at Baltimore, and the Baltimore City Head Start Pediatric HIV Project. Because data collection excluded children who are currently living in non-relative foster care placements, not all eligible children were able to participate in the present study. In the end, a total of 31 caregivers were approached to participate; 7 declined and 24 agreed. Of the 24 who agreed to participate, 3 children were excluded from the final analyses after a review of clinic records revealed that they were not the siblings of an infected child, making them ineligible for the present study. No information regarding the caregivers who declined to participate was available. As a result, any potential differences between the participating and eligible but not participating child-caregiver dyads were unable to be explored.

The 22 caregivers of the 52 children were all African-American women ranging in age from 26-62 years (M=37.92; SD=9.48). The sample consisted of 79% biological mothers, 13% biological grandmothers, 4% aunts, 2% step-parents, and 2% adoptive parents. Sixteen percent (16%) of the caregivers were married, 40% were separated, 2% were divorced, 2% were widowed, and 40% have never been married. Mean grade level completed by the caregivers was about the 10th grade (M=10.65, SD=1.48) and 42% of the caregivers were not employed outside of the home, with 10% receiving disability. Fifty-four percent (54%) had another adult living in the home who participated in child rearing and in helping with household expenses. A total of 56% caregivers reported earning a combined income of less than $10,000 annually and lived in homes with an average of 7.85 persons (SD= 3.35; range from 2-12 family members). All of the caregivers (100%) reported receiving some type of financial assistance such as SSI (social security benefits), Medical Assistance, AFDC (Aid to Families with Dependent Children), and/or food stamps. Forty-six percent (46%) of the caregivers reported moving three or more times in the past five years with the number of moves ranging from 1-10 moves.

A total of 52 children participated in the present study, 29 were male (56%) and 23 were females (44%). The children ranged in age from 6 to 16 (M=10.29; SD=3.25) and all were African American (100%). Nineteen (36%) of the children knew that their parent has been diagnosed with HIV/AIDS while only 17 (33%) knew that they had a brother or sister who carried the same diagnosis. Although only 33% knew that their sibling had HIV/AIDS, 36 (69%) knew that their sibling had been diagnosed with some type of illness (e.g., sickle cell disease, blood disorder, cancer, etc.). Despite the lack of information the children received about their parent's or sibling's illness, only 16 (31%) had asked their caregiver direct questions about the health of their parent or sibling.

Caregivers reported that 16 (31%) of the children's siblings are described as symptomatic with the number of hospitalizations ranging from 0-30 + (M=3.58; SD=7.29) and 19 (36%) of the children's mothers are described as symptomatic with the number of hospitalizations ranging from 0-30 + (M=3.24; SD=6.53). Many of the children, 31 (60%), had exposure to an HIV related death with children having experienced the loss of mothers, fathers, siblings, aunts/uncles, cousins, and step-parents (M=1.00, SD=1.30).

Nineteen (37%) of the children assisted their parent in choosing who would take care of them if their parent was no longer able to do so or needed assistance, however, 38 (73%) knew if something happened to their parent, someone was designated as their guardian. Over half of the children (61%) were thought to have no available social supports and only 20 (39%) of the caregivers could identify someone to whom their child could confide if needed. Several of the children had already been referred for mental health services (15 children, 29%) to assist them in coping with family illness and loss, behavioral problems, and in learning to express their feelings appropriately. A listing of the sources of support for uninfected children known by their caregivers is provided in Table 1.

Procedures

The research protocol, approved by the institutional review boards of the University of Maryland at Baltimore School of Medicine and the University of Oklahoma, included a consent form, assent form, demographic questionnaire, and four questionnaires. All children and their caregivers were asked to complete the assessment instruments (see Appendices) in a conference room at the medical center. They were instructed how to complete each instrument according to standardized administration procedures by the study coordinator or research assistants. Each participant was given the opportunity to have the questionnaires read aloud or be given assistance or explanations when needed. All children under the age of 11 were presented the questionnaires orally. Informed consent and assent were obtained from all child-caregiver dyads who agreed to participate. Upon completion of the questionnaires, child-caregiver dyads received twenty dollars in financial compensation for their participation.

Measures of Predictor Variables

Predictor variables were categorized into six components in the model. Each component is based upon the independent variables that were chosen from the model piloted in this study. The manner in which this information was obtained is summarized below. A demographic questionnaire was developed for the purpose of this study to collect background information on family composition and status, risk factors, illness knowledge, and sources of support. This questionnaire was administered to the caregiver.

Knowledge of family member's HIV diagnosis

Disclosure of the parent's or sibling's illness to the uninfected children was assessed with simple 'yes'/'no' questions on the background information questionnaire. All of the infected caregivers (100%) reported that they had disclosed their diagnosis and/or their child's HIV status. Eighty-one percent of the non-maternal caregivers acknowledged disclosing the infected child's diagnosis to someone. Extended family (86%), grandparents (40%), and uninfected children (36%) living in the home were most often identified as the people to whom the caregiver disclosed information about their own, the child's or the parent's diagnosis. Table 2 provides a detailed account of the groups of people who were reported to know of the parent's diagnosis. These groups differ from those who know of the infected child's diagnosis. Extended family (61%), grandparents (36%), and uninfected children in the home (25% for other siblings and 33% for sibling participating in this study). Table 3 presents a breakdown of the groups of people who are aware of the infected child's diagnosis. The limited number of uninfected children in this sample who know of a parent's or sibling's diagnosis prevented comparisons between groups.

Permanency Planning

Participation in plans for future custody arrangements. Determining whether a child has taken part in choosing with whom they would live if their parent(s) becomes unable to care for them due to illness or death was assessed with simple 'yes'/'no' questions on the background information questionnaire. Caregivers reported that only 19 (37%) of the children had been a part of the decision making process to determine with whom they would live if they became unable to care for them. Forty-two percent (42%) of the caregivers identified their parents, the child's grandparents, as the appointed guardian while 25% reported that they would rely upon another family member. Fifteen percent (15%) of the caregivers would choose one of the child's older siblings to be his/her guardian, however, several caregivers indicated that they would choose the child's other parent (10%) or a family friend (2%). Six percent (6%) of the caregivers had "no idea" with whom they would leave their child and had not given much thought to establishing custody arrangements. Categorizing with whom they would live was obtained by asking that the caregiver write in the relationship of the person that they have identified as the future guardian.

Knowledge of future custody arrangements. Despite not being a part of the decision making process, 38 (73%) of the children had reportedly been told with whom they would live if something happened to their parent/caregiver in the future. Knowledge of future placement was also assessed with a 'yes'/'no' question on the background information sheet completed by each caregiver. Information pertaining to whether permanent documentable custody plans had been created was not gathered during this study. Therefore, it is not known whether these plans were formal or informal.

Previous Experience with HIV Related Death

Experience with death(s) related to HIV was assessed with a 'yes'/'no' question on the background information questionnaire. Over half of the children (60%) have lost a family member to an HIV/AIDS related illness. A listing of the relationships of the family members that have died is presented in Table 4. The children in this study have experienced an average of one HIV/AIDS related death in a family member with 5 (6%) of the children having lost five members of their family to an HIV/AIDS related illness.

Stability of Living Arrangements

An unstable environment was characterized by frequent moves, defined for the purpose of this study as three or more moves in five years. The stability of the child's living arrangements was determined by the caregiver's response to a question that asked for the number of times that they have moved in the last five years. Forty-six percent (46%) of the caregivers reported having moved three or more times during the past five years with the number of moves ranging from 0-10 times (M=3.4; SD=3.29).

Social Support

Social support available to the uninfected child was assessed with questions on the background information questionnaire that asked for the caregiver to identify the child's sources of support. Only 20 (39%) of the children were described as having "someone with whom they can confide."

A listing of the child's sources of support identified by the caregivers in this study is presented in Table 1.

Coping Behaviors

Kidcope. Child coping was measured using the Kidcope (Spirito, Stark, & Knapp, 1992; Spirito, Stark, & Williams, 1988), a self-report measure designed to assess coping strategies. The Kidcope consists of 13 items which estimate the frequency with which they are utilized and the efficacy of 10 common cognitive and behavioral coping strategies: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support, or resignation. Psychometric testing revealed Pearson test-retest correlations of the Kidcope's frequency items at 3 days, 7 days, and 10 weeks apart ranging from .56-.72, .07-.83, and .15-.43 respectively (Spirito, Stark, & Williams, 1988). Concurrent validity is supported by the correlations between Kidcope items and previously standardized measures of coping, however, due to each item representing an independent coping strategy and the use of varied coping responses, reliability coefficients may be lower than those for scales including multiple items (Spirito et al., 1988).

Demographic Factors

Several demographic parameters were obtained; including the uninfected child's race and gender, the caregiver's age, gender, marital status, educational level, occupation, relationship to the child, length of caregiving relationship, and income. These parameters were not included in the statistical analyses due to the lack of variability within these parameters.

Parent and child illness severity was obtained from caregiver reports due to the inability to access parent medical charts to obtain specific medical data (e.g., CD^4 count, viral loads, etc.). Caregivers reported whether the parent (themselves) or the child is symptomatic and the number of hospitalizations that they have experienced. Although this approach is consistent with other approaches in the literature (Thompson, Gil, Burbach, Keith, & Kinney, 1993), it was not included in the analyses due to the parents uncertainty regarding changes in their own and their infected children's status related to treatment advances. Father presence and parent substance abuse history were also excluded from the current statistical analyses due to the difficulties in gathering accurate information.

Measures of Criterion Variables

The instruments chosen for use in this study have been used in previous experimental research to identify the risk factors that contribute to emotional and behavioral problems in children (Banez, & Compas, 1990; Beck & Rosenberg, 1986; Jensen, Bloedau, Degroot, Ussery, & Davis, 1990; Johnson, Boney, & Brown, 1991). Data were collected from the uninfected child and his/her caregiver using questionnaires to measure the dependent variables of behavioral problems, depression, and anxiety to assess their psychological adjustment.

Behavioral and Emotional Problems. The Child Behavior Checklist (CBCL/4-18; Achenbach, 1991) was designed to obtain a systematic report of children's behavioral or emotional problems and social competence as seen by their parent/caregiver. The CBCL is a 118 item parent/caregiver-report instrument that yields total problem scores (total, internalizing, and externalizing) and syndrome scale scores. Psychometric testing revealed one-week, one-year, and two-year test-retest correlations for CBCL problem scale variables at .89, .75, and .71 respectively and syndrome scale internal consistency correlations among certain subsets of items ranging from .62 to .96 (Achenbach, 1991). Evidence for content and criterion-related validity is supported by the ability of CBCL items to significantly discriminate between referred and nonreferred children. Construct validity is also supported by significant correlates between CBCL scales with two other instruments that measure similar constructs (Achenbach, 1991, p. 84). Reliability and validity of the CBCL items have also been extensively reported in the literature (Achenbach, 1991; Achenbach & Edelbrock, 1983; Verhulst, Althaus, & Berden, 1987) and have been significantly associated with clinically referred samples. The total problem T score and the T scores from each of the two broad groupings of syndromes, internalizing and externalizing, were used in the present study: CBCL total (Total Problem Score; overall index of children's behavioral/emotional problems), CBCL internal (Internalizing T Score; the frequency of inhibited and overcontrolled behaviors), and CBCL external (Externalizing T Score; the frequency of aggressive and undercontrolled behaviors). Elevated scores have been associated with children who have been referred to a mental health setting.

Depression. Depression was assessed using the Children's Depression Inventory (CDI; Kovacs, 1992), a 27 item self-rated symptom oriented scale designed to assess a variety of symptoms associated with depression such as sleep disturbance, appetite loss, suicidal thoughts, hopelessness, and general dysphoria. The CDI is a modified version of the Beck Depression Inventory, commonly used with adults, that measures behavior, thoughts, or feelings that may be characteristic of childhood depression (Kaslow & Rehm, 1991). Each item consists of three brief statements that describe a range of possible responses for each symptom ranging from normal responses to indicators of moderate to severe depressive symptoms. Elevated scores on the CDI have been associated with heightened levels of anxiety, low levels of self-esteem, high levels of hopelessness, and negative cognitive attributions (Kovacs, 1992; Ollendick & Yule, 1990; Ollendick, Yule, & Ollier, 1991). The CDI is a reliable and valid measure of depression that has been reported to have acceptable internal consistencies ranging from .71 to.89, test-retest reliability ranging from .38 to .87 at one-week to .74 to.83 at three-week test-retest correlations (Kovacs, 1992). Evidence for discriminant, concurrent, and construct validity have been statistically supported in previous research along with strong correlations between measures of related constructs such as anxiety and self-esteem (Kovacs, 1992; Kazdin, 1988). The CDI total T score was used in the present study, with higher scores reflecting the presence of depressive symptoms.

Anxiety. Anxiety was measured using the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985),a 37-item self-report questionnaire designed to assess the presence or absence of a variety of anxiety related symptoms. According to Silverman (as cited in Stallings & March, 1995) , the RCMAS assesses general distress with an emphasis on anxiety. The scale yields a total anxiety score and three anxiety factor scores (physiological anxiety, worry/oversensitivity, and concentration). Psychometric testing revealed three-week and nine month test-retest correlations for the Total Anxiety score at .98 and .68 respectively and internal consistency correlations ranging from .79 to .85 (Reynolds & Richmond, 1985). Evidence for construct and concurrent validity have been reported with the trait scale of the State-Trait Anxiety Inventory for Children (King, Gullone, & Ollendick, 1991; Reynolds & Paget, 1983; Stallings & March, 1995). The Total Anxiety T score was used in the present study with a higher score indicated a greater level of general distress.

Results

Child Psychological Adjustment

Child psychological adjustment was assessed through the use of the Child Behavior Checklist (CBCL), Children's Depression Inventory (CDI), and the Revised Children's Manifest Anxiety Scale (RCMAS). Means and standard deviations for the Child Behavior Checklist, Children's Depression Inventory, and Revised Children's Manifest Anxiety Scale are listed in Table 5.

To identify whether the children living in HIV/AIDS affected homes were perceived by their caregivers as having significant behavioral and emotional difficulties, children's scores on the CBCL were compared with the available standardized norms. For those indices where children's scores fell in the clinical range (t score greater than 60), one-way analyses of variances were conducted to compare children's scores on selected variables.

Children's scores on the Total Problem Score (M=61.96; SD=12.84) were within the borderline clinical range. However, robust differences were noted in the T scores between children who knew of their parent's diagnosis versus those that did not, children who knew of their sibling's HIV/AIDS diagnosis versus those that did not, children who had a stable living arrangement (less than 3 moves in 5 years) versus those that did not, and those that had experienced an HIV/AIDS related death in their family versus those that had not. Table 6 presents the means and standard deviations for the Child

Behavior Checklist, Children's Depression Inventory, and the Revised Children's Manifest Anxiety Scale broken down by selected independent variables.

