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THE FAMILY HEALTH PROJECT: A MULTIDISCIPLINARY LONGITUDINAL INVESTIGATION OF CHILDREN WHOSE MOTHERS ARE HIV INFECTED

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ABSTRACT. *This article introduces The Family Health Project, a multidisciplinary longitudinal investigation of children and their HIV-infected mothers and a comparison sample from the same inner-city environment. The background literature, purpose of the Project, advantages and challenges of interdisciplinary collaboration, methods of study including participant and design issues, overview of preliminary findings, clinical implications, and social policy implications are presented. Beyond introducing a new and important project examining a neglected sample in our society, the present article is intended to provide useful guidelines for other multidisciplinary large-scale clinical research projects. © 1998 Elsevier Science Ltd*

THE FAMILY Health Project is a multidisciplinary longitudinal research project designed to examine the psychosocial adjustment of children whose mothers are HIV infected. Women are one of the fastest growing groups of individuals in the HIV/AIDS epidemic, and most of these women are of childbearing age (Centers for Disease Control and Prevention, 1996). As such, this Project is an important vehicle for identifying and studying a growing but thus far neglected group of children. In addition, The Family Health Project presents one model for conducting longitudinal research with an understudied ethnic minority sample living in a high-risk environment. In doing so, we have faced challenging theoretical, empirical, and practical issues, such as col-

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laboration across disciplines and institutions, cultural sensitivity in instrument selection or development and interviewing, selection and recruitment of an appropriate comparison sample, and retention of participants across years. This article is designed to provide a rationale and overview of The Family Health Project. We introduce the Project by providing a brief background and goals and then turn our attention to the issues we faced, methods of study we employed, preliminary findings, and their implications. Our intention is to introduce the reader to an important clinical study and to provide some insights into large-scale multidisciplinary research.

BACKGROUND LITERATURE AND PURPOSE OF THE FAMILY HEALTH PROJECT

The prevalence of HIV/AIDS in women is and will continue to be a societal problem of major proportion. The Centers for Disease Control and Prevention (CDC) reported that, as of December 1996, 85,500 women had been diagnosed with AIDS. This number represents a dramatic increase (from 6% to 15%) over the past decade in the percentage of total AIDS cases represented by women (Centers for Disease Control and Prevention, 1996). It is expected that the proportion of female AIDS cases will continue to increase (Cameron, 1994). Approximately 55% of women with AIDS are African American (Centers for Disease Control and Prevention, 1996), and the majority of these women hail from economically poor urban communities. Women who are African American and living in poverty are subjected to more acute and chronic stressors than most other women, including illness and imprisonment of loved ones, changes in income, and unique parenting stresses (Belle, 1984; Forehand & Kotchick, 1996; McLanahan, 1983). Thus, many HIV-infected women must cope not only with seriously compromised health but also with the stress that accompanies living in poverty.

The vast majority of HIV-infected women are in their childbearing years (Centers for Disease Control and Prevention, 1996), and more than half of them currently have children (Chu & Diaz, 1993; Michaels & Levine, 1992; Schable et al., 1995). The impact of parental HIV/AIDS on children may range from rejection and discrimination by others to compromised parenting and, eventually, to orphanhood. In fact, by the year 2000, it has been estimated that as many as 125,000 children in the United States will have been affected and orphaned by maternal HIV (Michaels & Levine, 1992). Despite this staggering figure, there is a lack of empirical research focusing on these women and their children (Armistead & Forehand, 1995; Cameron, 1994). Because they are not infected themselves, the children of infected women are often overlooked by health care workers and researchers (Taylor-Brown, 1991). Consequently, we have very limited knowledge regarding the social, psychological, economic, and environmental factors affecting women who are HIV infected and their noninfected children. One thing that does seem clear is that, as a result of the physical and psychological sequelae of HIV infection and the stressors present in their communities of residence, the children of women who are HIV infected are likely to be at high risk for a variety of emotional and behavioral problems, as well as for engaging in the risk behaviors associated with HIV infection (Armistead & Forehand, 1995; Levine, 1995). Thus, research is needed for the development of prevention and intervention efforts targeting these children. Moreover, such research is necessary to inform public policy directed at the orphans of the HIV epidemic.

With the support of the CDC, the present investigators currently track and regularly assess one of the few, if not the only, samples of HIV-infected women and their noninfected school-age children in the United States. The families reside in inner-city New

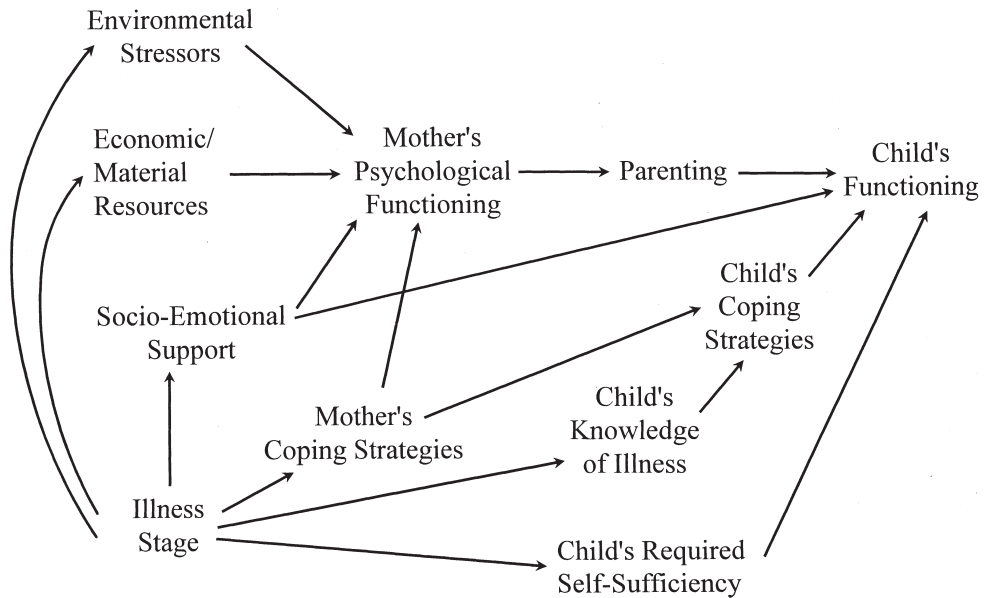


FIGURE 1. Proposed framework for factors associated with child's psychosocial adjustment.

