

CHAPTER 4

METHODOLOGY

This chapter will examine the methodology of the proposed study to ensure that its design is appropriate to 1) provide answers to the research questions posed, and 2) to adequately control for variance (Kerlinger, 1992). To that end, the research design of the study will be explained, including the location of the study, the relevance of the location, and the criteria utilized to select study subjects. A power analysis will also be conducted to ascertain the appropriate sample size to address the questions under investigation. The method of data collection and operationalization of the variables will be discussed, with the relevant reliability and validity of the measures examined. Lastly, the proposed plan for data analysis will be put forward, as well as the utilization of specific diagnostic test and missing values analysis to ensure data integrity. Through this examination of the research plan, the two criteria posited by Kerlinger will be met and a higher level of confidence in the findings will result.

RESEARCH DESIGN

Since the early 1980s, child welfare has been impacted by the growing numbers of children infected/affected by HIV/AIDS. In Maryland, this crisis began in the early 1990's with the Pediatric HIV/AIDS Health Care Demonstration Projects reporting 99 children at that time infected with AIDS and growing annually (Groze, Haines-Simeon, & Persse, 1993). This resulted in over 10 children with, or at-risk of, HIV infection entering the foster care system each year in Maryland. To help alleviate this epidemic, a federal demonstration project was initiated in the state of Maryland that was funded by the Abandoned Infants Assistance Act of 1988 (Groza et al., 1997). The Family-

Centered, Community-Based Transagency Model for Children Affected by HIV/AIDS (FaCT Project) was based on a similar program serving HIV infected/affected children in Boston (Groza et al.). This exploratory research project was designed to promote family permanency through the provision of case management and advocacy services (Groze, Haines-Simeon & Persse, 1993).

The project was a statewide initiative administered by the state public child welfare system. Case management services were offered to families to assist them in securing services to maintain the family structure. Services included, but were not limited to, arranging for medical assistance, respite care, family support groups, transportation and financial support (Groza et al., 1997).

Utilizing the data gathered through the FaCT program, this study will conduct an exploratory non-experimental cross-sectional study utilizing a convenience sample of caregivers of children infected and/or affected by HIV/AIDS. Caregivers will be categorized as either birth mothers, or other caregivers (birth fathers, other relatives, and foster or adoptive parents). The responses of these two groups to questions on stressors, sources of social support and stress-arousal levels will be analyzed in both bivariate and multivariate models.

Sample Criteria

FaCT Program Inclusion Criteria. Families could be referred to the FaCT program through public and private social service agencies, as well as being self-referred. The protocol for program participation included meeting any one of the following criteria: having a child who was born drug affected, having a child referred as at-risk due to parental substance abuse, having a child born HIV positive, or having a child referred

as at-risk due to the mother's HIV positive diagnosis (Groze, Haines-Simeon & Persse, 1993). Birth, foster, adoptive parents and other caregivers were all eligible to participate, as inclusion was child focused. From the initial family meeting an index child was targeted. For families with only one child, the index child was determined de facto. However, for those families with more than one child meeting the eligibility criteria, the targeted child was the most severely infected/affected, *or*, if two or more children were equally infected/affected, the youngest child, who was considered most at-risk, was chosen.

This selection criteria resulted in 229 birth families (includes mothers, fathers, grandmothers and other relatives) 56 foster families (includes kin and non-kin foster parents) and 7 adoptive families participating in the project from 1991-1997 (Groza et al., 1997).