Children who knew that their parent was diagnosed with HIV/AIDS were described by their caregivers as being more withdrawn, depressed, and isolative (M=65.89; SD=11.41) than their peers who were unaware of their parent's diagnosis (M=54.79; SD=11.35) as indicated on the internalizing syndrome scale of the CBCL (F [1, 50]=11.50, p<.001). Overall, the children who knew of their parent's diagnosis were portrayed as having more behavioral and emotional problems (M=68.26; SD=10.50) than the children living in HIV/AIDS homes that had not been given information (M=58.33; SD=12.79) about the health of their parent (F [1, 50]=8.23, p<.05). Although as a group these children's CBCL total problem scores were only in the borderline clinical range, clinically they seem to be experiencing more behavioral and emotional problems than the normative sample.

Children who knew of their sibling's diagnosis were described by their caregivers as experiencing more significant behavioral and emotional problems (M=67.88; SD=10.83) than their peers who did not know of their sibling's diagnosis (M=59.09; SD=12.89), F[1,50]=5.88, p<.05). The children who knew that their brother or sister was diagnosed with HIV/AIDS reportedly were more withdrawn and anxious (M=66.35; SD=10.94) than children who were not aware that their sibling had a terminal and life threatening illness (M=55.20; SD=11.65) on the CBCL internalizing syndrome scale (F [1, 50]=10.90; p<.005).

However, as a group, the children were not in the clinical range for this scale (M=58.85; SD=12.49) or on either self-report measure that examined depression and anxiety.

Children who have experienced an HIV/AIDS related death in a family member were described by their caregivers as experiencing significant behavioral and emotional problems, evidenced by the higher T scores on all three scales of the CBCL than did children who have not experienced such a death. These scores were significantly higher than the published CBCL norms (M=50; SD=10), suggesting that children who have lost a family member to HIV/AIDS are experiencing more psychological distress than the normal population. In general, the children who had experienced an HIV/AIDS related death were portrayed as having more significant behavioral and emotional problems (M=66.35; SD=12.43) than the children who had not (M=55.48; SD=10.71) lost a family member (F [1, 50]=10.69, p<.005). Children who have lost a family member to an HIV/AIDS related illness were more likely to be described as aggressive and noncompliant (M=65.68; SD=13.26) than children who have not encountered such a death (M=58.24; SD=9.99), F [1, 50]=4.76, p<.05). These children were also characterized as being more anxious and withdrawn (M=62.94; SD=12.47) than children who have not lost a family member to HIV/AIDS (M=52.81; SD=10.01), F[1, 50]=9.62, p<.005).

Caregivers reported that children who had lived in an unstable living arrangement typified by frequent moves, experienced more behavioral and emotional problems than the normal population. These children likewise exhibited higher T scores on the externalizing syndrome scale of the CBCL (M=66.67; SD=13.98) when compared with the children who lived in a stable home (M=59.25; SD=10.11), F[1, 50]=4.89, p<.05).

With respect to social support, children who were identified as having someone that they could talk to about life stressors were perceived as more anxious and depressed (M=64.75; SD=10.95) than children who did not have someone to confide in (M=55.16; SD=12.10) on the CBCL internalizing syndrome scale (F [1, 50]=8.30; p<.01).

Children who knew with whom they would be living if something happened to their parent or caregiver did not differ significantly from children who did not know on any of the indices. As a group, children who knew of the custody plans made by their caregiver did not endorse more items associated with depression or anxiety on either self-report measure when compared with children who did know with whom they would live if their parent/caregiver became unable to care for them. Children who participated in making their own custody plans were not significantly different from their peers who did not participate in permanency planning (see Table 6). Neither group self-reported experiencing depressive symptoms or anxiety that were clinically significant.

Association of situation specific stressors and resources to child psychological adjustment

To gain a better understanding of how situation specific stressors and resources correlate with the psychological adjustment of uninfected children living in an HIV/AIDS affected family, zero-order correlations were conducted. As a result of the preliminary nature of this study, the significance level was set at .05 despite the risk of a Type I error resulting from the large number of correlations computed. Therefore, the following results should be interpreted with caution.

Knowledge of a parent's HIV/AIDS diagnosis correlated significantly with scores on the CBCL (total and internalizing) and the CDI. This differed from knowledge of a sibling's HIV/AIDS diagnosis which only correlated significantly with the parent report measure (CBCL total and CBCL internalizing). Knowing the parent's diagnosis was also correlated with knowing the sibling's diagnosis, age, and the availability of social support. This suggests that older children have more information and have greater access to the resources that they may need. Having had an HIV/AIDS related death in their family is significantly correlated with having participated in custody plans and is negatively correlated with a stable living arrangement. Significant negative correlations were also found between children who had knowledge of a parent or siblings HIV diagnosis and their CBCL scores (total, internalizing, and externalizing).

Coping behaviors did not correlate significantly with any of the indices of child psychological adjustment. Thus, the coping behaviors predicted to be included in the model were not entered into the regression analyses. Zero-order correlations between coping behaviors and child adjustment variables are presented in Table 7.

Multivariate Analyses

Multiple regression analyses were conducted to assess the unique and combined contributions of variables of the proposed model to child psychosocial adjustment beyond that accounted for by demographic parameters. Univariate analyses were performed on each index of adjustment (CBCL Total Problem score, CBCL Internalizing and Externalizing Syndrome Scores, CDI Total Score, and RCMAS Total Anxiety Score). Stepwise multiple regression was used to identify the specific stressors and resources that would best support the final model for each dependent variable (Tabachnick & Fidell, 1989). This method was chosen to eliminate variables that are inordinate in order to produce a model for use in future research. The entry of variables was determined based upon statistical criteria (probability of $\underline{F}$ to enter < .05, probability of $\underline{F}$ to remove >.10) and by the above mentioned model. Each variable was introduced to the regression equation one at a time and removed if the squared part correlation was nonsignificant (Hays, 1988). All data was included in the analyses, as there were no outliers affecting the normality, linearity, or homoscedasticity of the residuals.

Table 9 summarizes the results of the stepwise analysis to determine if use of CBCL total score is a valuable indicator of psychological adjustment in uninfected children living in an HIV/AIDS affected family. The estimate provided by adjusted R^2 show that 24% of the variance was predicted by the model (R^2=.238; p=.016). Having an HIV/AIDS related death in the family accounted for 16% of the variance with age adding an 8% increment of the variance in CBCL Total Problem Score. Available social support and knowledge of a sibling's or parent's HIV/AIDS diagnosis were excluded because they failed to add significantly to the predictiveness of the model.

The results of the stepwise regression for the CBCL Internalizing Syndrome Scale score are presented in Table 10. Age, available social support, and a family member's death to an HIV/AIDS related illness combined to predict 38% (adjusted R^2) of the variance in this index of child psychological adjustment. However, knowledge of a parent's illness was excluded from the final model despite contributing to 17% of the variance when entered. The relationship between knowledge and caregiver's report of internalizing behaviors did not maintain its significance after social support was entered into the model.

Results of the analysis for the CBCL Externalizing Syndrome Scale score as an index of child adjustment are summarized in Table 11. Based on the estimate provided by the adjusted R^2, 15% of the variance was predicted by the final model. Stability in one's living arrangements accounted for 7% of the variance with age accounting for an additional 8%. These findings suggest that an unstable environment at a young age may contribute to behavioral problems. Results of the stepwise regression for the index of childhood depression are presented in Table 12. Age was the only predictor allowed entry into the model which accounted for 16% (Adjusted R^2) of the variance.

No stressors or resources were significant predictors on the anxiety index. Thus, no variables met the criteria for entry into the equation. In comparing results of the regression analyses mentioned above, age, stability of one's living arrangements, knowledge of a parent's diagnosis, family history of an HIV/AIDS related death, and available social support for the child all contributed to the variance in scores on the measures chosen to assess child psychological adjustment.

Discussion

The present study was designed to assess the emotional adjustment of children who have multiple family members diagnosed with HIV/AIDS. A theoretical model was created and tested to discern if there are certain stressors or resources that would predict if an uninfected child living in an HIV affected family is at risk for psychological adjustment problems. Stressors related to having multiple family members with a terminal and debilitating illness, multiple losses/anticipated losses, and situation specific stressors unique to an HIV diagnosis (e.g., secrecy, stigma, health of caregiver, family stability, future placement) were identified. Having a family member infected with HIV was viewed as a stressor to which the child struggles to adapt.

The current model extends beyond previous models that had failed to include the uninfected children living in HIV/AIDS affected families. The model was created to be a heuristic tool for conceptualizing how support, stressors, and coping skills relate to a child's psychological adjustment. As a group, these children were characterized by clinically elevated levels of psychological distress. Specifically, children who have experienced an HIV/AIDS related death in their family, have had their parent's or sibling's diagnosis disclosed to them, have a lack of available social supports and/or lack a stable living environment are at greater risk for developing behavioral and/or emotional problems. Demographic parameters failed to distinguish between children due to the commonalties in income, race, educational level, unemployment and other unrelated stressors that each family experiences in the course of their daily lives (e.g., substance abuse, family violence, exposure to violence in the neighborhood).

Although health status of the caregiver and sibling have both direct and indirect influences on individual family members, assessing how they relate to a child's psychological adjustment was beyond the scope of this study. Lesar and colleagues (1996) empirically examined the relationship between severity and impact of a child's health status, availability of resources, and the demands associated with caring for an HIV-infected child. The findings from this study suggest that health status and additional or unusual caregiving demands influence a parents' perceived level of stress. However, their findings did not indicate whether children living in HIV/AIDS affected families would also experience significant stress. Factors that contribute to the stress experienced by family members are likely to change over time. This is particularly true for the uninfected children, who will move through different developmental stages within the course of their parents and siblings disease. This highlights the need for longitudinal research that explores the stressors, resources, and risk factors unique to each age group.

This study expanded upon work that has been done with children of terminally ill parents and siblings of chronically ill children. A family member with a chronic or terminal illness significantly impacts the family system due to the additional burdens that are placed on families due to the severity and complexity of their illness. The family member's illness often disrupts the entire family system due to the numerous stressors that are associated with illness, hospitalization, anticipatory loss, and death. The long-term effects associated with parent and sibling illness have been well documented in the literature (Fanos & Wiener, 1994; Sargent, Sahler, Roghmann, Mulhern, Barbarian, Carpenter, Copeland, Dolgin, & Zeltzer, 1995; Reynolds, Miller, Jelalian, & Spirito, 1995; Worden, 1996). However, the empirical literature has failed to address the additional stressors experienced by children who have multiple family members with a terminal illness. In addition, children in HIV/AIDS affected families experience numerous stressors: multiple losses, many hospitalizations of more than one family member, stigma, guilt, ostracism, secrecy, and poverty.

HIV/AIDS is a multigenerational disease where death and losses occur across generations. The burden of raising children often shifts to an older generation of extended family members after the parent is no longer able to care for his/her children due to severe illness or death. According to Michaels and Levine (1992), over 80,000 children will become orphans of the AIDS virus by the year 2000. These "orphans" have been neglected by the prevailing health care system which has focused solely on the infected family member, denying that the illness directly impacts the entire family system. The stigma associated with HIV/AIDS often prevents these families from seeking formal or informal means of social support. The presence of support is viewed as a resource which positively influences adaptation and buffers the potentially negative effects of stress associated with HIV illness in one or more family members (Lesar, et al., 1996). However, parents are often resistant to disclosing their HIV status due to the guilt that they experience about their role in transmission of the disease through drug use and/or sexual behavior (Lipson, 1993). Parents often fear that they will be rejected or treated differently by family and/or friends. As a result, the stigma of HIV/AIDS perpetuates a "silence" which prevents family members from seeking support. In the current study, 61% of the children reportedly do not have "someone with whom they could confide." Children are often not allowed to seek support or acknowledge that they know of their family member's illness. Instead, caregivers may go to great lengths to keep the illness a secret in order to manage their own anxieties. Caregivers may decide not to disclose the HIV status of the infected family members due to the belief that their children will be unable to "keep a secret" or comprehend the illness. Thus, the secrecy, stigma, and uncertainty of AIDS limits the child's access to external supports and places them at greater risk for developing emotional and behavioral problems.

Results from the present study supports previous research documenting the impact of family illness on a child's psychosocial functioning (Fanos & Wiener, 1994; Gallo, et al., 1992; Sargent, et al., 1995). Specifically, children who knew of their parent's and sibling's diagnosis were described as having emotional and behavioral symptoms of distress. Similar findings have been reported in studies that have assessed the adjustment of siblings of children with cancer (Sargent, et al., 1995) and cystic fibrosis (Fanos & Wiener, 1994). In addition to having a family member that is diagnosed with a terminal illness, children in HIV/AIDS affected families have often experienced one or more HIV/AIDS related deaths in their family. The children in this study who had lost a family member to an HIV/AIDS related illness were portrayed as having more significant behavioral and emotional problems when compared with their peers who had not experienced such a death.

The findings of this study further indicate that children who have experienced an HIV/AIDS related death are more likely to have unstable living arrangements. Consequently, other factors may be attributable to the child's psychological adjustment other than the influence of a family member's HIV/AIDS diagnosis. The observed relationships between age, knowledge of a parent's or sibling's diagnosis, and experience with an HIV/AIDS related death can have several interpretations. First, older children are more likely to have been given information about their family member's illness as a function of their age and developmental level. Caregivers often delay disclosing information about HIV/AIDS until they perceive the child as being old enough to understand the implications of the diagnosis and refrain from breaking the family secret. Second, older children are likely to have observed changes caused by the HIV infection in their infected family members, experienced changes in their daily routine, and/or experienced an HIV/AIDS related death.

Although several variables predicted outcome, knowledge of custody plans, participation in custody arrangements, and the utilization of specific coping behaviors did not predict child adjustment. However, the children in this sample differed when compared to those in previous research (Forsyth, et al., 1996). The children in the present study experienced more HIV/AIDS related deaths, lived in homes where there was more than one infected family member, and had a greater number of mothers that described themselves as symptomatic. Despite the differences, children in both samples exhibited symptoms of psychological distress. Forsyth and colleagues (1996), however, reported that children of HIV infected mothers were more likely to be "particularly quiet and withdrawn" rather than engaging in "acting out behaviors" (p. 1020). With regard to behavioral problems, children in the present study were also described as aggressive, noncompliant, and oppositional. Measurement strategies (CBCL, CDI, RCMAS) used to assess psychological outcome were the same across studies, highlighting the differences in demographic and illness parameters.