Orleans and are African American and of low socioeconomic status. A demographically similar group of mothers who are not HIV infected and their children also are being followed. The sample is being assessed on four occasions across a 6-year time span. During this time span, approximately half of the HIV-infected women are expected to die as a result of their illness. Their children will continue to be assessed along with the primary caretaker who assumes guardianship after the mother's death.

The Family Health Project was designed from the viewpoint that familial factors play a considerable role in child psychosocial adjustment. Specifically, the central tenet of the Project is that, as the number of noninfected children with HIV-infected mothers continues to increase, it will be important to identify empirically which children are likely to need psychosocial prevention or intervention programs and which child and family process variables should be incorporated into such programs. Thus, the first question to be answered is, Do children whose mothers are HIV infected display more difficulties in psychosocial adjustment compared to children whose mothers are not HIV infected? If the answer to this question is yes, then the next question becomes, What family and child process variables serve as mechanisms in the relationship between maternal illness and child functioning? The first 3 years of The Family Health Project have primarily focused on collecting data to answer these two questions.

Figure 1 presents the general framework from which these questions are being addressed. This framework includes the broader environment in which these women live as well as the relationship between their health and their children's psychosocial adjustment. As shown in Figure 1, multiple constructs have been assessed, and hypotheses regarding their direct and/or indirect associations with child adjustment have been proposed. Thus, the primary goal of The Family Health Project is to examine associations between the mother's stage of illness, aspects of the broader environmental context (i.e., stressors she experiences, the economic or material resources that are

available to her, and socioemotional support she receives), family variables, child variables, and child adjustment. As evident in Figure 1, we view these broader environmental variables as not only influencing the family variables (e.g., mother's psychological functioning) but also being influenced by the mother's stage of illness.

Another goal of the Project is to follow these children as their mothers become increasingly ill. As HIV progresses, many of the mothers will experience increasingly negative physical and psychological states, including physical debilitation, decline in cognitive abilities, repeated hospitalizations, and depression (Taylor-Brown, 1991). Her declining physical and psychological state may impair a mother's ability to care effectively for her children, resulting in even further impairment in child adjustment (Melvin & Sherr, 1993). Specifically, the mother may find herself too ill to care for her child(ren) independently, and parenting may be further compromised by repeated hospitalizations. The living arrangement for the child may require alterations in the form of a co-caregiver moving in with the family, the family moving in with a co-caregiver, or the children being placed with another adult.

Another consideration for HIV-infected mothers as they become increasingly ill is placement for their child upon death (Armistead & Forehand, 1995). Custody planning is perhaps the most challenging task that an infected mother faces and often is made more difficult by complicated legal and social service regulations (Levine, 1995). An assessment of how, if at all, these mothers arrange for alternative care for their children, the barriers they face in doing so, and the resources necessary for facilitating this most difficult task are additional foci of The Family Health Project.

The final major goal of The Family Health Project is to follow these children after the death of their mothers to ascertain the impact of this major family event on child psychosocial functioning. As researchers (e.g., Bowlby, 1980) have long noted, the loss of a parent to death plays a significant role in childhood problems, such as depression and externalizing problems. The death of a mother, as opposed to a father, has been identified as particularly distressing to children due, at least in part, to the fact that a mother's death results in the greatest discontinuity in the life of a child (Silverman, Nickman, & Worden, 1992). In addition to the stress generally associated with maternal loss, orphans of the HIV epidemic face a number of unique stressors, including stigma, isolation, and instability, all of which have been hypothesized to be particularly traumatic for these children (Michaels & Levine, 1992). Due to its longitudinal design and follow-up with new primary caregivers, The Family Health Project has a unique opportunity to investigate the psychosocial adjustment to orphanhood of children of the HIV/AIDS epidemic.

Initially, given the lack of empirical study, descriptive data focusing on the plight of AIDS orphans are being gathered. Our particular focus is on the transitions in living placements faced by these children. It is expected that, although some children may remain in their own homes with caring family members, thereby reducing both home and school transitions and risk of separation from siblings, other children may not be permanently placed for years after their mother's death if at all (Cameron, 1994). Thus, there are a variety of transitions that a child whose mother dies from AIDS may endure, including changes in housing, neighborhoods, schools, and separations from siblings. An empirical assessment of which transitions are typically faced by these children and how the children adjust to the transitions is critical in order to understand what factors can serve a protective role for children who experience the trauma of the loss of their mother to HIV/AIDS (Levine, 1995).

Of equal or more importance to the number and types of transitions, family process variables (e.g., caregiver parenting, caregiver distress) in the new home environment

in which the child resides after maternal death must be considered. In the same way that such variables may be targets for prevention and intervention in the child's initial home environment with her or his mother, they are perhaps even more important in the new home as the child attempts to grieve the loss of her or his mother while simultaneously adjusting to a new environment. As Silverman et al. (1992) noted, death of a parent is not a single stressful event but a process to which a child must adapt; thus, many of the children in this sample and their new caregivers will be followed for 2 years beyond the death of their mothers.