This Study's Inclusion Criteria. The sample of caregivers for this study will be made up of persons meeting the following criteria:

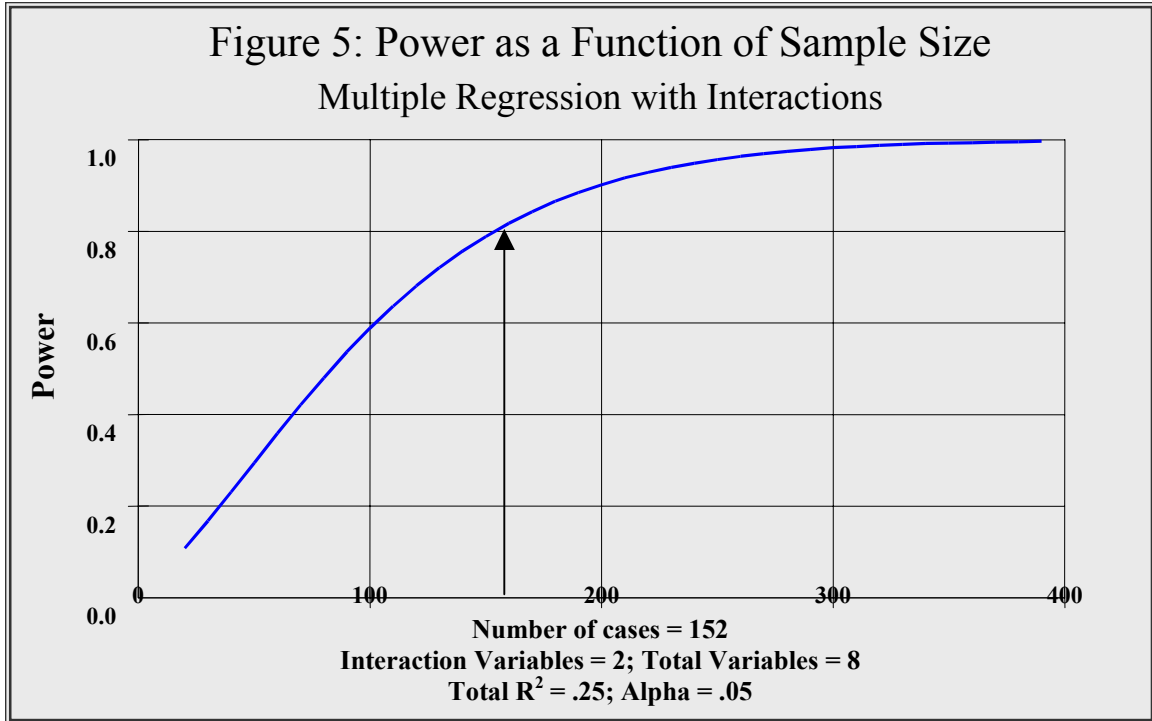
- The caregiver must have been caring for a child meeting the eligibility requirements for the FaCT program at some point during the years 1991-1997.
- The caregiver must have physical custody of the child at the time of inquiry.
- The caregiver must have been caring specifically for a child who was infected and/or affected by HIV/AIDS. This excludes those caregivers caring for children affected only by substance abuse.
- The child must have been determined to be HIV negative or HIV positive. This excludes those children with an undetermined diagnostic status.

Power Analysis/Sample Size

An estimate of sample size was determined through the use of the statistical procedure of a power analysis. This procedure was developed by J. Cohen (1988) to help researchers reduce the risk of a Type II error, the acceptance of a null hypothesis that is actually false. Each of the regression equations calculated in the final model will include 8 independent variables in the set of interest (three personal factors, two stressor variables, one conditioning variable, and two multiplicative interaction variables [for example, see Table 8 below]), which will yield a total R^2 of .25. The adjusted R^2 score used in this calculation is significantly lower than a score of .37 found in a similar sample of caregivers (Hughes & Caliandro, 1996). The lower score was used to determine the most conservative score for a reasonable estimate.