Psychosocial factors appeared to be robust predictors of emotional and behavioral problems. Available social support, previous experience with an HIV/AIDS related death, stability in one's living arrangements, and age emerged as significant predictors for the indices of child adjustment completed by the caregiver. Families that have experienced significant changes in their composition and routine perceived their children as experiencing more significant psychological distress. Yet, age appeared to be the only significant predictor for either self-report measure of psychological adjustment completed by the child. This is not surprising, given that children in HIV/AIDS affected families tend not to communicate about the disease (Fanos & Wiener,1994).

Further research is needed to determine what factors determine how and when parents/caregivers decide what they will tell their children. The secrecy surrounding the diagnosis of HIV often interferes with medical care and prevents families from accepting referrals to other health care providers. All too often, caregivers assume that because they have not told their child about the HIV status of the infected family members, the child does not know. However, clinical examples cited in the literature (Nagler, Adnopoz, & Forsyth, 1995) suggest that children do know that *something* is wrong, only it does not have a name.

The relationship between coping behaviors and psychological adjustment in uninfected children living in HIV/AIDS affected homes has not previously been examined in the literature. In the present study, relationships between coping behaviors and child psychological adjustment on either of the child self-report indices were not significant. Spirito (1996) suggested that in studies where coping is a variable of interest, the use of a self-report screening measure should be followed by a clinical interview that asks for the child to explain their use of the coping strategies that were endorsed. However, the time needed for such data collection limits the viability of such an approach. Also, the child's lack of knowledge and/or attempts to conceal their family secret may have inhibited their responses.

The current study has a number of methodological limitations. The generalizability of the present findings to the population of HIV/AIDS affected families is limited by the small, nonrandomized sample of child-caregiver dyads who completed the measures. Participants were recruited at a clinic attended by their HIV infected siblings and volunteered to participate. Children who lived in non-relative foster care were excluded from the study due to the inherent difficulties in obtaining consent from the state and in collecting background data from outside sources. As a result, the families who participated may not be representative of all HIV/AIDS affected families. Therefore, studies that include children who have been removed from their homes and separated from their families should be pursued. In addition, the data was collected at an inner city medical center that serves a predominantly African-American, lower socioeconomic population. The families in this study earned incomes well below the national average (56% below $10,000 a year), relied upon financial assistance (100%), had limited access to available resources, and were confronted with extraordinary stressors (e.g., unemployment, poverty, lack of education, substance abuse, and family violence). Thus, studies that include a more diverse population would alleviate the sampling bias that could have affected this data. Additionally, a sample which includes matched control subjects who share many of the environmental risk factors (e.g., poverty, lack of education, substance abuse, and exposure to violence) would allow the researcher to isolate effects due to HIV/AIDS.

Despite the fact that the 52 children who participated in this study came from 22 families, the interdependence of the sample may not have biased the results due to the unique relationships among family members. Many of the children have different fathers, siblings, and extended family members within each family. Moreover, disclosure status in the family varies between siblings.

The use of child self-report data provides evidence that the children in HIV/AIDS affected families see themselves differently than do their caregivers. The intrinsic difficulties in obtaining accurate self-report data from children who live in a "culture of secrecy" where they are instructed to avoid discussion of illness or stressors suggests that the use of such measures may be counterproductive. In addition, many of the self-report measures were not created for use with an urban minority population. It is possible that the constructs for which the measures are derived do not accurately reflect the life experiences of inner city minority youth. Therefore, future studies should combine the use of self-report measures and a clinical interview to identify the psychological phenomenon specific to adjustment to living in an HIV/AIDS affected family.

Previous research suggest that the psychological assessment of children is best explained by several individuals completing multiple measures to offer more than one perspective (Kaslow & Rehm, 1991; Thompson, Gil, Burbach, Keith, & Kinney, 1993; Thompson & Gustafson, 1996). Obtaining data from parents and extended family members who provide respite care in addition to school personnel would have strengthened this study.

Global measures of depression and anxiety may not have adequately reflected the issues that confront these children. Further evaluation and the development of culturally sensitive instruments that capture the complex nature of adjusting to multiple illness and loss is needed. In addition, many constructs that were not included in the current study warrant further investigation. The relationships between knowledge of HIV/AIDS in a parent or sibling, self-esteem, interpersonal difficulties, and school performance need preliminary exploration. In light of the current findings from this study, additional work is needed to determine the relationships between experience with HIV/AIDS related deaths, self-esteem, peer relationships, and school performance.

According to Forsyth and colleagues (1996) large studies that collect extensive data are needed to identify the important factors that influence children's adjustment to HIV/AIDS. The development of intervention programs based upon the identified factors and complex issues and needs of these families should be implemented and evaluated. Longitudinal research would significantly add to the limited literature that has addressed the psychological needs of uninfected family members living in HIV/AIDS affected families. The majority of studies that appear in the literature are not empirical, instead they are descriptive studies which have failed to achieve scientific rigor. Future studies should make efforts to randomize samples, increase the sample size, and use comparison groups. Differences in the psychological adjustment of children with symptomatic family members, deceased family members, and asymptomatic family members should be considered due to the preliminary findings shown in this study. Specifically, uninfected children who have lost a parent(s) or sibling(s) secondary to HIV/AIDS and who are living with a symptomatic family member are at risk for adverse psychological consequences. Future research should also attempt to explore other variables not included in the present study. Anger, aggression, and antisocial behavior reported in the adolescents in this study may place them in danger of subsequent involvement in the juvenile justice system or in other 'high risk' behaviors. Future research should also focus on resiliency factors and the positive effects that chronic illness or loss may have on the uninfected child.

Previous theoretical models have failed to address the unique stressors associated with terminal illness in multiple family members. As has been recommended in previous reviews of the literature, theoretically based studies that focus on the challenges confronted by families coping with terminal illness in multiple family members, losses, and the extraordinary stressors that impact HIV/AIDS affected families are needed. This study was an initial attempt to support a theoretical model based upon the family adaptational model developed by Lesar and colleagues (1996). Although the present findings must be interpreted cautiously, the results suggest that there is a need for support programs and psychotherapeutic interventions for HIV/AIDS affected families. Professionals working with HIV affected families should provide HIV sensitive care as a part of a multidisciplinary team. Each member should possess: 1) a basic understanding of the etiology of HIV infection, epidemiology of HIV infection, and the prognosis and course of the illness, 2) be able to perform ongoing family assessments, identifying when a family member is in need of additional support or developmentally appropriate information, 3) be aware of the high risk for child abuse and neglect and of the appropriate resources, and 4) know of the issues facing families with chronic fatal illness while providing confidentiality (Boland, M. cited from Pizzo, P.A., & Wilfert, C. M., p. 162).

Families affected by HIV/AIDS often have difficulty accessing health services that are responsive to their mental health, medical, financial, social and cultural needs. As a result, many families do not follow through with recommendations for psychotherapeutic intervention until there is a crisis situation. Clinicians should be aware of the information the children in the family possess and familiarize themselves with cognitive development. The amount and type of information that is shared about the parent's or sibling's HIV/AIDS diagnosis or death should be based upon the child's level of cognitive development and the amount and type of support they receive (Eiser, 1990; Harbeck & Peterson, 1992).

Families would benefit from receiving services from clinicians who incorporate cultural awareness into their methods of intervention. It is imperative that these families become empowered to use their own strengths and resources to produce change and advocate for services. The challenge of living with a fatal illness may be compounded for families who are already confronted by the stresses of poverty, unemployment, single parenthood, limited education, and drug use. Research that supports the development of culturally sensitive treatment will likely improve families response to medical care, assist them in gaining access to mental health services, and ensure that programs are developed for families affected by HIV/AIDS.

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Table 1

Sources of social support for uninfected children in an HIV/AIDS affected family

Source of Support	# of caregivers identifying sources of support
Parent	10
Sibling (brother/sister)	8
Other family member/ Relative	3
Grandparent	4
Therapist/Counselor	2
Friend	1
No One	32

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

Table 2

Persons having knowledge of mother's HIV/ AIDS diagnosis

Category of Others	# of caregivers identifying
Family/relatives	45
Grandparents (mother's parents)[a]	21
Child (uninfected)[a]	19
Other children (siblings of uninfected child)[a]	7
Spouse/Partner	7
Friends	6
School	6
Agencies/ Service Providers (e.g., Physician, Case Manager, Health Department, Therapist)	1
Everyone knows	2

Note: Caregivers were able to identify more than one person/ group of people.
[a] As identified separately from family/relative category.

Table 3

Persons having knowledge of infected child's HIV/AIDS diagnosis

Category of Others	# of caregivers identifying
Family/ Relatives	32
Grandparents (mother's parents)[a]	19
Child	17
Other children (siblings of uninfected child)[a]	13
No One	10
Infected child	6
School Personnel	6
Spouse/ Partner	5
Agencies/ Service Providers (e.g., Physician, Case Manager, Health Department, Therapist)	1
Everyone knows	2

Note: Caregivers were able to identify more than one person/group of people.
[a]As identified separately from family/relative category.

Table 4

Persons diagnosed with HIV/AIDS in the family

Category of family member	# Living in the home	# Living outside of the home	#Deceased
Mother	36	5	4
Father	7	12	5
Brother/Sister	54	1	3
Step-Parent	1	8	4
Aunt/Uncle	0	13	14
Cousin	0	3	16
No one	2	5	21

Note. Caregivers were able to identify more than one person in each category.

Table 5

Descriptive statistics for child adjustment variables

Variable	M	SD
Criterion		
Child Behavior Checklist		
Total Problem Score	61.96[a]	12.84
Internalizing Score	58.85	12.49
Externalizing Score	62.67[a]	12.50
Withdrawn	60.81[a]	10.67
Somatic Complaints	59.46	8.99
Anxious/Depressed	59.15	11.02
Social Problems	60.37[a]	9.82
Thought Problems	62.31[a]	11.69
Attention Problems	61.52[a]	12.72
Delinquent Behavior	61.87[a]	10.29
Aggressive Behavior	64.46[a]	14.28
Children's Depression Inventory		
Total CDI Score	54.06	9.12
Anhedonia	54.13	10.96
Ineffectiveness	50.92	8.77
Interpersonal Problems	62.02[a]	16.26
Negative Mood	52.90	9.30
Negative Self-Esteem	48.13	8.61
Revised Children's Manifest Anxiety Scale		
Total Anxiety	52.67	8.48
Physiological Anxiety	10.35	2.49
Worry/ Oversensitivity	10.23	2.72
Social Concerns/ Concentration	10.00	2.54
Lie	11.37	2.74

[a]Indicate *T* scores in the clinically significant range.

Table 6

<u>Means, standard deviations based upon independent variable distribution</u>

Independent Variable	N	CBCL Total[a]	CBCL Internal[b]	CBCL External[c]	CDI Total[d]	RCMAS Total[e]
Child Knowledge of Parent's Illness	Yes=19	68.26	65.89	66.37	50.68	51.21
		10.50	11.41	11.55	7.25	7.73
	No=33	58.33	54.79	60.55	56.0	53.52
		12.79	11.35	12.70	9.60	8.81
Child Knowledge of Sibling's Illness	Yes=17	67.88	66.35	65.47	51.06	51.94
		10.83	10.94	11.91	7.55	7.19
	No=35	59.09	55.20	61.31	55.51	53.03
		12.89	11.65	12.72	9.55	9.12
HIV Related Deaths	Yes=31	66.35	62.94	65.68	53.94	51.65
		12.43	12.47	13.26	9.29	9.25
	No=21	55.48	52.81	58.24	54.24	54.19
		10.71	10.01	9.99	9.08	7.14
Social Support	Yes=20	64.35	64.75	62.20	51.60	51.75
		12.42	10.95	12.74	7.63	6.33
	No=32	60.47	55.16	62.97	55.59	53.25
		13.07	12.10	12.54	9.73	9.63
Stable Living Arrangements	Yes=28	58.86	56.11	59.25	54.86	53.18
		11.71	12.41	10.11	8.91	9.11
	No=24	65.58	62.04	66.67	53.13	52.08
		13.39	12.05	13.98	9.46	7.82
Knowledge of Custody Plans	Yes=38	61.71	58.32	62.34	55.08	53.42
		13.27	13.26	13.07	8.87	14.25
	No=14	62.64	60.29	63.57	51.29	50.64
		12.06	10.42	11.20	9.54	6.11
Participation In Custody Plans	Yes=19	64.16	60.79	65.21	54.63	51.84
		14.01	12.07	15.01	8.91	9.08
	No=33	60.70	57.73	61.21	53.73	53.15
		12.16	12.77	10.78	9.36	8.22

[a] Child Behavior Checklist Total Problem Score; [b] Child Behavior Checklist Internalizing Syndrome Score; [c] Child Behavior Checklist Externalizing Syndrome Score; [d] CDI Total Score; [e] Revised Children's Manifest Anxiety Total Score.

Table 7

Zero-order correlations between specific stressors, resources and child adjustment variables

Variable	2	3	4	5	6	7	8	9	10	11	12	13
1 CBCL total^{a}	872^{i}	898^{i}	- 042	- 027	- 376^{g}	- 324^{f}	- 148	- 420^{h}	- 131	032	264	245
2 CBCL internal^{b}		$.633^{i}$	- 139	- 040	- 432^{i}	- 423^{h}	- 377^{g}	- 402^{h}	- 119	070	.239	251
3 CBCL external^{c}			028	001	- 227	- 158	030	- 295^{f}	- 156	044	299^{f}	.250
4 CDI total^{d}				269	284^{f}	231	215	016	- 048	- 186	- 096	- 425^{h}
5 RCMAS total^{e}					132	061	087	149	075	- 147	- 065	- 083
6 Knowledge that Parent's HIV+						918^{i}	467^{i}	218	005	100	- 018	- 515^{i}
7 Knowledge that Sibling's HIV+							544^{i}	156	067	.238	070	- 460^{i}
8 Social Support								- 155	057	- 233	018	- 175
9 HIV Deaths									380^{h}	207	- 526^{i}	133
10 Participation in Custody Plans										281^{f}	- 499^{i}	.105
11 Knowledge of Custody Plans											134	040
12 Stable Living Arrangements												- 167
13 Age												

^{a}Child Behavior Checklist Total; ^{b}Child Behavior Checklist Internalizing; ^{c}Child Behavior Checklist Externalizing; ^{d}Children's Depression Inventory; ^{e}Revised Children's Manifest Anxiety Scale; $^{f}p < .05$; $^{g}p < .01$; $^{h}p < .005$; $^{i}p < .001$

Table 8

Zero-order correlations between coping behaviors and child adjustment variables

Variable	2	3	4	5	6	7	8	9	10	11	12
1. CBCL total[a]	.872[i]	.898[i]	-.042	-.027	-.091	-.034	.009	.103	.027	.035	.245
2. CBCL internal[b]		.633[i]	-.139	-.040	.003	-.132	-.096	146	.101	-.002	.251
3. CBCL external[c]			.028	001	-.128	.073	.085	.083	.016	.021	.250
4 *CDI total*[d]				.269	.071	.155	-.012	042	-.094	.149	-.425[h]
5 RCMAS total[e]					.235	.242	- 018	151	.109	.255	-.083
6. Social Withdrawal						.170	-.007	.324[f]	.476[i]	.181	-.175
7. Resignation							.165	.101	.081	.075	.143
8. Blaming Others								-.056	.165	-.020	.383[h]
9. Problem-Solving									.122	.471[i]	-.080
10. Cognitive Restructuring										.249	.048
11. Social Support											-.196
12. Age											

[a]Child Behavior Checklist Total; [b]Child Behavior Checklist Internalizing; [c]Child Behavior Checklist Externalizing; [d]Children's Depression Inventory; [e]Revised Children's Manifest Anxiety Scale; [f]$p<.05$; [g]$p<.01$; [h]$p<.005$; [i]$p<.001$

Table 9

Multiple regression analysis for the prediction of CBCL total

Model	Predictor Variables	*R*	*R*²	*R*² *Adjusted*	*F*
1	(Constant) HIV Deaths	.420	.176	.160	10.689[c]
2	(Constant) HIV Deaths Age	.518	.268	.238	8.985[d]
3	(Constant) HIV Deaths Age	.518	.268	.238	8.985[bd]

[a] Method: Stepwise (Criteria: Probability of F to enter <.05, Probability of F to remove>.10.