It is hypothesized that transitions HIV/AIDS orphans experience and the family processes operating in the new home environment are of primary importance with regard to the child's psychosocial adjustment to orphanhood. Additionally, other factors may play a role in adjustment. More specifically, the stigma and secrecy that surround HIV may influence the orphan's psychosocial adjustment in a variety of ways. As a result of HIV-related shame and avoidance on the part of the mother and alternative caregivers, an orphan may not have the opportunity to participate in the rituals around death and/or to discuss her or his mother's illness with important adults (Zayas & Romano, 1994). This may isolate the child from receiving information from others that may assist her or him in understanding the loss of her or his mother. In conjunction with the disruption caused by transitions and the history of living with an ill mother, the aforementioned barriers to effective bereavement may result in disruption in psychosocial adjustment for the orphans of the HIV epidemic. For example, a child who is unable to mourn the death of a parent successfully is typically less prepared to accept new parental figures (Anderson, 1994). In essence, these children are a vulnerable group; thus, they require the attention of researchers who can then knowledgeably guide policy and develop prevention or intervention programs designed to prevent psychosocial difficulties.

Figure 2 presents the model serving as the framework for assessing the impact of the mother's HIV-related death on child psychosocial adjustment. As illustrated by the model, it is expected that three sets of factors will influence child adjustment: (a) those operating before the mother's death (e.g., parenting, permanency planning), (b) number of transitions in residence after her death, and (c) the new home environment. It is expected that aspects of the environmental context (i.e., environmental stressors, economic or material resources, socioemotional support) will continue to be important in the new home environment.

Prior to delineating the methods, overview of findings, and their implications, we turn our attention to the matter of interdisciplinary collaboration. Our position is that such collaboration is a necessary ingredient in large-scale projects with understudied populations that face multiple environmental stressors. Thus, it is an important aspect of this article that deserves attention.

MULTIDISCIPLINARY COLLABORATION: ADVANTAGES AND CHALLENGES

This Project is reflective of the trend toward multidisciplinary collaboration in clinical research. The principal investigators of the study include two family or child clinical psychologists, a medical sociologist, and a doctoral level specialist in medical social work. Additional investigators on the Project include a developmental psychologist, a medical doctor, and a social or health psychologist. The latter investigator is a representative of the Project's funding agency, the CDC. Individuals in this agency have served as active collaborators in the process of conceptualization and administration of the Project. Furthermore,

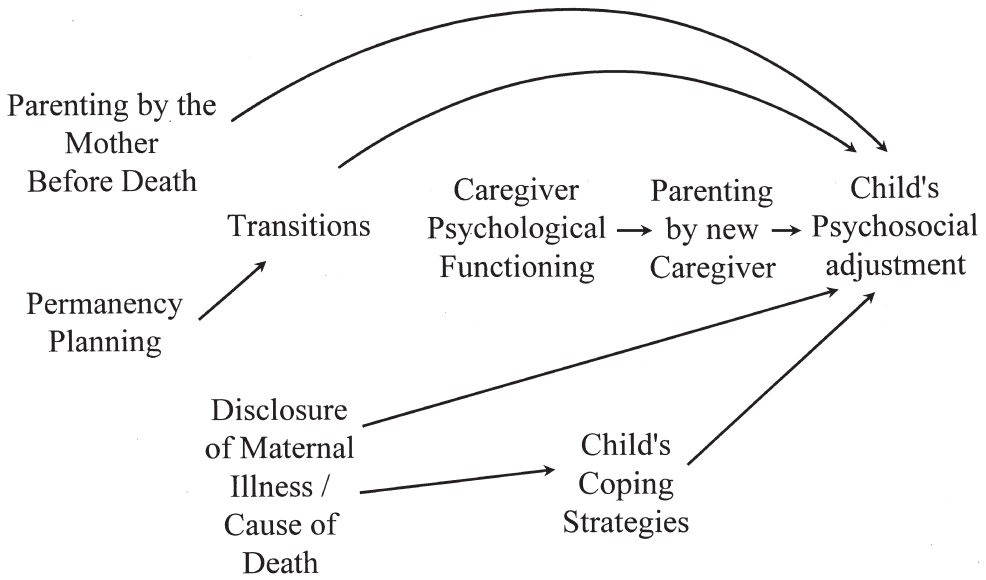


FIGURE 2. Proposed framework for factors associated with child's psychosocial adjustment after mother's death.

the CDC representative functioned as the primary liaison between the principal investigators and the CDC by attending the major planning and administrative meetings during the first 2 years of the study. This active role has been invaluable not only due to the unique contributions of the individual but also because it facilitated communication between CDC administrators and the principal investigators, thus minimizing misunderstandings and holdups in the funding agency-researcher relationship.

The multidisciplinary approach to clinical research has several benefits as well as some challenges. Multidisciplinary collaboration may not only have conceptual advantages but may also serve a practical function in utilizing research results. As the focus has intensified on the practical applications of clinical research, it has become clear that narrow studies of isolated clinical issues have limited relevance for the provision of clinical services. Instead, a holistic research approach may contribute more to our understanding of clinical phenomena, as well as have more direct implications for clinical treatment and public policy. A holistic research approach incorporates the study of contextual factors that are both proximal and distal to the clinical phenomenon under investigation, ranging from intrapsychic to interpersonal to sociological influences. For instance, in the current Project, we have attempted to optimize the thorough and sensitive assessment and interpretation of contextual factors relevant to African American, urban-dwelling women and their children who are coping with multiple stressors, such as poverty and residence in dangerous environments, in addition to HIV (in half of the cases). To accomplish these tasks, as previously noted, our work is informed by the unique perspectives of specialists in multiple areas, including medical sociology, social work, public health, health psychology, developmental psychology, clinical psychology, family psychology, and medicine, as well as women and children residing in impoverished, urban environments.

The benefits of multidisciplinary collaboration are accompanied by some unique challenges that occur as professionals with independent visions and agendas work to-

gether. Despite the common goal of collaborators to conduct high-quality research with meaningful implications, the process of collaboration can be complicated. As we have found, the number and complexity of conceptual, methodological, practical, and interpretive issues involved in conducting research increase exponentially when multiple professionals from different schools of thought are contributing to the process. Throughout the course of planning and implementing The Family Health Project, several administrative practices have emerged to facilitate this process. Although our methods of administration are not assumed to be appropriate for all collaborative efforts, it is hoped that the following brief delineation of our practices may be useful to others who begin similar undertakings in the future.