[b] F for final model=8.98, p <.001.

[c] p <.005

[d] p <.001

Table 10

Multiple regression analysis for the prediction of CBCL internalizing

Model	Predictor Variables	*R*	R^2	R^2 *Adjusted*	*F*
1	(Constant) CHILDKW[a]	.432	.187	.171	11.503[g]
2	(Constant) CHILDKW[a] HIVDTH[b]	.535	.286	.257	9.83[g]
3	(Constant) CHILDKW[a] HIVDTH[b] CHSPPT[c]	.616	.380	.341	9.80[g]
4	(Constant) HIVDTH[b] CHSPPT[c]	.600	.359	.333	13.75[g]
5	(Constant) HIVDTH[b] CHSPPT[c] Age	.646	.417	.381	11.46[g]

[a] Child knowledge of parent's HIV diagnosis

[b] HIV deaths experienced in family

[c] Social support for the child

[d] Method: Stepwise (Criteria: Probability of F to enter <.05, Probability of F to remove>.10.

[e] F for final model=11.46, p <.001.

[f] p <.005

[g] p <.001

Table 11

Multiple regression analysis for the prediction of CBCL externalizing

Model	Predictor Variables	*R*	*R*^{2}	*R*^{2} *Adjusted*	*F*
1	(Constant) STBLIV[a]	.299	.089	.071	4.89[d]
2	(Constant) STBLIV Age	.427	.182	.149	5.45[e]

[a] Stable living arrangements

[b] Method: Stepwise (Criteria: Probability of F to enter <.05, Probability of F to remove>.10.

[c] F for final model=5.45, p <.01.

[d] p <.05

[e] p<.01

Table 12

Multiple regression analysis for the prediction of CDI

Model	Predictor Variables	*R*	R^2	R^2 *Adjusted*	*F*
	(Constant)				
1	Age	.425	.180	.164	11.008[c]

[a]Method: Stepwise (Criteria: Probability of F to enter <.05, Probability of F to remove>.10.
[b]F for final model=11.008, p <..005
[c]p <.005

AIDS Orphans: The Psychological Adjustment of Children With Multiple Family Members With a Terminal Illness

Introduction

Uninfected children in HIV affected families may be exposed to a series of associated major psychological risk factors—stigma, secrecy, exposure to acute and chronic illness, death of parents and/or siblings, separations, losses, orphanhood, and foster home placements. The burden of living with HIV impacts the entire family system, not only the family members that are infected. Previous research has indicated that there is a need for models to assess the psychosocial adjustment of the uninfected children who live in an affected family.

Based upon the work done with children and families with other illnesses, a conceptual model has been developed to address the unique psychological issues that coexist with a diagnosis of HIV—the stigma, secrecy, guilt, ostracism, and multiple losses. This study will be based upon the family adaptational model developed by Lesar, Gerber, and Semmel (1996) that combines family systems theory and an ecological framework. The model proposes that specific family stressors have both indirect and direct influences upon each family member. The literature review will provide background information about the prevalence of AIDS, modes of transmission, the disease course of AIDS, and the psychological adjustment of family members living in

HIV/AIDS affected families. The study will take into consideration the previous research done with families coping with a parent's illness and/or sibling's illness. In addition, the study will incorporate the empirical and theoretical literature that has addressed children's concepts of death and their ability to cope with the loss of a family member.

The purpose of this study is to assess the emotional adjustment of children who have multiple family members diagnosed with a terminal illness, Acquired Immunodeficiency Syndrome (AIDS)/ Human Immunodeficiency Virus (HIV). This study will contribute to the lack of empirical literature and assist practitioners with identifying the factors that contribute to more adaptive coping strategies in uninfected children.

Review of the Literature

Prevalence of AIDS

In 1981, the first cases of an unrecognized immunodeficiency disorder that affected both children and their mothers were reported (Novick, 1989). The Centers for Disease Control (CDC) defined this new disease as an "acquired immunodeficiency syndrome" that had an unknown etiology, however, many similarities between the affected children were noted. The children were often born to minority women who were intravenous drug users, had multiple sexual partners, and lived in large urban areas (Aleman, Kloser, Kreibick, Steiner, & Boyd-Franklin, 1995).

Acquired Immunodeficiency Syndrome (AIDS) is the leading cause of death in African-American women (aged 25-44 years) and more than half of the reported AIDS cases in 1994 were among women of color (Abercrombie, 1996; Boland, 1996). The majority of these women were likely to be infected through heterosexual intercourse during their adolescence. In women, heterosexual contact with an infected man and intravenous (IV) drug use are the most common modes of transmission and have caused the rapid increase in the rate of occurrence. (Abercrombie, 1996; Boland, 1996).

The rapid spread of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) have dramatically affected today's society. It is estimated by the World Health Organization that by 1992 over thirteen million adults and one million children were infected. The epidemiology of

HIV transmission has continued to spread beyond the first identified risk groups (homosexual men, intravenous drug users, and prostitutes) at a growing rate (Black, Nair, & Harrington, 1994; Nicholas & Abrams, 1992). AIDS has become the fourth leading cause of death in women ages 25 to 44 years and is the leading cause of death in children under four years of age (Forsyth, 1995; National Institute of Allergy and Infectious Disease, 1995). Women and children currently represent the fastest growing segment of the population that is newly infected (Sherwen & Tross, 1995).

According to Ellerbrock, Bush, Chamberland, and Oxtobyr (as cited in Forsyth, Damour, Nagler & Adnopoz, 1996) "approximately 85% of women with AIDS are of reproductive age at the time of diagnosis and the majority already have children." (p.1015) Forsyth (1995) estimated that by the year 2000, approximately thirteen million women worldwide will be infected and will orphan between five and ten million children.

Perinatal Transmission

The rise in the rate of infection from heterosexual sex and intravenous drug use has lead to the increased number of infected children. Pediatric AIDS cases represented less than 2 percent of the total reported cases in 1989, however, as the trends have changed to include more women affected by the virus, the number of children affected continues to escalate (Task Force on Pediatric AIDS, 1989). Perinatal transmission of HIV is the leading cause of Pediatric HIV worldwide (Adam, 1989; Task Force on Pediatric AIDS, 1989). The majority of these children are infected either during pregnancy, at birth, or postnatally through breastfeeding. The numbers of infected mothers and at risk children continues to increase as the HIV infected women are often unaware of their diagnosis (Nicholas & Abrams, 1992). The current mother-infant transmission rate is reported to be between 13 to 33 percent (Andiman, 1995) with approximately 1,000 to 2,000 infected infants diagnosed each year.

The ability to interrupt transmission from mother to child has been reported in previous studies that were part of AIDS Clinical Trials Group Protocol 076 (Boland, 1996). The women in these studies were administered zidovudine (ZDV) during pregnancy, intravenously during labor and delivery, and dispensed the medication orally to their infants for their first 6 weeks of life (Boland, 1996). The results from this study have produced significant changes in the standard of care for HIV infected women. The rate of perinatal transmission for women and children on the ZDV regimen has been reduced from 24% to 3%, consequently there has been an increase in the number of uninfected children born to infected mothers who receive treatment (Connor, Sperling, Gelber, et al., 1994).

According to Cohn (1993) women with AIDS or symptomatic HIV are more likely to transmit HIV to their fetus in utero than women who are asymptomatic. Research suggests that women who have "advanced disease, a low CD4+ count, a low CD4+: CD8+ cell ratio and the presence of the virus and viral-associated proteins in the blood are associated with transmission of the virus to the infant" (Andiman, 1995, p. 33). An asymptomatic infant born to an infected mother is not diagnosed as seropositive until supportive data, positive results on IgG antibody tests (ELISA and Western Blot), are consistent for at least 18 months due to the presence of the mother's HIV antibodies remaining in the child's circulation for the first few months of life. A definitive diagnosis of HIV infection for an at risk infant can not be made until several virologic, serologic, and molecular biologic tests are consistently absent of a seropositive rating (CDC, 1994). The most widely used screening test is the enzyme linked immunoabsorbent assay (ELISA), which "detects circulating antibodies when a patient's serum is reacted with viral lysate (broken down viral particles), and is confirmed with the Western Blot Technique, which measures "antibodies that have developed in reaction to specific viral proteins" (Novick, 1989, p. 3). Antigen detection techniques are also used to make a definitive diagnosis by culturing the virus from blood or tissue.

Despite the recent focus of research and programs on pediatric populations, the impact of mother-infant transmission on the women and their families has been overlooked (Aleman, Kloser, Kreibick, Steiner, & Boyd-Franklin, 1995). Women with HIV who become pregnant are often viewed negatively and tend to be seen as "vessels of transmission" (Anderson, Landry, & Kerby, 1991). Infected women and their children each have individual medical and mental health needs, as well as family needs, that have been overlooked.

Diagnosis and Disease Course

Science has made numerous advancements in the treatment of HIV related diseases which have resulted in lengthening the time that an infected person remains asymptomatic. Over time, the virus damages the immune system to the point that it is no longer able to defend itself against infection (Olson, Hustzi, Mason, & Seibert, 1989). A person who is infected with the virus may have a long clinical latency period (asymptomatic infection), before their immune system is damaged to the point that it can no longer protect the body against developing infections. The length of the clinical latency period, time from infection to onset of AIDS defining symptoms, has extended due to the advances in antiretroviral therapy. In adults, the median clinical latency period has ranged from seven to ten years before an AIDS diagnosis is made. The length of a child's clinical latency period and time before death is shorter than that for adults. Although 10 to 15 percent of vertically infected children die before four years of age, many children are now living beyond seven years of age (Andiman, 1995). The length of survival has changed due to the recent advances in the standard of care. The clinical course of HIV infection varies greatly between individuals, often with extended asymptomatic periods prior to onset of AIDS defining illnesses.

A diagnosis of AIDS can be made when an HIV infected adult has <200 CD4 T-lymphocytes, a CD4 T-lymphocyte percentage of total lymphocytes of <14% or specifically for women, invasive cervical cancer, pulmonary tuberculosis, and recurrent pneumonia (Abercrombie, 1996; CDC, 1993). Prior to revisions in the criteria, women often went undiagnosed and untreated, resulting in their shorter survival time (Aleman et al., 1995). Many of the symptoms associated with the initial exposure of HIV and subsequent infection resemble common flu-like symptoms and are often overlooked. Health care providers often misdiagnose "anemia, hepatitis, oral or vaginal candidiasis, and weight loss as being stress related in young menstruating women" (Aleman et al., 1995, p. 94). As a result, many women do not learn of their own diagnosis until they give birth to an infant that is identified as HIV infected.

Women who are symptomatic often differ from men in that they may begin to have recurrent and chronic gynecological symptoms, a greater incidence of candida infections, mucocutane herpes simplex infection, and receive a diagnosis later in their disease course (Ambercrombie, 1996). When a woman's CD4 count is less than 200 mm3, symptomatology may include anemia, thrush, hairy leukoplakia, diarrhea, weight loss, fever, sweats, lymphadenopathy, vaginitis, shingles, herpes genitalis, veneral warts, dermatitis, hair loss, neuropathy, or myopathy (Aleman et al., 1995). An AIDS diagnosis is made when an opportunistic infection (pneumocystic pneumonia), various forms of candida, cryptococcal meningitis, toxoplasmosis, cervical cancer, chronic herpes simplex virus, wasting syndrome, or a gynecological disturbance (abnormal pap smear or the presence of sexually transmitted diseases) are noted. As a woman's CD4 count falls, more opportunistic infections, bacterial infections, and chronic illnesses occur until death. Many of these women begin to have difficulty caring for themselves and their children, relying upon extended family members to become actively involved in their daily lives. Although several members in a family may be infected with HIV, they each may manifest the disease in different ways. Children's disease courses vary considerably from those of adults.

The symptomology of HIV infection in children are distinct from those in adults. Children often develop recognizable symptoms and signs within the first year of life. About one quarter of infected infants develop opportunistic infections or encephalopathy by 12 months of age (rapid progressors) while the remainder progress more slowly. The rapid progressors are likely to present with failure to thrive, recurrent bacterial infections, chronic or recurrent diarrhea, lymphadenopathy, chronic pneumonitis (PLH, LIP), recalcitrant thrush, developmental delay, HIV wasting syndrome (severe weight loss, weakness, chronic diarrhea, and unexplained fever), or HIV related encephalopathy (Andiman, 1995; Novick, 1989). Many infected children are at risk for abnormal neurodevelopment due to prenatal drug exposure and impoverished living environments (Wachtel, Tepper, Houck, Nair, Thompson, & Johnson, 1993).

The cause of morbidity in HIV infected children is secondary to bacterial infections, opportunistic infections (such as pneumocystis carinii pneumonia (PCP), cryoptosporidiosis candidiasis (esophageal and pulmonary), and neurodevelopmental abnormality (acquired microencephaly, encephalopathy, and pyramidal tract signs--cognitive deficits with developmental delays). As a result of their illness and in response to the many side effects caused by various treatments, children are likely to report physical symptoms such as pain, loss of function and mobility, weakness, changes in cognition, seizures, itching, and skin lesions (Czariecki, 1996, p. 208). The child experiencing these changes may describe feeling a host of conflicting emotions (anger, fear, depression, guilt, anxiety, etc.) that they have difficulty understanding.

Caring for a Family Member with HIV/AIDS

Uninfected family members living in an affected home are likely to witness profound physical and emotional alterations and experience significant changes in their daily routines as HIV infection progresses. Oftentimes infected family members have appeared to be physically healthy during their period of clinical latency, which is followed by a delayed onset of symptoms. After a period of time, the family begins to observe changes in the infected family member as the disease becomes progressively more debilitating. Children are likely to ask questions about their observations in an attempt to gain information. If the caregiver does not provide enough information to satisfy the child's curiosity, he/she may create their own explanations which are likely to involve self-blame, punishment, and false information.

HIV/AIDS carries a stigma that prevents caregivers from sharing their diagnosis with their children. The diagnosis is often kept a secret to maintain a sense of normalcy in the home (Lesar, Gerber, & Semmel, 1996). They often worry that the children will be unable to keep the "secret" from teachers, classmates, and other family members (Forsyth, Damour, Nagler, & Adnopoz, 1996; Stuber, 1992). Thus, children frequently are not told of their parent or sibling's diagnosis or if they have been told that they have an illness, the information may be inaccurate (e.g., "your sister has sickle cell disease"). In a study that examined the stress in families with HIV infected children, 70% of the caregivers reported that they disclosed their HIV diagnosis only to their immediate family members. The stigma associated with HIV was described as the most common fear of these caregivers (Lesar et al., 1996). Parents have reported being treated differently by friends, relatives, child care providers, medical staff, and school personnel after they have disclosed information about their HIV diagnosis (Lesar, et al., 1996). They often feel ashamed and guilty for engaging in high risk behaviors thus, there is a lack of candor within the home. Secrecy then contributes to a loss of social support and a self-imposed isolation that contributes to the parent's feelings of hopelessness, depression, and guilt (Boland, 1990).

As the infected family member's infection progresses, daily routines become disrupted due to the numerous medical appointments and the number of care providers that perform home-based delivery of their services (e.g., direct nursing care, social work intervention, different types of therapy--physical, respiratory, occupational and educational services). The influx of providers and medical equipment may be disruptive and anxiety provoking. Their presence alludes to the severity of the illness and to the uncertainty of their prognosis. Attention is now directed toward the ill family member, leaving the uninfected children feeling "isolated, neglected, and worried" (Andiman, 1995, p. 43). Their interactions with peers and involvement in regular activities are limited as the family becomes focused on the ill member. Roles may be reversed as the well children are asked to provide physical care for their sick parent or sibling. The number of clinic appointments, hospitalizations, medications, and treatments increase as the parent or sibling becomes sicker.

The families struggle to live with a chronic illness and anticipate future losses. For many there is a "paradoxical dilemma" of "how to maintain normality of life to at least some degree while preparing themselves emotionally for the painful inevitability of death" (Boyd-Franklin, Drelich, Schwolsky-Fitch, 1995, p. 179). Anticipating the losses initiates the mourning process after the family member has a prolonged illness, disfigurement, or neurological complications (Worden, 1991). For the families affected with AIDS, observing a once healthy family member "waste away" brings thoughts of their pending death before the family member reaches the final stages of illness. Many AIDS patients endure central nervous system damage that has profound effects on their cognitive functioning. These patients may have memory loss, decreased motor functioning, impaired expressive language abilities, and other complications associated with neurological deterioration. Significant changes in the person's emotional and behavioral functioning are likely to occur as the patient's disease state progresses. These types of changes are often the most difficult on family members who are experiencing anticipatory grief associated with the loss of the family member who has not yet died.

Anderson (1995) addressed the roller-coaster of emotions that family members will encounter as a sibling or parent's death is preceded by a series of episodic acute illnesses from which they recover, giving the family temporary respite until the following crisis. Many family members begin grieving the loss of the infected parent or child after they observe significant changes in the ill person's emotional or cognitive functioning. He/she may begin to withdraw from family and friends as they become depressed, bedridden, or experience neurological disease that affects their cognitive abilities. The ill person becomes "lost to the child although he/she is still alive" (Anderson, 1995, p. 62) and may hamper pleasant memories.

Psychological Adjustment in HIV/ AIDS Affected Families

HIV/AIDS differs significantly from other chronic and life threatening illnesses due to the complex psychological and social issues that confront AIDS infected families (Boland, 1990). It is a stigmatized disease that is an "ultimately fatal illness in one or more family members" (Boland, 1996, p. 161). As a result of the association with high risk behaviors, families feel a need for secrecy and a fear of social isolation if the diagnosis in known. Families with HIV/AIDS often struggle with deciding whom they can tell, if anyone, about the child's or parent's condition (Anderson, 1995). Due to the stigma and discrimination associated with the diagnosis, families resist informing extended family members, school personnel or neighbors about their condition. The risk of being ostracized is real and at times is necessary for the family to remain active within their community (V. J. Tepper, personal communication, January 4, 1997).

Families affected by HIV experience significant psychosocial problems including multiple losses, stigma, shame, guilt, and secrecy. Parents may have difficulty disclosing their child's diagnosis to their families due to the role that he/she plays in transmitting the virus. The parent may then have to disclose information about their own drug use or that of their partner's. Although previous research suggests that children benefit from knowing about their illness, many adults fear the social stigma associated with the transmission of the disease. The stigma contributes to the silence that accompanies this disease. As a result of the silence, families often do not get the support that they need during a time of loss, upheaval, and despair.

Many of the children that survive the death of their infected parent live with other relatives, adoptive parents, or are placed in foster care. Children are often placed outside of their mother's care directly from the newborn nursery because of their mother's inability to provide adequate care due to a host of psychosocial and medical issues: their own HIV-related illness, other health problems, circumstances related to drug-use or other economic and social stresses (Anderson, 1995). A parent's inability to care for their children may be temporary (e.g., during a brief hospitalization for an acute illness) or permanent (e.g., parent is no longer able to care for the child due to severe illness or death). If a parent cannot take care of his/her children, a relative or friend may be asked to take care of the children. However, many parents do not have a person that they could ask or the person they ask may be unwilling to care for the children (Aleman, et al., 1995).

Michaels and Levine (1992) estimated that 45,600 children and adolescents in the United States would be orphaned by 1996 and the number would increase to 82,000 by the year 2000. HIV infected women have been encouraged to establish future custody plans for their children, however, most do not plan because of their fear of disclosure, denial, lack of a potential guardian, and inadequate legal advice. The majority of HIV affected children will be placed in formal or informal foster care that may be in a relative's home, group setting, or with adoptive parents (Forsyth, 1995; Nicholas & Abrams, 1992).

Death occurs across generational boundaries, affecting the lives of each member of a family. The numerous deaths within a family do not allow time for each member to sufficiently mourn each loss before another occurs (Steiner, Boyd-Franklin, & Boland, 1995). According to Steiner, Boyd-Franklin, and Boland (1995) family members each experience feelings of guilt and anger. Infected parents are often angry at their partners or themselves for acquiring the virus and passing it on to their children. Grandparents may feel guilty for not having prevented their children from engaging in high risk behaviors (drug use, prostitution, promiscuity).

The psychological effects of a family member's HIV infection on uninfected children remains an understudied area in the empirical literature (Forsyth et al., 1996). One study has been published that specifically focused on the psychological adjustment of uninfected children on HIV-infected parents. Forsyth and colleagues (1996) assessed the psychological impact of HIV on 26 uninfected children in affected families (54% female, 46% male; 70% African American; mean age 9.8 years). When compared to children that were from families without chronic illness, they were more withdrawn, depressed and had more problems with attention. This study demonstrated that uninfected children in an affected family are at risk for developing psychological symptoms as a result of having a parent with an HIV/AIDS diagnosis. Nevertheless, the data should be interpreted with caution given the small sample size, biases in the sample selection (volunteers), and the symptom status of the mothers (7% deceased, 38% symptomatic, 53% asymptomatic). In addition, the children in this study had limited experience with death compared to most HIV affected families (8 of the 26 had lost a relative to HIV/AIDS) and the majority lived in households where there was only one infected family member (50% had one infected parent, 11% had both parents infected, and 31% also had an infected sibling). Research has failed to address the unique issues and stressors that influence the families adjustment to chronic illness in more than one family member. Specifically, the adjustment of the uninfected children living in HIV/AIDS infected families where there are several chronically ill family members.

Theoretical Models Used to Explain Adaptation to Chronic Illness

Current theoretical models of coping with a family member's chronic illness can not be used to adequately address the unique psychological issues that coexist with a diagnosis of HIV--the stigma, secrecy, guilt, ostracism, and multiple losses. Proposed models of adjustment to pediatric chronic illness fail to take into account the extraordinary stressors that impact HIV/AIDS-affected families (e.g., poverty, unstable living situations, unemployment, lack of education, substance abuse, and family violence). Previous empirical research has also ignored the extraordinary circumstances which these families encounter besides adjustment to a member's chronic illness.

In the absence of an appropriate theoretical model to address families with an HIV infected child, Lesar, Gerber, and Semmel (1996) developed a family adaptational model. This model combines the concepts used in the stress and coping models with ecological systems theory to illustrate the effects that an HIV infected child's illness has on the family's functioning. The disease is viewed as a "family disease" that threatens the family's existence. Relying upon a combination of family systems theory and an ecological framework, the model suggests that "specific stressors reverberate through a family having both direct and indirect influences upon its members" (Lesar, et al., 1996, p. 225). The model acknowledges that a child with perinatal infection has at least one other family member (the mother) that is also infected with HIV and experiences multiple unrelated stressors in the course of their daily lives (e.g., poverty, unstable living arrangements, and possible substance abuse). In a study to empirically test their model, Lesar and colleagues (1996) examined the relationship between severity and impact of the child's health status, availability of resources and support, and additional or unusual caregiving demands. The combination of the caregiver's HIV status, parenting stress ratings, and the specific burdens involved in providing daily care for a chronically ill child accounted for 62% of the variance in family functioning. Results from this study suggest that the use of the family adaptational model is useful in studying families with children infected with HIV, however, the findings do not adequately speak to the complex relationships between family members with a terminal illness, multiple losses, and the secrecy associated with the diagnosis.

A model is proposed in this study that incorporates the stressors related to having multiple family members with a chronic debilitating illness, multiple losses/anticipated losses, and those unique to an HIV diagnosis (e.g., secrecy, stigma, health of caregiver, family stability, future placement) is proposed in this study. The proposed model extends beyond previous models that have not addressed the uninfected children living in HIV/AIDS affected families. In this model, shown in Figure 1, having a family member infected with HIV is viewed as a potential stressor to which the child and family system endeavor to adjust. It serves as a heuristic tool for conceptualizing how support, stressors, and coping skills relate to child and caregiver adjustment. The model's focus is on the psychological adjustment of children and how it is affected by different stressors, perceptions of the stressors, demographic parameters (age, gender, father presence, number of siblings, and caregiver's relationship), illness parameters (severity and changes in functioning), caregiver adjustment, and available supports.

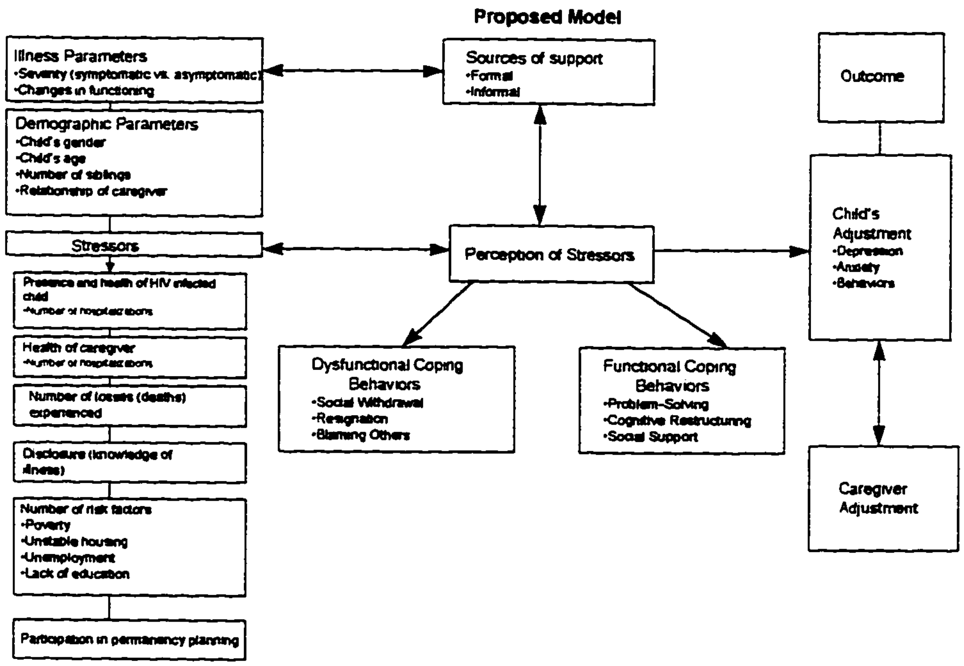

Figure 1. Proposed model of psychological adjustment in children with multiple family members infected with HIV/AIDS.

Adjustment to Chronic Illness in the Family

Coping with general life stresses and chronic illness occurs within a social context (Compas, Worsham, & Ey, 1992). Families are resources that provide the support and information that help children cope with difficult situations. Parents can serve as models who influence the coping strategies that individual family members choose to utilize. However, families often can impede coping processes and affect the coping efforts of family members in a negative way.

Family functioning is often measured in terms of their cohesion, expressiveness, organization, independence, and control (Moos & Moos, 1981). The families level of functioning directly impacts the child's psychological adjustment (Thompson & Gustafson, 1996). The literature supports a relationship between children's adjustment and parental stress and distress (Banez & Compas, 1990).

A family member with a chronic illness significantly impacts the other individuals within the family due to the distress caused by the numerous disruptions in the family, frequent separations from caregivers, disruption of daily routines, lack of information about the illness, focus of the family on the ill member, repeated hospitalizations, exposure to numerous painful procedures, and fear of death (Sargent, et al., 1995). Children differ from adults in their understanding and reactions to illness based upon their developmental level. Their views regarding the concepts of health and illness develop through a series of systematic stages which parallel those described by Piaget (Eiser & Eiser, 1987; Eiser, Eiser, & Lang, 1989; Harbeck & Peterson, 1992).

Parental Illness

Children with a parent diagnosed with a terminal illness are faced with significant psychosocial stresses. The parent's illness disrupts the entire family system, forcing other family members to make changes to their daily routine to assist with their health care needs (Baker, Nieswiadomy, & Arnold, 1988; Brooks, 1991). A parent's illness specifically causes major stress on the family because of the numerous functions that he/she performs by being a partner in a marital relationship, parent, manager of the household, employee, and friend (Johnston, Martin, Martin, & Gumaer, 1992). The nature and extent of changes within the family's structure are dependent upon the length and severity of the parent's illness. These changes will continue to challenge the system's ability to cope and re-balance itself in an effort to provide stability. Families may adopt maladaptive behaviors as a reaction to the stress caused by the uncertainty of the parent's illness. One such behavior is to limit the communication within the family.