Perhaps the most fundamental characteristic of our administrative structure is that, although our Project has four principal investigators and multiple other investigators, it has one primary principal investigator. It is the role of this person to serve as the "team captain" by conducting group meetings, serving as the main liaison with the funding agency, making final decisions regarding administration and publication issues, and generally assuming ultimate leadership of the Project. We believe that this structure has contributed to the efficiency of communication and decision making among contributors to the Project.

A strong emphasis has been placed on the communication of clear and structured expectations among the collaborators of The Family Health Project. Given that multiple individuals in different geographical locations are involved in data collection and publication, several procedures have been implemented to ensure that data are maintained and utilized in as consistent and up to date manner as possible across sites of data analysis. First, routine, scheduled (e.g., quarterly) updates and exchanges of data are conducted by a data manager in order to maximize the consistency of working data across collaborators. Furthermore, a Construct Catalog serves as a cumulative record in which data constructs are theoretically described and mathematically defined for future reference and use.

Clearly, the primary goal of The Family Health Project is to build a foundation of information from our empirical observations that can ultimately serve the population being studied. This information may inform specific clinical interventions as well as public policy. Therefore, it is a high priority to report the results of our research in a timely manner and in a variety of venues. For this purpose, a Publication Board was created to set goals for the dissemination of information, to ensure the quality and conceptual cohesion of products, to monitor the efficiency of the process, and to make decisions regarding authorship. This system revolves around two types of published products. *Primary publications* are those that address the central constructs and aims of the Project, and they include all principal investigators as authors. *Specialty publications* address questions that are not central issues to the Project. Authors of a specialty publication include only those individuals who make specific contributions to the conceptualization of the article, although the other collaborators are acknowledged as "The Family Health Project Research Group" with individual names footnoted.

With our system, an individual collaborator assumes responsibility for one or more topics or ideas that she or he would like to develop for an article. A brief proposal is submitted to the Publication Board, and, if accepted, the author is allotted 1 year in which to produce the manuscript. If the 1-year deadline is not met, the individual's "rights" to the topic are forfeited, and another author may assume responsibility for pursuing the idea. This time line for article completion is useful because it provides a mechanism for accountability among collaborators and ensures that a topic area is not "lost" if an individual collaborator

rator is not able reach The Family Health Project's goal for efficient information dissemination. When a manuscript is completed, it is submitted to the Publication Board, which essentially serves as a peer review committee. The Publication Board either acknowledges the manuscript's readiness to be submitted for publication or suggests revisions regarding issues that are considered to be fundamentally problematic.

We strongly advocate a multidisciplinary approach! One discipline (e.g., psychology) is simply not adequate to study the complex problems facing our society. We now turn to the methods we are employing in The Family Health Project and some of the issues we faced when determining our methodology and when selecting, recruiting, and retaining participants.

METHOD

Participant Selection

The mothers and children involved in this research Project are central to its continuation. There are many difficulties inherent in maintaining a longitudinal sample, including attrition. Although some researchers address the problem of attrition by recruiting large samples with the expectation of participant loss, this method was neither possible nor desired within the current study. Instead, we have chosen to identify the number of participants we believed we could realistically follow over 6 years and then implement tracking and retention procedures to maintain the vast majority of the sample.

We chose to focus exclusively on African American mothers and children for a number of reasons. As previously stated, the majority of women who are HIV infected (55%) are African American (Centers for Disease Control and Prevention, 1996), yet this population has received little attention in the literature. Additionally, the locale of the study (New Orleans) is populated primarily by African Americans, and the target clinics from which the HIV-infected sample was recruited mostly serve African American patients. Thus, to maintain consistency in the sample and to address important questions in an understudied population, African American families were recruited for the present investigation.

The children in our study were not HIV infected. We chose to focus on these children because most offspring of HIV-infected women are not infected. The children ranged in age from 6 to 11 years at initial recruitment. We selected this age range for three reasons: (a) It is difficult to assess children younger than 6 years via self-report measures, (b) research suggests that significant behavior change occurs with the transition to adolescence, and (c) family stress may differentially impact the behavior of preadolescents versus adolescents (e.g., Compas et al., 1994; Forehand, Neighbors, & Wierson, 1991; Links, Boyle, & Offord, 1989). Following the children longitudinally will eventually require consideration of issues associated with the transition to adolescence; however, our position was that an initial assessment of a previously unstudied family stressor should occur in a restricted age range representing one developmental stage.

Recruitment and retention issues were identified as being of paramount importance and were carefully considered. Recruitment of mothers who are HIV infected was expected to be difficult because of the stigmatization associated with HIV/AIDS and the resultant desired privacy. Furthermore, because of the transitions of the child upon her or his mother's death, retention was an important issue. Throughout the Project, these issues were addressed, in part, by stressing participant confidentiality, respect, and appreciation.

In selecting our HIV-infected sample, we recruited only those women whose CD4 count (a prognostic value for predicting the development of AIDS in people who are

HIV infected) fell below 600, indicating a relatively advanced stage of infection. To remove the potential confounding effects of intravenous drug use and because of the difficulty of longitudinally following drug users, we elected to restrict our sample to women reporting no intravenous drug use during the 6 months prior to recruitment.

Several issues emerged in recruitment of the comparison sample. First, recruiting a sample that would be comparable to the HIV-infected sample on all characteristics except HIV infection was a challenging task. As explained more fully later in this article, we recruited the comparison sample from the schools that served the children of HIV-infected women. Second, as the noninfected women and their children were drawn from the same neighborhoods as the HIV-infected sample, there was concern about violation of confidentiality for the HIV-infected women. Therefore, the Project was explained as focusing on family health problems. Third, we faced the issue of how to determine if the women in the comparison sample were HIV infected. It was decided that testing was not feasible due to the cost and invasiveness of such procedures, as well as having to explain the purpose of the testing. Recent testing of community samples similar to our comparison group indicates that less than 1% of the population self-identify as noninfected when they actually are HIV infected (J. Moore, personal communication, 1996). Therefore, we asked women in the comparison sample to list all of their chronic illnesses with the intention of eliminating any who disclosed being HIV infected. None of the women indicated they were infected; therefore, none had to be eliminated from the Project. We currently are facing the issue of how to deal with a comparison sample woman who is diagnosed with HIV during the course of the study. Issues regarding participants are ongoing and challenging!

Participants

Participants in The Family Health Project, at first assessment, included 107 HIV-infected women and one of their noninfected children, and 150 women who did not self-identify as being HIV infected (subsequently referred to as noninfected) and one of their noninfected children. All participants are African American and were recruited from Orleans Parish, Louisiana, which represents the inner-city area of New Orleans. Information on the families gathered from the first assessment indicates that the two groups are closely matched, in that we found no differences across the groups on most of the demographic variables (e.g., child age and gender, mother's educational level and marital status, and family income). Across the sample, approximately 30% of the mothers are employed, 15% are currently married, 61% have never married, 56% have completed high school, and 75% have annual household incomes of \$10,000 or less.

To be eligible to participate in the study, mothers were required to be between 18 and 45 years of age, have at least one biological noninfected child between 6 and 11 years of age, report no use of intravenous drugs in the past 6 months, and report living with the identified target child. Inclusion criteria for the target child consisted of being identified by the mother as not being HIV infected, attending regular (i.e., not special education) classes in school, and living with her or his mother. If more than one child in a family was eligible to participate, the target child was randomly selected.

As already noted, an additional criterion for women in the HIV-infected sample was having a CD4 count under 600 at the time of entry into the Project. The disease status of the HIV-infected women was classified from medical records according to CDC HIV staging procedures. At the initial assessment, 49%, 23%, and 28% of the HIV-infected women were asymptomatic, symptomatic, and had AIDS, respectively. After 3 years, 21 of the HIV-infected mothers within this sample have died from the AIDS vi-

rus. Nineteen of the children whose mothers have died currently reside with a grandmother and continue to participate in our study.

Recruitment

Participants in the HIV-infected group were recruited across 2 years from the primary public HIV clinic in the city of New Orleans (93%) and from the local private practices of physicians treating HIV-infected females (7%). A physician identified the potential pool of participants based on the criteria described before. Upon visiting the physician for their regularly scheduled checkup, women who met the inclusion criteria were approached by a Project staff member who explained the study, confirmed eligibility, and obtained consent from each woman. A time for data collection was then scheduled. It should be noted that less than 15% of mothers initially reported that they had disclosed their HIV status to the participating child. To keep this information confidential, interviewers were trained not to ask children directly about their mother's HIV status, and each mother was assured that information regarding her health would not be disclosed to her child during interviewing. Before each interview, the child's assent was solicited, and the study was explained as examining the effects of family health problems on mother-child relationships. All mothers and children were assured that all responses given during data collection were confidential except for any disclosure of child abuse or neglect and potential homicidal or suicidal behavior.

A stratified random sample of mothers who subsequently self-identified as not being HIV infected was drawn from schools serving the zip code areas from which the majority of the HIV-infected sample reside. An administrator within the school system was identified as a liaison person who assisted the Project staff in contacting and gaining cooperation from target schools. Mother-child dyads were recruited through five of the six public schools serving the targeted zip code areas (i.e., one principal opted not to participate) in an attempt to reduce bias and allow for maximized matching of community environment and socioeconomic status between the groups. The noninfected sample was stratified based on the gender and age of the child, as well as the school attended, and was drawn in two equal waves that spanned 2 school years. Letters that briefly described the study and invited families to participate were sent to all eligible mothers. In each of the two waves of recruitment, the sample consisted of the first 15 women from each school to indicate interest in participation via the timely return of a reply card. Women in the noninfected sample identified themselves as seronegative in the first assessment interview by verbally indicating that they did not have HIV. As was noted earlier, previous research with similar samples has indicated that the percentage of women who self-identify as non-HIV-infected but actually are HIV infected is less than 1% (J. Moore, personal communication, 1996).

For the HIV-infected group, 95% of the mothers who were approached agreed to participate and completed the first assessment. Of the noninfected mothers, 94% returned their card indicating an interest in participating. Among those who were selected for participation based on first return of their cards, 100% did participate.

Retention

Two assessments occurred over the course of the first 3 years of the Project. Of the original sample, 96% participated in Assessment 2, which occurred 12–14 months after Assessment 1. Of the 21 mothers who died, 19 of their children have been successfully retained in the sample with the new caregiver.

Various procedures have been utilized to retain the current sample successfully. The first strategy involves obtaining the names of several contact people who always will know the family's location. Additionally, small gifts (e.g., children's toys) as well as a payment of \$50 per interview are given at each interview, and a taxicab is sent to transport families without personal means of transportation to and from the data collection sessions. Furthermore, holiday and birthday cards are sent to each mother and child participant. For children whose mothers have died, the death of the mother is identified through clinic records, contact with clinic personnel, return of greeting cards, and obituaries. Contact persons for the family are immediately contacted, and placement of the child is determined. To allow for initial alleviation of grief, the new caregiver (usually a relative of the deceased mother) is not contacted regarding participation in the Project until 6 months after the death of the mother. However, during this 6-month period, greeting cards are sent to the children, which allows for continued tracking. Subsequent to the new caregiver's attendance at the first data collection session, she or he begins receiving greeting cards as well.