Lack of communication about the illness, how each member feels, and individual perceptions was evident among family members in Titler, Cohen, and Craft's (1991) study of the impact of adult critical care hospitalization. Parents were seen as being supportive of their children while also attempting to shield them from information that they believed was too anxiety-provoking. These parents believed that their children were unable to comprehend the experience thus, they "protected" their children by not communicating to them about the hospitalized parent's illness nor permitting them to visit the hospitalized parent. They feared that the sight of all of the tubes, wires, and machines on the unit might further upset the child and the ill parent. The children in the Titler et al. (1991) study described themselves as feeling uncertain and vulnerable during the time of their parent's hospitalization. They stated that they were unsure of what happened to bring their parent to the hospital and did not know what to expect next. Many of the children spoke of fearing the loss (death) of their parent and/or their love.

According to Titler and colleagues (1991), the intensity and types of emotion expressed by the children relied heavily upon the circumstances which surrounded the onset of the critical illness. It was common for the children to feel guilty, afraid, angry, and frustrated as they were faced with this threatening experience. Effects of overriding threat were displayed in many forms by these children. Frequent reports of feeling acutely ill were made by these children during their parent's hospitalization. It was observed that the younger children, age 12 or younger, were more likely to complain of not feeling well. Titler and colleagues (1991) inferred that this was a possible attempt to express the feelings which they were unable to verbalize, as most of the younger children had little contact with their hospitalized parent, were not given information regarding their parent's illness, and had not been able to adequately express their feelings.

Furthermore, Titler and colleagues (1991) reported that the children who did not visit their hospitalized parent were identified as the most affected by structural changes within the home. Their daily routines were disrupted as they stayed with friends or relatives, experienced changes in their meal and bedtime patterns, and had increased contact with people whom they did not regularly interact. These changes contributed to decreased school attendance, poor academic performance, and strained interactions with their peers. As a result, a new family organization emerged that was perceived as less stable than the one that the children had known prior to their parent's illness. Parent-child relationships were likely to be impaired due to the child's feelings of isolation and rejection caused by the unavoidable separations that occurred during hospitalizations. Currently, few studies have assessed the long term impact of parental physical illness on children even though it is believed to be a cause of psychiatric illness in children (Gallo, Breitmayer, Knafl, & Zoeller, 1992; Glass, 1985; Johnston et al., 1992; Roy, 1991).

Sibling Illness

Children who have a sibling in the hospital often experience many of the same stressors as children who are hospitalized for their own illness. Stressful situations that have been identified in hospitalized children include separation from parents, loss of self-control, and confusion over medical procedures. According to Pidgeon (1981), these aspects of hospitalization create a series of real, imagined, or potential threats for the child. The nature of the threat depends upon the child's age and level of development, previous experiences with such threats, amount and type of relevant information they possess, and the amount and type of support they receive (Eiser, 1990). Hospitalization provides many stressors which may intensify a sibling's reactions such as unfamiliarity with hospital environment and personnel, separation from caregiver, disruption of typical routines, loss of control over daily events, and misconceptions about the purpose of their brother or sister's hospitalization (Peterson, 1989; Siegel & Hudson, 1992).

A child's ability to effectively cope with a sibling's illness and hospitalization is dependent upon their ability to assess the situation and the coping resources that they have available to them. Coping can be defined as cognitive and behavioral responses that are used to manage internal and/or external demands created by stressful situations. Lazarus and Folkman (1984) described coping strategies as mediators between stressful situations and how one adjusts to these same situations. Their model of cognitive appraisal emphasizes two fundamental types of coping. The first type, problem-focused coping, "refers to efforts to change or master some aspect of the person, the environment, or the relation between these two elements that is perceived as stressful" (Compas, et al., 1992, p. 8). The second type of coping, emotion-focused coping, "refers to efforts to manage or regulate the negative emotions associated with the stressful episode" (Compas, et al., 1992, p.8). Both forms of coping are generally used to address stressful situations, however, research has shown that in pediatric populations more active problem focused efforts have been associated with more beneficial responses (Peterson, 1989). This involves seeking information, taking direct or indirect action, or using intrapsychic processes such as defense mechanisms to regulate the emotion. How a child copes with a problem directly relates to his/her adjustment to the situation.

The brothers and sisters of children with chronic illnesses have reported feeling resentful, angry, anxious, depressed, jealous, guilty, and afraid (Fanos & Wiener, 1994; Sargent et al., 1995). Long-term effects of a sibling's illness and death have been found in adults who lost a sibling to cystic fibrosis (Fanos & Wiener, 1994). They described feeling guilty about surviving and having not been ill. After they reached new developmental milestones that their sibling did not achieve, they began to revisit their feelings of guilt and often began to worry that they themselves would die at an early age.

Research findings have consistently indicated that the family crises of childhood illnesses (e.g., cancer, diabetes) can have a profound impact on a sibling's psychosocial functioning (Menke, 1987; Sargent, et al., 1995). Several studies have reported that these siblings experience adjustment problems, emotional symptoms of distress, and behavioral symptoms of distress (Bendor, 1990; Carpenter & Sahler, 1991; Walker, 1988). Unsuccessful adaptation of siblings may be associated with: (1) insufficient or infrequent parental communication about their brother or sister's illness, (2) limited participation in their sibling's treatment or care, (3) feelings of physical and emotional isolation from their parents, and (4) insufficient resources to provide them with emotional, social, and peer support. In a study that examined the responses of 254 siblings of children with cancer, Sargent and colleagues (1995) found significant age differences in adjustment. Healthy siblings reported feeling most distressed about the lack of attention they received, the number of family separations and disruptions, their sibling's medical treatments and possible death. Nevertheless, these siblings reported being closer to their siblings and feeling more compassionate towards their families. Older children were viewed as having greater patience and awareness of the needs of their ill siblings. The literature on childhood chronic illness suggests that young children are more likely to have difficulty adjusting to the disruptions in their lives and have fewer resources available to assist them with coping (Sargent et al., 1995).

Coping With the Loss of a Family Member

The response of children to the death of a significant person often assumes a specific pattern which may be interpreted as simulating a pathological form of mourning described in adults (Miller, 1971). As a result, it is often difficult to determine whether a child's reactions are maladaptive or if they are modeled after the reactions of their parents or caretakers. Children are likely to be more upset by the loss of parental support and the depression and anxiety shown by their caregivers than the actual loss itself (Boyd-Franklin, Drelich, & Schwolsky-Fitch, 1995).

Children's concepts of death and dying

A child's response to death is influenced by their previous experiences with death, availability of support, parent or caretaker's demeanor, the nature of the person's death, and his/her developmental age (Wolfelt, 1996). Their ability to understand the concept of death is dependent upon the their level of cognitive, emotional, and social development (Worden, 1996). A Piagetian framework has frequently been used to demonstrate how death is interpreted and experienced differently at each age and/or stage of cognitive development (Koocher & Gudas, 1992). According to this model, each child's conceptualizations of death continue to evolve as he/she gains additional information and has new experiences. Their acquisition of the four subconcepts of death parallels their cognitive development, understanding concepts in a stepwise progression. Each subcomponent builds upon the next, resulting in an understanding of the permanence of death. According to Reynolds, Miller, Jelalian, & Spirito (1995), the four subcomponents of the death concept identified in previous research are irreversibility (the understanding that death is final and irreversible), universality (knowledge that all living things (plants, animals, and human beings will die), nonfunctionality (all life-defining functions will cease with death), and causality (an understanding of the objective causes of death). Although many children attain these concepts in the above stated sequence, variability does exist (Reynolds et al., 1995).

Most researchers believe that death can be understood by children after the arrival of "concrete operations" at 6 or 7 years of age (Brent, 1983; Koocher et al., 1992; Reynolds et al., 1995; Worden, 1996). The child at this stage of cognitive development is able to comprehend and view death as permanent, however, may have difficulty with more abstract concepts. Corr (1995) cautions against relying exclusively upon a developmental theory due to it's disregard for personal experiences and individual personalities.

Loss of a Parent

The death of a parent is a psychological trauma which threatens the child's social and emotional development. According to Furman (as cited in Siegel, Mesagno, & Christ, 1990) "no other event is comparable in psychological significance because the death of a parent deprives children of so much opportunity to love and be loved and confronts them with a formidable adaptive task" (p. 168). It is not a single, discrete event, but rather a life transition compiled of a series of changes that take place prior to and following this significant loss . The loss often precipitates many stressful changes such as alterations in the family's daily routines, financial status, residence, and the caretaker's ability to provide emotional and physical support (Reynolds et al., 1995; Siegel, Mesagno, & Christ, 1990; Worden, 1996).

It is a loss that does not end, continually being re-visited as the child moves through each stage of development. The parent will continue to be remembered at each special occasion, anniversary of an important event (e.g., parent's date of birth, anniversary of their death, etc.) and during periods of stress. There is "no way to avoid the pain of losing a parent" (Adams-Greenly & Moynihan, 1983, p. 228). Children often are unable to understand the death of their parent yet, they are subjected to the same rules of conduct as adults. The ability to understand the death of a parent is greater among children who already have a realistic concept of death. The child's ability to mourn (express his/her grief) is dependent upon the relationship that he/she had with their deceased parent and the stage of cognitive development that the child is in at the time of his/her parent's death (Wolfenstein, 1977).

Bereavement is often a time of helplessness, lowered self-esteem, and diminished self-worth. Mourning is the process that allows the child to adapt to his/her loss. If this process is interrupted, the child's future growth is at risk and he/she may develop future adjustment problems and/or psychiatric illnesses (Adams-Greenly, & Moynihan, 1983; Becker, & Margolin, 1967; Bowlby, 1980; Koocher, et al., 1992). The child's emotional development is likely to be arrested at the level he/she had reached at the time of his/her parent's death (Brent, 1983; Furman, 1974; Gelcer, 1983). As a result, the loss of a parent may symbolically be re-enacted in other relationships in an attempt to resolve unfinished issues.

Children who lose a parent are at risk for developing emotional disturbances. These children may manifest symptoms in childhood and adulthood which could include: sadness; anxiety; confusion; eating, sleeping, and toileting problems; somatic complaints; disruptive behaviors; social and emotional withdrawal; suicide attempts; loss of interest in favorite pastimes; decreased attention span; learning problems; decreased effectiveness in school; and expressions of guilt over past experiences (Brent, 1983; Furman, 1983; Gelcer, 1983; Koocher et al., 1992; Worden 1996). Many maladaptive coping strategies may be used by children who mourn the loss of a parent. According to Adams-Greenly and Moynihan (1983) children may be in denial, have a reversal of affect, identify with the deceased parent, and have an intense attachment to the lost parent. In addition, children may have a persisting demand to be cared for, feel a vindictive rage against the world, and believe that they can force the parent to return by showing the extent to which they are suffering. Finally, some children may create a self-inflicted repetition of loss via other relationships. The child's ability to cope with parental death is influenced by their maturational level, cognitive ability to comprehend death, previous experiences with loss, and the support given by the surviving parent and other significant people.

A parent's death will have both short and long term effects on the child. Furman (1974) described bereavement as a threefold task--to cope with the immediate impact of the circumstances, to mourn, and to resume one's emotional life. The degree of success depends upon the intrafamilial communication and the shared expression of feelings. A child's adjustment is "related to the surviving parent's ability to offer physical and emotional comfort; provide an environment in which the child feels able to express distressing or conflicting thoughts, feelings, and fantasies about the loss; and maintain stability and consistency in the child's environment" (Reynolds, et al., 1995, p. 157). Children who do not have a supportive and caring environment that strives to minimize the number of changes and open the lines of communication are at risk for poor psychological adjustment.

Loss of a Sibling

Sibling loss differs significantly from that of parental loss due to the impact that the loss has on the parents and the lack of support that is available to be given to bereaved siblings. Often the focus is on the bereaved parent who needs for the surviving child to "be strong" (Reynolds et al., 1995). According to Worden (1996), the caregivers grief may interfere with their ability to parent or be emotionally available to their surviving children. They are likely to experience the parents' mourning and withdrawal as an additional loss (Brent, 1983). This loss is often amplified for children of single parents who do not have another person that can help with parenting.

Bereaved parents may in turn look to the surviving child to "make up for a child's loss" (Worden, 1996, p. 117). As a result of feeling guilty for surviving and a desire to please their parent, he/she may feel obligated and attempt to step into the vacated sibling's role (Brent, 1983). Healthy children who feel cheated out of their parents attention are likely to feel angry at their sibling and their parents, resenting the preferential treatment that their ill sibling receives and experience guilt and self-blame after the death (Barakat, Sills, & LaBagnara, 1995; Sourkes, 1980). Young children may view their sibling's death as abandonment, punishment, or the realization of unacceptable wishes. These children are likely to have difficulty with school and peer relationships, have declining academic performances, and develop maladaptive coping strategies. Children may present with somatic complaints, regress under stress--acting like a younger child who is in greater need of physical affection (Adams-Greenly & Moynihan, 1983; Brent, 1983).

Loss of a Parent or Sibling to an AIDS-Related Illness

Losing a parent, sibling or other family member to AIDS is likely to complicate the mourning process (Boyd-Franklin, Drelich, & Schwolsky-Fitch, 1995). The task of mourning a family member who suffers an AIDS related death is confounded by the number of losses within one family, the social stigma associated with AIDS, and the challenges to the family's stability. Often family members have not had enough time to mourn one loss before another occurs (Boyd-Franklin, Drelich, & Schwolsky-Fitch, 1995).

The "illness and cause of death are often kept secret" because of the stigma and discrimination associated with AIDS (Siegel & Gorey, 1994, p. S67). Family members are likely to be ashamed and afraid of the repercussions that are a result of disclosure. Due to the risk behaviors associated with HIV transmission, extended family members may feel anger and resentment towards the parents for burdening them with their care and that of their children. These families often live under a veil of silence, refusing to acknowledge the illness and their need for support. Siegel and Gorey (1994) spoke of the overload experienced by families when they lose several friends and relatives within a short period of time.

Mourning a parent may be difficult for a child who has lost a parent infected with HIV due to the lack of factual information that is often not shared surrounding the cause of death. As a result, children may not be given the opportunity to openly express their feelings about the loss or modify their misconceptions about their understanding of the illness or cause of death. Previous research indicates that children benefit from receiving developmentally appropriate information, being included in decision-making, having their feelings and thoughts validated, and remaining involved in age-related activities (Adams-Greenly & Moynihan, 1983). Families who strive to achieve some sort of semblance that mirrors the child's previous experience are likely to enhance the child's sense of control. Despite the efforts that families make to avoid further disruptions, children may be placed in foster care, moved between temporary placements, or separated from significant others due to the lack of custody planning and/or available support (Siegel & Gorey, 1994).

Proposed Study

Rationale

Pediatric AIDS has become the newest chronic illness in childhood according to the Center for Disease Control with more than 12,000 children in the United States currently infected and more than 1,000 additional children becoming infected each year (Center for Disease Control, 1995; Lipson, 1993; Maieron, Roberts, & Prentice-Dunn, 1996). Within families with multiple HIV/AIDS infected members are also many uninfected children. These children will outlive their infected parents, siblings, extended family members, and neighbors.

The issues that confront these orphans of the AIDS epidemic are similar to those of their infected siblings—they too will lose a parent, be asked to maintain the family's "secret" and will live in fear of their parent's and sibling's diagnosis being discovered. The uninfected child may be responsible for "performing physical tasks as well as providing attention and emotional support and supervision for other children and the parent. This role reversal with the parents sets up expectations for the child that may be difficult to achieve, or can be achieved at the cost of one's own development and childhood activities" (Anderson, 1995, p. 62).

The family's level of distress impacts the uninfected child's emotional adjustment, regardless of whether the parent's or child's HIV status has been disclosed. The uninfected child's ability to cope with the family's level of distress (including HIV infection in a family member, poverty, changes in their living situation, social supports) is directly related to the family's openness to communicate about the future and make decisive plans.

The empirical and theoretical literature on the effect of HIV infection on the psychosocial adjustment of the uninfected children in the family is virtually nonexistent. The uninfected children in HIV affected families are at risk for adverse psychological consequences. The purpose of this study is to assess the emotional adjustment of children who have multiple family members diagnosed with a terminal illness, Acquired Immunodeficiency Syndrome (AIDS)/ Human Immunodeficiency Virus (HIV). Specifically, this study will contribute to the empirical literature by examining the psychological adjustment of uninfected children living in HIV/AIDS affected families.

Hypotheses

Using the proposed model as a guide, the adjustment of uninfected children living in an HIV/AIDS affected family will be empirically tested by examining the following hypotheses.

1. It is hypothesized that knowledge of a parent's and/or sibling's HIV/AIDS diagnosis is related to psychological adjustment.
2. It is hypothesized that knowledge of future custody arrangements is related to psychological adjustment in children anticipating the death of their caregiver.
3. It is hypothesized that participating in custody arrangements is related to psychological adjustment in children who are anticipating the loss of a parent.
4. It is hypothesized that previous experience with death/multiple deaths is related to psychological adjustment in children living in affected families.
5. It is hypothesized that social support is related to psychological adjustment.
6. It is hypothesized that a stable and consistent living arrangement impacts psychological adjustment.

METHOD

Research Design

Descriptive data will be collected to assess the degree of relationship between various combinations of the predictor variables (knowledge of parent/sibling illness, previous death experiences, participation in choosing future living situation, social support, and a history of a stable living situation) and several dependent variables related to child psychological adjustment (Child Behavior Checklist/4-18; Achenbach, 1991; Children's Depression Inventory; Kovacs, 1992; Kidcope; Spirito, Stark, & Williams, 1988; Revised Children's Manifest Anxiety Scale; Reynolds & Richmond, 1985). Standardized questionnaires will be used to collect the data at an urban clinic serving the identified population.

Participants

A minimum of 50 care providers (defined as the individual who is responsible for the primary care of the children in the family such as the biological mother, grandparent, or foster parent) and children ages 6-16 who have a sibling and a parent who have been infected with HIV will be recruited for participation in the proposed study. Preliminary review of the potential subject pool indicates 90 families with at least one child who is accessible for recruitment. Participants will be the uninfected children of HIV positive women who have a sibling that is followed by the Pediatric AIDS Care and Evaluation Program (PACE Program) in the Division of Pediatric Immunology at Maryland's Hospital for Children at the

University of Maryland at Baltimore. To be enrolled in the study the uninfected children must meet the following criteria: (1) between the ages of 6-16 years; (2) from a family with an HIV infected mother and sibling; (3) fluency in English; and (4) agree to participate in the study. When families have more than one uninfected child that meet these criteria, all children will be eligible to participate in this study. Children and/or care providers who have a known psychiatric history or a developmental disability that would prevent them from completing the questionnaires will be excluded from this study. Children who are currently living in non-relative foster care placements will also be excluded due to the inherent difficulties in obtaining consent and in collecting background data from outside sources.

Previous chart reviews have identified when HIV infected children have siblings between the ages of 6-16. The study coordinator will review weekly clinical schedules and approach each care provider of the children that meets the criteria to participate in this study. At this time, the care provider will learn of the purpose of this study; to learn how children with multiple family members diagnosed with a terminal illness are adjusting, and the family will be invited to participate. After the consent forms, approved by the hospital and the University of Oklahoma's Institutional Review Board (IRB) are signed, the caregiver-child dyad will be scheduled to complete the assessment instruments. Families who agree to participate in the study and complete the questionnaires will be reimbursed for their time with a $10 gift certificate. Transportation will be provided for all family members who accompany the caregiver and uninfected sibling to the medical center.

The population of families who attend the PACE program are predominantly African-American, from a disadvantaged inner city household in neighborhoods where illicit drug use is high. The majority of these families are indigent and receive both medical assistance and AFDC (Aid to Families with Dependent Children). Many of the parents and caregivers have not disclosed either their own or their children's HIV status to any family member. To respect the families decision to not share this information, HIV/AIDS will at no time be mentioned to the children participating in this study. They will be told that the study coordinator is interested in how children who live in an inner city think, feel, and cope with problems in their daily life. All references to this study at the University of Maryland at Baltimore will omit the words "AIDS" or "HIV." On any written material provided to the children the study will be called "The Psychological Adjustment of Children Living in an Inner City" to insure confidentiality.

Site

The Pediatric AIDS Program at the University of Maryland is administratively within the Department of Pediatrics in the School of Medicine at the University of Maryland at Baltimore (UMAB). It is affiliated with the University of Maryland Hospital and a part of the University of Maryland Medical System (UMMS). The Pediatric AIDS program is an integrated effort between the

Division of Pediatric Immunology, the Division of Behavioral and Developmental Pediatrics, and several other divisions within the Department of Pediatrics. The program was initially funded by the National Institute on Drug Abuse to identify and enroll women and children who were at risk for, or already infected by HIV in order to document the prevalence of HIV infection. It is also one of the AIDS Clinical Trial Groups (ACTG) pediatric sites that has direct access to the latest treatment protocols. The staff have provided care to HIV positive women and children since 1986 and have followed over 600 HIV at-risk (uninfected children born to infected mothers) and infected children.

Procedures

All children and their caregivers will be asked to complete the assessment instruments in a conference room at the medical center. They will be instructed in how to complete each instrument according to standardized administration procedures. The study coordinator and research assistants will be available to read the questionnaires to the children and caregivers who need assistance. Previous research indicates that the psychological assessment of children is best explained by several individuals completing multiple measures to offer more than one perspective (Kaslow & Rehm, 1991; Thompson, Gil, Burbach, Keith, & Kinney, 1993; Thompson & Gustafson, 1996). Four measures will be used in this study three to be completed by the uninfected sibling: The Children's Depression Inventory (CDI), Revised Children's Manifest Anxiety Scale (RCMAS), and the Kidcope, and one by the caregiver: The Child Behavior Checklist (CBCL). A questionnaire will be given to the careprovider requesting demographic information, a report of current family health status, and their knowledge of what the child understands regarding his/her sibling's and parent's illness.

The instruments chosen for use in this study have been used in previous experimental research to identify the risk factors that contribute to emotional and behavioral problems in children (Banez, & Compas, 1990; Beck & Rosenberg, 1986; Jensen, Bloedau, Degroot, Ussery, & Davis, 1990; Johnson, Boney, & Brown, 1991).

Instruments

The Child Behavior Checklist (CBCL/4-18; Achenbach, 1991) was designed to obtain a systematic report of children's behavioral or emotional problems and social competence as seen by their parent/caregiver. There are 20 competence items and 118 problem items plus two open ended items that the parent/caregiver must complete. The problem items were derived from information obtained from clinical case records and expert opinions. CBCL problem items include both internalizing and externalizing behaviors, and nine syndrome scales (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behavior, aggressive behavior, and sex problems). Parents also endorse items relating to the amount and quality of the child's participation in activities, involvement with social organizations, school performance and friendships. Reliability and validity of the CBCL items have been extensively reported in the literature (Achenbach, 1991;

Achenbach & Edelbrock, 1983; Verhulst, Althaus, & Berden, 1987) and were significantly associated with clinically referred samples.

The Children's Depression Inventory (CDI; Kovacs, 1992) is the "most widely used and research measure of childhood depression" (Kazdin, 1988, p. 174). It was the first standardized self-report inventory of depressive symptoms for younger age groups. The CDI has frequently been used in research with school aged children and adolescents (Kovacs, 1992). It is a 27 item self-rated symptom oriented scale designed to assess a variety of symptoms associated with depression such as sleep disturbance, appetite loss, suicidal thoughts, hopelessness, and general dysphoria. The CDI is a modified version of the Beck Depression Inventory, commonly used with adults (Kaslow & Rehm, 1991). Each item consists of three brief statements that describe a range of possible responses for each symptom ranging from normal responses to indicators of moderate to severe depressive symptoms. Elevated scores on the CDI have been associated with heightened levels of anxiety, low levels of self-esteem, high levels of hopelessness, and negative cognitive attributions (Kovacs, 1992; Ollendick & Yule, 1990; Ollendick, Yule, & Ollier, 1991). The CDI is a reliable and valid measure of depression that has been reported to have acceptable internal consistency, test-retest reliability, discriminant and construct validity (including content, criterion, and convergent) (Kovacs, 1992; Kazdin, 1988).

The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985) is a revision of the Children's Manifest Anxiety Scale by

Castaneda, McCandless, and Palmero (as cited in Reynolds & Richmond, 1985) which was in turn a modification for children of Taylor's Manifest Anxiety Scale (Stallings & March, 1995). The current RCMAS is a 37-item self-report questionnaire designed to assess the presence or absence of a variety of anxiety related symptoms. According to Silverman (as cited in Stallings & March, 1995) , the RCMAS assesses general distress with an emphasis on anxiety. The scale yields three anxiety factors: physiological anxiety, worry/oversensitivity, and concentration. High internal consistency, test-retest reliability, and concurrent validity with the trait scale of the State-Trait Anxiety Inventory for Children have been reported for the RCMAS (King, Gullone, & Ollendick, 1991; Reynolds & Paget, 1983; Stallings & March, 1995).

The Kidcope (Spirito, Stark, & Knapp, 1992; Spirito, Stark, & Williams, 1988) is a self-report measure that assesses 10 common cognitive and behavioral coping strategies utilized by children and adolescents. The frequency and the perceived efficacy of each strategy is determined by the child's or adolescent's self-report of how they cope with a selected personal stressor. Age-appropriate versions of the Kidcope have been developed for younger (ages 7 to 12 years) and older (ages 13-18 years) children. The child reports whether he/she is more likely to use distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support, or resignation to cope with a stressor. Coping is a process that changes over time to reflect the impact of specific stressors. In response to different situations, various cognitive and behavioral strategies may be used at any given time. Concurrent validity and internal consistency have been reported (Spirito, Stark, & Williams, 1988), however, due to each item representing an independent coping strategy and the use of varied coping responses, reliability coefficients may be lower than those for scales including multiple items.

Data Management

Once completed by the participants and scored by the research assistant, all instruments, consent forms, and demographic information sheets which are pertinent to each individual participant will be stored together in a locked file cabinet. Complete confidentiality will be assured by providing each participant with his/her personal identification number. Names of participants will be written on a separate sheet next to their identification number and kept separately in a locked file cabinet along with all other instruments. The names of all participants will be kept for possible follow-up. Once follow-up is complete, or if a decision is rendered to forgo follow-up, all lists of names and any consent forms with subject names on them will be destroyed. All data collected will be identified, if needed, only by identification number and only when absolutely necessary. At no time will names or specific identifying data particular to any participant be written in a report or presented in a public meeting.

Data Analysis

Descriptive statistics will be used to provide initial information about the sample. The mean, range, and standard deviation, as well as cumulative frequencies, will be calculated for each measure and for information provided in the background information forms.

Stepwise regression analyses will be performed to test the predictor variables: (1) Knowledge of illness, (2) exposure to death, (3) participation in the selection of future living arrangements following the death of caregiver, (4) social support/stability of previous living arrangements, and (5) coping style. These analyses will be used to evaluate the efficacy of the proposed model in predicting the outcomes of the uninfected child's adjustment to living in a family affected by HIV/AIDS.

The University of Oklahoma

OFFICE OF RESEARCH ADMINISTRATION

April 2, 1997

Ms. Teresa L. Collins-Jones
905 Radcliffe Road
Towson, Maryland 21204

Dear Ms. Collins-Jones:

The Institutional Review Board-Norman Campus, has reviewed the requested additional information you provided for your proposal, "AIDS Orphans: The Psychological Adjustment of Children With Multiple Family Members With a Terminal Illness." The Board found that this research would not constitute a risk to participants beyond those of normal, everyday life except in the area of privacy which is adequately protected by the confidentiality procedures. Therefore, the Board has approved the use of human subjects in this research.

This approval is for a period of twelve months from this date, provided that the research procedures are not changed significantly from those described in your "Application for Approval of the Use of Human Subjects" and attachments. Should you wish to deviate significantly from the described subject procedures, you must notify me and obtain prior approval from the Board for the changes.

At the end of the research, you must submit a short report describing your use of human subjects in the research and the results obtained. Should the research extend beyond twelve months, a progress report must be submitted with the request for re-approval, and a final report must be submitted at the end of the research.

Sincerely yours,

Karen M. Petry

Karen M. Petry
Administrative Officer
Institutional Review Board-Norman Campus

KMP:sg
97-102

cc: Dr. E. Laurette Taylor, Chair, IRB
Dr. Terry M. Pace, Educational Psychology

1000 Asp Avenue, Suite 314, Norman, Oklahoma 73019-0430 PHONE: (405) 325-4757 FAX: (405) 325-6029

UNIVERSITY OF MARYLAND
AT BALTIMORE
INSTITUTIONAL REVIEW BOARD

655 W. Baltimore Street,
Baltimore, MD 21201-1559

BRB 14-016
email: ORS@schmed01.ab.umd.edu
voice: (410) 706-5037

Date: Friday, January 17, 1997

TO: VICKI TEPPER, Ph.D.
PEDIATRICS
630 W. FAYETTE ST., ROOM 5-671

FROM: UMAB Institutional Review Board
ASSURANCE Number: **M1174-01NR**

RE: IRB PROTOCOL #1296051

"THE PSYCHOLOGICAL ADJUSTMENT OF CHILDREN WHO LIVE IN THE INNER CITY"

Expires: 01/17/99

Report required yearly

Response to correspondence dated: 01/08/97

This is to certify that the Institutional Review Board has reviewed your response to their queries and fully approved your protocol. The enclosed stamped consent form is valid until the next anniversary of this protocol.