Cultural Sensitivity: Instrument Development and Interviewer Characteristics

African Americans have been neglected in the social science literature, and the majority of measures existing prior to the onset of The Family Health Project have been standardized on White, middle-class individuals. In their existing format, most of the available measures were deemed inappropriate for use in The Family Health Project, given the demographic differences between the target population and the standardization samples. Thus, to utilize only measures that were culturally sensitive and otherwise appropriate for the target population, several steps were taken.

First, based on the available literature and related theory, an outline of the constructs to be evaluated was created. This outline was revised and expanded based on a focus group conducted with African American women who were HIV infected. The focus group was assembled at a support organization for women living with HIV. Ten HIV-infected women with children participated and were paid \$30 each in compensation for their time and effort. The women were given an overview of the Project and asked to provide their assistance as experts in the area of African American families coping with maternal HIV infection. Some of the constructs most germane to the purposes of the Project, as well as who reported the measures of each construct, are listed in Table 1.

Following the focus group, measures of the constructs were selected or created and pilot tested with a group of African American women who matched the demographic characteristics of the study sample and had children in the same age range. These women were not known to be HIV infected.

Next, two more focus groups, both consisting of HIV-infected African American women residing in New Orleans, were conducted with the goals of further refining constructs and improving the sensitivity of the measures. These groups also provided information regarding recruitment and attrition issues (e.g., what interviewer characteristics were important and how mothers could be made most comfortable in agreeing to let their children participate). The first of these two groups consisted of five women, and the second group contained 10 women. Again, each woman was paid \$30 for her time and effort. All focus groups were cofacilitated by a clinical psychologist and a sociologist or social worker.

Subsequent to the focus groups, a meeting of selected members of The Family Health Project and a grant consultant with expertise in projects focusing on African American families was held to integrate information obtained during focus groups, pi-

TABLE 1. General Areas Assessed

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1. Demographic information^a
 2. Composition of household^a
 3. Disclosure of HIV infection to child and others^b
 4. Permanency planning for child^c
 5. Number and types of living transitions experienced by child^a
 6. Family economic resources^c
 7. Use of social services^a
 8. Environmental stressors^a
 9. Socioemotional support^a
 10. Religious beliefs and behavior^a
 11. Mother psychological adjustment^d
 12. Parenting^a
 13. Coping strategies^a
 14. Knowledge of illness^a
 15. Child psychosocial adjustment
 - a. Externalizing problems^c
 - b. Internalizing problems^c
 - c. Prosocial competence^a
 - d. Cognitive competence^{a,f}
 16. Mother's medical records^g
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^aMother and child report.

^bMother report, HIV-infected group only.

^cMother report.

^dMother report of her adjustment and interviewer rating.

^eMother report, child report, interviewer rating.

^fWide Range Achievement Test—Revised.

^gHIV-infected group only.

loting, and previous projects with African American families. Based on this meeting, measures were further revised and then piloted again with a number of African American women (not known to be infected) and their children. Finally, all measures were field tested with HIV-infected African American women who resided in New Orleans.

Regarding interviewer characteristics, the only preferences expressed by focus group participants and pilot participants were that the persons be culturally sensitive, have good listening skills, and be nonjudgmental. Mothers were specifically asked at each of the three focus groups, and during individual piloting, their opinions regarding the impact of interviewers' gender and ethnicity. Mothers indicated that neither interviewer ethnicity nor gender was an issue for them in terms of their willingness to self-disclose, their general comfort level, and willingness to return for subsequent assessments. Thus, ethnicity was not a basis for selection of interviewers. Because the psychosocial interview inquires about extremely personal information (e.g., history of rape and sexual abuse), only female interviewers were used in this interview with mothers. With this exception, gender was not a consideration in selecting and assigning interviewers.

Instrument Selection

As has been noted, constructs germane to the Project were delineated (see Table 1), and then measures were selected to assess these constructs. When possible, instruments standardized with samples that included individuals similar to those we are

studying were selected for use. When such instruments were not available, we selected instruments that had been used successfully with samples demographically different from the participants in the current Project (e.g., Whites). Finally, for some constructs where measures did not exist, we developed our own questions.

Prior to data analyses, we developed the following format for determining the preliminary analyses that would be conducted with each instrument. The steps followed depended on whether the instrument had been utilized with samples similar to the one we were studying. For instruments not used with similar samples, or designed by our staff, confirmatory factor analysis (with retention of items loading .40 and higher) was conducted. Subsequently, an alpha coefficient for retained items was calculated. For instruments with standardization data with samples similar to the current one, only an alpha coefficient was calculated. Only instruments with an alpha coefficient of .70 or higher were retained.

Further information about the exact measures used can be obtained from the corresponding author, Rex Forehand.

Interviewers and Interviewer Training

Because two types of interviews were administered to each participant (sociodemographic and psychosocial interviews), two sets of interviewers were utilized. Interviewers in both sets interviewed approximately equal numbers of participants from the HIV-infected and noninfected groups. The first set consisted of individuals (PhD medical sociologists, licensed social workers, and graduate students in public health) from the New Orleans area who were employed by either Louisiana State University Medical School or Tulane University. All five individuals had extensive experience working with inner-city African American HIV-infected and noninfected women. The second set of interviewers consisted of clinical psychology graduate students and PhD-licensed clinical psychologists from the University of Georgia. All of these individuals had extensive experience in interviewing and assessing adults and/or children concerning their individual and interpersonal psychosocial functioning.

All interviewers were thoroughly trained in the use of their respective instruments during the exploratory and pilot phases of the Project with the goals of ensuring cross-interviewer reliability and enhancing sensitivity to cultural and socioeconomic status differences. During the training period, interviewers piloted the instrument in rotating pairs to maximize interinterviewer reliability, reduce bias, and standardize presentation of questions across interviewers. Intensive training of new interviewers occurs at least once a year. As noted earlier, confidentiality, respect, appreciation for participation, good listening skills, and being nonjudgmental are an integral part of the training.

Procedure

Four assessments, each consisting of sociodemographic and psychosocial interviews, are conducted for each mother/caregiver-child dyad. Between Assessments 1 and 2, a 12- to 14-month interval is used; between Assessments 2 and 3, an 18- to 20-month interval is used; and between Assessments 3 and 4, a 16- to 18-month interval is utilized. The time between assessments after Assessment 2 was extended to address more adequately the primary concerns of the Project: (a) the psychosocial adjustment of the children as their mothers become progressively more ill and (b) the psychosocial adjustment of the children beyond their mother's death. By using the longer time inter-

val, a more sensitive test of each question can occur as mothers become more ill and more mothers die. The set interval between assessments is excepted in the case where mothers die, as the first assessment with the new caregiver occurs 6 months after her death. A 6-month interval was selected to allow the child to begin to adjust to her or his mother's death and her or his new living arrangement. An 18- to 20-month interval is utilized between the first and second assessments with the caregiver.

For each assessment, the mother/caregiver-child dyad is given two appointments for interviews that take place at either Louisiana State University Medical Center (for the maternal HIV-infected group) or the child's school (for the maternal noninfected group). Women and children are interviewed separately at each assessment. It is necessary to divide each assessment into two interviews (a sociodemographic interview and a psychosocial interview), separated by 2–14 days, for two reasons. First, the large amount of information gathered at each assessment prohibits a single interview session. Second, the sociodemographic interview is designed to obtain some information regarding emotionally laden topics such as permanency planning, transitions, and disclosure. We believe that mothers and children may need time to recuperate emotionally from this interview before completing the psychosocial interview.

To hold constant the impact that the child's attendance at school may have on the interaction patterns between mother or caregiver and child, all assessments for both groups of families are conducted while the child's school is in session.

On arrival, mothers or caregivers and children are consented, reminded of issues related to confidentiality, and separately administered the assessment interview. Both the mother's or caregiver's and child's sociodemographic interviews last approximately 1 hr. The psychosocial interview lasts approximately 2 hr for mothers or caregivers and 1 hr for children. All materials, including the consent forms, are administered orally to participants. Moreover, in the psychosocial interview, cue cards containing the descriptors (e.g., "not true," "sometimes true," and "often true"), their corresponding numeric values, and pictorial representations of the descriptors are used. After each interview, the mother or caregiver is paid \$50 to compensate for her time and effort, and children are allowed to choose a small toy.

A medical chart review and abstraction is completed for each HIV-infected mother after each of the four assessments. A range of medical data, including CD4 counts, CD8 counts, and opportunistic diseases, is collected. Additionally, academic grades, conduct grades, and attendance records are obtained from the school records of all participating children.

OVERVIEW OF FINDINGS AND CURRENT PROJECTS

Our strategy for data analysis and dissemination can be summarized as follows: First, we examine if children's psychosocial adjustment (i.e., internalizing problems, externalizing problems, cognitive competence, prosocial competence) differs between children whose mothers are HIV infected versus those whose mothers are not HIV infected. This comparison is made across repeated assessments as mothers become progressively more ill. Second, we identify processes that may account for psychosocial adjustment differences between these two groups of children. For example, the roles of maternal distress, parenting, and stage of illness in child psychosocial adjustment in families where the mother is HIV infected are being examined cross-sectionally, with additional longitudinal analyses planned. We also have the opportunity to examine the child's psychosocial adjustment after the death of the mother and the factors, in-

cluding the roles of transitions in living arrangements, family process variables (e.g., caregiver parenting), and utilization of social services, that relate to such adjustment. The final output of our Project includes recommendations for prevention and intervention programs for these children, which are based on our examination of family processes associated with child psychosocial adjustment.

To this point, our data analyses suggest the following. First, children of mothers who are HIV infected are reported by mothers and/or children to demonstrate more internalizing problems (e.g., anxiety, depression), externalizing problems (e.g., aggression), and lower levels of social and cognitive competence than children of noninfected mothers (Forehand et al., 1998). Our early examination of environmental and family process variables that may play a role in these differences (and that may be amenable to prevention efforts) suggests that individual child variables (e.g., understanding of illness) and family process variables (e.g., parenting) are related to the psychosocial adjustment of children whose mothers are HIV infected (Armistead et al., in press; Kotchick et al., 1997).

Several additional family process variables beyond parenting that may assist in the explanation of the differences in psychosocial functioning between children whose mothers are and are not HIV infected are currently being examined. Studies are under way that examine the following: (a) the role of maternal depression in mediating the relationship between maternal HIV infection and child depression, (b) the relation of stage of maternal illness (asymptomatic, symptomatic, AIDS) to child psychosocial adjustment, (c) the manner in which family configuration (e.g., single mothers or extended family relations living in the home) relates to child psychosocial functioning and permanency planning (i.e., arranging for the care of children after the mother is deceased) among HIV-infected women, (d) the mother's disclosure of her HIV to others (e.g., child, friends, neighbors, extended family), (e) the cumulative and independent impact of various risk factors (e.g., a child's stressful life events, maternal HIV status, perceived economic stress) and protective factors (e.g., family routines or parental monitoring) on child psychosocial functioning, (f) the manner in which various sources of social support (e.g., friends, neighbors, family members) for both mothers and children relate to maternal and child psychosocial functioning, and (g) factors (e.g., family structure, maternal process, and maternal-child process variables) that contribute to resiliency in children living in high-risk environments whose mothers are HIV infected.

Once differences in family process and other variables between families with and without an HIV-infected mother have been ascertained, structural equation modeling in which proposed relationships among variables, with child psychosocial adjustment as the outcome variable, can be examined. For example, the variables proposed in the models presented in Figures 1 and 2 (see the section on background and purpose at the beginning of this article) are examined and, within limitations imposed by sample size, incorporated into regression equations.