You must notify the IRB if the project is altered in any way (change in location, personnel, number of subjects, age of subjects, or any change in research protocol). If you have any questions, please do not hesitate to contact the Office for Research Subjects by email (ORS@schmed01.ab.umd.edu) or by phone (at 706-5037).

Paul Fishman /mz

Paul Fishman, M.D., Ph.D
Chairman, IRB

UNIVERSITY OF MARYLAND
SCHOOL OF MEDICINE

DEPARTMENT OF PEDIATRICS

Division of Behavioral and Developmental Pediatrics
[illegible] West Fayette Street
Baltimore Maryland 21201-[illegible]
FAX (410) [illegible]

4/7/97

PARENT/ GUARDIAN CONSENT FORM

Title of Research Project: "The Psychological Adjustment of Children Who Live In An Inner City"

Investigators:	Vicki J. Tepper, Ph.D.	Phone:	706-3542
	Teresa L. Collins-Jones, M.A.		706-3083
	Prasanna Nair, M.D., M.P.H		328-2533
	John J. Farley, M.D., M.P.H		706-8220
	Peter E. Vink, M.D.		706-8220

Purpose of the Study:
You are being asked to participate in a research study to help us understand how uninfected children in families affected by HIV are dealing with family stress. The aim of this project is to identify issues that may assist these children and their families in coping with stress and loss associated with HIV/AIDS.

Procedures:
You and your child will be asked to spend approximately 30-45 minutes of your time completing several questionnaires. You will be asked to complete a brief demographic form that asks for basic information about you and your family, an inventory about the current stressors that are affecting your family, and a questionnaire that asks you to describe your uninfected child's current behaviors. Your child will be asked to answer questions about his/her feelings and how they handle everyday problems. At no time will your child be asked questions about anyone's illness or about HIV/ AIDS.

Risks/Discomforts:
Participation in this study involves no risks. Previous studies using the same questionnaires have never reported any negative effects for participants. However, you might feel uncomfortable being asked questions about yourself or your family. If this happens, you may ask us to stop for a while or you may withdraw from the study.

Benefits:
The information that you give will help health care professionals to better understand how children cope with the stresses of living with family members with HIV/AIDS, however, there is no direct benefit to you.

Confidentiality:
The records of this study are strictly confidential to the extent allowable by law. Neither you nor any member of your family will be identified in any report. The forms used for data collection will not have names on them, instead a number will identify each participant. Names of participants will be written only on the consent forms that will be kept in a locked file along

with all other forms. At no time will names or information that could identify a particular participant be written in a report or presented at a public meeting. All records will be destroyed after this study has ended.

Alternatives to Participation/Compensation:
Your participation in this study is entirely voluntary and you are able to withdraw from the study at any time without losing any benefits to which you are entitled. You also may refuse to answer any questions for any reason. This will in no way affect the service you and your family receives from the University of Maryland at Baltimore. There are no costs to you or your insurance company for enrolling in this study. You will receive a gift certificate of $10.00 for attending the assessment session and completing the questionnaires. If you have more than one child (ages 6 to 16) who can participate, you will receive an additional $10.00 gift certificate per child. Transportation and a snack will be provided to all participants in this project.

University Statement:
The University of Maryland at Baltimore cannot provide any financial compensation due to the injury suffered during this research study. Information about research may be obtained from the Human Volunteers Research Committee, UMAB, Bressler Research Building, Room 14-002, 655 West Baltimore Street, Baltimore, Maryland 21201. Phone: (410) 706-5037.

Should any problems or questions arise with regard to this study, you should contact the Principal Investigator, Dr. Vicki J. Tepper or these other staff members also involved in this study, Ms. Teresa L. Collins-Jones, Dr. Prasanna Nair, Dr. John J. Farley, or Dr. Peter E. Vink at the numbers listed on the previous page.

Subject Statement:
I have read the preceding information and agree to participate in this study. All of my questions have been answered and I have received a copy of this consent form.

Name of Child	Date
Signature of Parent/Guardian	Date
Signature of Investigator	Date
Signature of Witness	Date

RPN NO. 1296051

University of Maryland
Medical Center

UNIVERSITY OF MARYLAND
SCHOOL OF MEDICINE

DEPARTMENT OF PEDIATRICS

Division of Behavioral and Developmental Pediatrics
630 West Fayette Street
Baltimore, Maryland 21201-1585
FAX 410 706-0146

m4
4.7.97

CHILD/TEEN ASSENT FORM

Title of Research Project: "The Psychological Adjustment of Children Who Live In An Inner City"

Investigators:	Vicki J. Tepper, Ph.D.	Phone:	706-3542
	Teresa L. Collins-Jones, M.A.		706-3083
	Prasanna Nair, M.D., M.P.H.		328-2533
	John J. Farley, M.D., M.P.H.		706-8220
	Peter E. Vink, M.D.		706-8220

Purpose of the Study:
You are being asked to participate in a research study to help us understand how children who live in an inner city deal with the stressors of daily life.

Procedures:
You and your parent/guardian will be asked to complete several questionnaires that will take approximately 60 minutes to finish. Your parent/guardian will be asked to complete three different questionnaires about your family while you answer questions about your feelings and how you cope with everyday problems.

Risks/Discomforts:
Participation in this study involves no risks. Previous studies using the same questionnaires have never reported any negative effects for participants. However, you might feel uncomfortable being asked questions about yourself or your family. If this happens, you may ask us to stop for a while or you may withdraw from the study.

Benefits:
Your involvement will provide health care professionals to gain a better understanding of how children adjust to the many worries and concerns they have in their daily lives, however, there is no direct benefit to you.

Confidentiality:
The records of this study are strictly confidential to the extent allowable by law. Neither you nor any member of your family will be identified in any report. The forms used for data collection will have a number on them to identify you, instead of your name. Names of participants will be written only on the consent forms which will be kept in a
ocked file along with all other forms. At no time will names or specific identifying data particular to any participant be written in a report or presented at a public meeting. All records will be destroyed after this study has ended.

Alternatives to Participation/Compensation:
Your participation in this study is entirely voluntary and you are able to withdraw from the study at any time without penalty or loss of any benefits to which you are entitled. You also may refuse to answer any questions for any reason. This will in no way affect the service you and your family receive from the University of Maryland at Baltimore. There are no costs to you or your insurance company for enrolling in this study. Your parent/ guardian will receive a gift certificate of $10.00 for attending the assessment session and completing the questionnaires. Transportation and a snack will be provided to all participants in this project.

University Statement:
The University of Maryland at Baltimore cannot provide any financial compensation due to the injury suffered during this research study. Information about research may be obtained from the Human Volunteers Research Committee, UMAB, Bressler Research Building, Room 14-002, 655 West Baltimore Street, Baltimore, Maryland 21201. Phone: (410) 706-5037.

Should any problems or questions arise with regard to this study, you should contact the Principal Investigator, Dr. Vicki J. Tepper or these other staff members also involved in this study, Ms. Teresa L. Collins-Jones, Dr. Prasanna Nair, Dr. John Farley, or Dr. Peter Vink.

Subject Statement:
I have read the preceding information and agree to participate in this study under the conditions stated. All of my questions have been answered and I have received a copy of this consent form.

Signature of Child/Teen _______________ Date _______

Signature of Parent/Guardian _______________ Date _______

Signature of Investigator _______________ Date _______

Signature of Witness _______________ Date _______

Not Valid Without
IRB Stamp
APPROVED
JAN 17 1997
UNIVERSITY OF MARYLAND AT BALTIMORE
INSTITUTIONAL REVIEW BOARD
Valid One Year
Above Date

RPN No. 1296051

BACKGROUND INFORMATION
Parent Version

ID #:__________

Child's Gender: Male Female

Child's Age:_________ Birthday (Month, Day, Year):_______________

Parent Information:

Parent's Gender: Male Female

Parent's Race: African-American Asian-American Caucasian Latin-American Native-American Other

Parent's Age:________ Parent's Relationship to Child:_________________________

Parent's Marital Status: Single Married Separated Divorced Widowed

Parent's Number of Years of School Completed:______________

Parent's Occupation:_________________________

Other Adult(s) Living in the Home: Yes No

Occupation of Other Adult (s): __________________________

Annual (combined) Income:

$5, 000 or less

$5, 000 - $10,000

$10, 000- $15,000

$15, 000 - $20, 000

$20, 000 - $30, 000

$30, 000 - $40, 000

$40, 000 - $50, 000

$50, 000 or more

Household Information:

Length of time the child has lived with you:__________________________

Length of time the child has lived in his/her current home (apartment/house):_________

How many times has the child moved during the past five years:_______________

Who else lives in your home (with the child):

Name	Age	Relationship to the child

What type of assistance do you and your family currently receive?
(Home Health Nursing, WIC, Food Stamps, etc.)

____

____

HIV/AIDS Information:

Who in your home is diagnosed with HIV/AIDS?
Relationship to the child

____
____
____
____

Which of the child's family members that have been diagnosed with HIV/AIDS live outside of the home?

Relationship to the child

____
____
____
____

Who in your child's family has died from AIDS related causes?
Relationship to the child

____
____
____
____

Parent Illness Information:

When were you first diagnosed with HIV/AIDS? ________ (month/ year)
*If both parents, specify which date for each. ________(month/year)

Are you currently symptomatic? yes no
If so, date of onset : ______________ (month/ year)

Number of hospitalizations you've had:__________

Sibling Illness Information:

When was the child's sibling(s) first diagnosed with HIV/AIDS?________(month/ year)
*If more than one sibling, indicate relationship and current age next to date. ________(month/year)

Is the child's sibling (s) currently symptomatic? yes no
If so, date: ______________ (month/ year)

Number of hospitalizations for the child's sibling:________________

Disclosure:

Who has been told about your diagnosis?

Relationship	Who told	When were they told (month/year)
________________	______________	______________________
________________	______________	______________________
________________	______________	______________________
________________	______________	______________________

Who has been told about your child's diagnosis?

Relationship	Who told	When were they told (month/year)
________________	______________	______________________
________________	______________	______________________
________________	______________	______________________
________________	______________	______________________

Has your uninfected child asked questions about either your health or his/her siblings?

Yes No

What questions: ____
____
____

Does your uninfected child know that you or his/her sibling has an illness?

Yes No

If so, what do they know: ____
____
____

Supports:

Who do you talk with about the stressors associated with your illness and your child's?

Relationship
____
____
____

Who does your child talk with about your illness or his/her sibling's illness?

Relationship
____
____
____

Has your child received any professional counseling? Yes No

Have they been referred in the past? Yes No

Future Plans:

Who will the child live with when you are no longer able to care for him/her?

Relationship

____

Does the child have a good relationship with this person? Yes No

Does the child know of the plans for his/her placement? Yes No

Did the child get to participate in making these plans? Yes No

BACKGROUND INFORMATION
Caregiver Version

ID #:__________

Child's Gender: Male   Female

Child's Age:_________   Birthday (Month, Day, Year):_______________

Caregiver Information:

Caregiver's Gender: Male   Female

Caregiver's Race: African-American   Asian-American   Caucasian

Latin-American   Native-American   Other

Caregiver's Age:________   Caregiver's Relationship to Child:_______________

Caregiver's Marital Status: Single   Married   Separated   Divorced   Widowed

Caregiver's Number of Years of School Completed:______________

Caregiver's Occupation:________________________

Other Adult(s) Living in the Home: Yes   No

Occupation of Other Adult (s):   _________________________

Annual (combined) Income:

$5, 000 or less

$5, 000 - $10,000

$10, 000- $15,000

$15, 000 - $20, 000

$20, 000 - $30, 000

$30, 000 - $40, 000

$40, 000 - $50, 000

$50, 000 or more

Household Information:

Length of time the child has lived with you:___________________________

Length of time the child has lived in his/her current home (apartment/house):_________

How many times has the child moved during the past five years:_______________

Who else lives in your home (with the child):

Name	Age	Relationship to the child

What type of assistance do you and your family currently receive?
(Home Health Nursing, WIC, Food Stamps, etc.)

____

____

HIV/AIDS Information:

Who in your home is diagnosed with HIV/AIDS?
Relationship to the child

____
____
____
____

Which of the child's family members that have been diagnosed with HIV/AIDS live outside of the home?

Relationship to the child

____
____
____
____

Who in your child's family has died from AIDS related causes?
Relationship to the child

____
____
____
____

Parent Illness Information:

When was the child's mother first diagnosed with HIV/AIDS? ________ (month/ year)
*If both parents, specify which date for each. __________(month/year)

Is she currently symptomatic? yes no
If so, date of onset : ________________ (month/ year)

Number of hospitalizations she has had:___________

Sibling Illness Information:

When was the child's sibling(s) first diagnosed with HIV/AIDS?________(month/ year)
*If more than one sibling, indicate relationship and current age next to date. _________(month/year)

Is the child's sibling (s) currently symptomatic? yes no
If so, date: ________________ (month/ year)

Number of hospitalizations for the child's sibling:__________________

Disclosure:

Who has been told about the mother's diagnosis?

Relationship	Who told	When were they told (month/year)
________________	________________	________________________
________________	________________	________________________
________________	________________	________________________
________________	________________	________________________

Who has been told about your child's diagnosis?

Relationship	Who told	When were they told (month/year)
________________	________________	________________________
________________	________________	________________________
________________	________________	________________________
________________	________________	________________________

Has your uninfected child asked questions about either his/her mother's or sibling's health?

Yes No

What questions: ____
____
____

Does your uninfected child know that you or his/her sibling has an illness?

Yes No

If so, what do they know: ____
____
____

Supports:

Who do you talk with about the stressors associated with the mother's illness and your child's?

Relationship

____
____
____

Who does your child talk with about his/her mother's illness or his/her sibling's illness?

Relationship

____
____
____

Has your child received any professional counseling? Yes No

Have they been referred in the past? Yes No

Future Plans:

Who did the child live with when his/her mother was no longer able to care for him/her?

Relationship

____

Did the child have a good relationship with this person?	Yes	No
Did the child know of the plans for his/her placement?	Yes	No
Did the child get to participate in making these plans?	Yes	No