Although the psychosocial adjustment of children in the sample serves as the primary dependent variable of interest, the data are also used to investigate psychosocial outcomes for the women in the study. Two such studies are currently being conducted. The first examines the physical and mental health consequences of criminal victimization (e.g., physical and/or sexual assault). The second study examines the relationships among optimism, coping, and psychosocial functioning. Both studies make comparisons between women who are and are not HIV infected.

As research with inner-city African American samples is scarce, the data are also used to examine variables of specific interest in this population, independent of the

participants' HIV status. Those currently being examined include somatization in women and the psychosocial correlates of childhood depression.

PREVENTION AND INTERVENTION IMPLICATIONS

Delineation of differences in functioning between (a) HIV-infected women and their children and (b) a community control sample may serve to illuminate areas of psychosocial functioning to address in prevention and intervention programs. As Youngstrom (1993) noted, a major role for behavioral scientists in the AIDS epidemic is "in helping the infected individuals and their family members cope with the disease" (p. 25). This can be accomplished by assessing the experiences of persons infected with HIV and developing specialized intervention plans to address problems related to their disease (Youngstrom, 1993). For example, in an examination of parenting behavior and its relation to child psychosocial adjustment, Kotchick et al. (1997) found that the same parenting skills were associated with positive child outcomes across the HIV-infected and noninfected groups. In addition, HIV-infected mothers reported lower levels of effective parenting behaviors (e.g., monitoring) than mothers in the control sample. Together, these findings have two important implications for clinical intervention. First, the same parenting skills should be emphasized in programs designed to enhance parenting, regardless of maternal HIV status. Second, because mothers who are HIV infected demonstrate lower levels of specific parenting efforts, parenting interventions may need to be more intensive for mothers who are HIV infected than for other mothers.

The research studies in progress that address other differences between families affected by maternal HIV infection and those serving as community controls may highlight additional targets for intervention. For example, if HIV-infected women report lower levels of social and emotional support, programs targeting the expansion of their support networks or the involvement of relatives and others into their lives can be developed. Likewise, if the children of women who are HIV infected are found to demonstrate deficiencies in coping skills, our findings can inform the development of appropriate and sensitive coping skills training programs.

Beyond prevention and intervention implications derived from the comparison across groups at one point in time, assessing both groups multiple times will provide valuable information regarding the relationship between disease progression and psychosocial functioning. For example, differences between groups may not emerge on variables such as coping skills until the later stages of HIV disease. Such information will help identify when prevention and intervention programs are likely to have their greatest benefit.

Equally important are the implications resulting from the pathways in Figure 1. By examining these pathways, community, maternal, and child variables that forecast subsequent child adjustment can be identified. Identification of contributors to child adjustment will allow the field to move beyond focusing exclusively on deficits or excesses in the sample to an understanding of how difficulties in child functioning emerge, as well as which constructs should be addressed in our prevention and intervention efforts. For example, HIV-infected mothers demonstrate more compromised parenting practices than controls; however, if such practices were found to be unrelated to child functioning, then their importance as components in prevention and intervention strategies would be diminished.

Prevention and intervention implications of all HIV-related research must be derived, considered, and implemented with an appreciation and understanding of the

various cultural, ethnic, and socioeconomic subgroups that exist in contemporary American society. Prevention and intervention efforts must be sensitive to these group differences if they are to be effective. As such, programs need to be developed and tailored to the needs and characteristics of a particular group. The Family Health Project focuses on African American families residing in low-income urban environments. For this sample, an illness such as HIV infection, which does not typically have short-term health implications, may be of little concern relative to other environmental stressors (e.g., substandard housing, safety, etc.). Thus, for their messages to be heard, prevention and intervention efforts specific to living with HIV may also need to address those other needs that may be of more pressing importance. Furthermore, as proposed by DelaConcela (1989) and Amaro (1988), these efforts will need to be integrated into the local community, be linguistically and educational-level appropriate, be sensitive to the social realities of the targeted population, and be coordinated with social service programs. Our hope and intention is to utilize our research findings to provide recommendations for the development of prevention or intervention programs that conform to these requirements.

POLICY IMPLICATIONS

The initial efforts and responses of researchers and policy makers to the AIDS epidemic revolved around those infected and more recently around those who care for individuals with AIDS. However, as heterosexual women, and particularly African American women, continue to be overrepresented among HIV-infected individuals, their children emerge as a group that will require increasingly more attention from legislators and policy makers. Presently, we do not know who helps to care for these children as their mothers become increasingly ill and whether orphans of the AIDS epidemic stay within their extended families after their mother's death. Our findings will shed light on these issues. We believe many of these children will require governmental assistance with housing. When this occurs, permanent placements for older children, such as those we are studying, can be very difficult. These difficulties may necessitate extended stays in either foster or group homes, both of which are very costly for the government and are not necessarily the best environment for children. Unfortunately, information is not currently available for policy makers to utilize in developing social policies.

The Family Health Project will provide timely and crucial information for decision makers to employ when developing and evaluating social and family policies. It is hoped that these policies will help these women in their role as parents and will ease their children's transition from mother to caregiver. The foster care system is already overwhelmed, and, if current trends in the AIDS epidemic continue, the number of children who will need placement will continue to grow (Cameron, 1994). The results from The Family Health Project should provide empirical data to augment policy makers' ability to make informed and fact-based decisions.

CONCLUSIONS

Large-scale multidisciplinary longitudinal research examining difficult societal issues (e.g., HIV/AIDS) in marginalized segments of our population is difficult. We have found our best intentions, traditional ways of thinking about issues, and concern for individuals facing difficult issues to be challenged repeatedly. Questioning, emoting, and re-energizing ourselves have become key aspects of the human side of our objective, scientific research

efforts. However, the early payoffs have been immensely valuable. We have had the pleasure and honor of meeting strong women and children who challenge our world views and inspire us with their courage. We have had the chance to collect and disseminate important information that, it is hoped, will facilitate our understanding of families under stress, lead to the development of prevention and intervention programs for children in these families, and provide data for effective social policy implementation.

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