Table 8: Variables used in Regression Equation to Examine the Effect of Formal Support Services on Stress Levels	
<i>Personal Factors (3)</i>	
	Educational Level
	Another Child Ill?
	Caregiver's Health Limits
<i>Stressors (2)</i>	
	Index Child's Reported Health Status
	Level of Illness Management Tasks
<i>Conditioning Variables (1)</i>	
	Formal Service Supports
<i>Multiplicative Interaction Variables (2)</i>	
	Index Child's Reported Health Status X Formal Service Supports
	Level of Illness Management Tasks X Formal Service Supports
<i>Perception of Caregiver Burden (1)</i>	
	Stress Level

Utilizing the statistical program 'SamplePower 1.0', the power analysis will focus on the increment for the set of interest over and above any prior variables (i.e., 2 stressor variables yielding an increment of 0.05) (Borenstein, Rothstein & Cohen, 1997). With the given sample size of 152, alpha set at .05, and utilizing an interaction regression equation (such as the one illustrated in Table 8 above - the most rigorous of the calculations proposed), the study will have power of .80, which is generally used as an acceptable level of power (as illustrated in Figure 2). The test is based on controlling for the possibility of a type 2 error, which means that variables entered into the regression will serve to reduce the error term in the significance test and are included in the power analysis. This effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.



Data Collection

The data used in this study will be collected from the existing FaCT files. Each file will be examined to determine its acceptability in meeting the sample selection criteria. Data were originally gathered for each family by the FaCT caseworker 30 days after the initial referral (Groze, Haines-Simeon & Persse, 1993). If the caregiver was illiterate or unable to complete the questionnaire, the FaCT caseworker assisted the caregiver to complete the information. After the initial data collection period, data were collected at six-month intervals. However, due to attrition resulting from the caregiver or child's deteriorating health, death or other factors, only the initial interview data are utilized. In addition, although data were collected from 1991 through 1997, information collected over the project duration will be combined to form one dataset. The questions

and instruments utilized remained constant over time, thus enabling comparability. Also, HIV/AIDS reconstruction as a chronic (albeit still ultimately terminal) illness had occurred prior to 1991 with the advent of the new medical treatments available for children (Beaudin & Chambre, 1996; FDA, 1996; Meyers & Weitzman, 1991). The FaCT project did not collect specific medical data on the children; thus, it is impossible to know the medical regime of each index child. Therefore, it is assumed that each at least had the availability of drug treatments to prolong life. As such, the cohorts are considered equivalent and will be combined to form the study sample.

Variables – Operationalization and Instrumentation

The instruments used to collect data included a 61 item self-administered questionnaire consisting of primarily closed-ended questions. This study will utilize approximately 48% of the questions contained within the questionnaire. The measure contained 29 specific questions on the demographics of the index child, caregiver and family, as well as on the child's health and caregiver sources of support. Of the remainder of the questions, several were considered redundant (i.e., asking for both age and date of birth) and the rest were not considered relevant to this investigation. For example, one question asks, "If this child is not living with you, when do you think he will return" which violates one of the criteria for inclusion on this study (i.e., physical custody). Other non-included questions focus on, for example, various aspects of the birth mother's history that were not also asked of the other caregivers and are therefore non-comparable.

Secondary data utilization contains many unique challenges such as a mismatch between the primary and secondary research objectives (Kiecolt & Nathan, 1985). As

such, data may only be available in forms that are not ideal (Kiecolt & Nathan). To that end, the independent variables, as discussed below, are all either single item measures or summated composite scores of two combined questions. As such, the respective validity and reliability of the questions poses specific strengths and limitations that will be addressed. One of the strengths of the measures is that they meet the criteria to be considered to have face and logical validity (i.e., content validity); which is that the test *appears* to be measuring what it purports to measure, and that the question(s) are representative of the content or subject to be examined (Blythe & Tripodi, 1989; Newman & Newman, 1994). The relevance and the representativeness of the variable to the concept are obvious in the basic content of the question and its range of responses (Blythe & Tripodi). Therefore, a measure is valid when it converges with expectations derived from other knowledge about the subject matter (Jacob, 1984).

Sensitivity to the item under investigation is an area of concern. However, Blythe and Tripodi (1989) posit that “a rating scale with 10 levels...is not more sensitive than a rating scale with 3 levels, unless there is evidence that the *client* can reliably discriminate among these 10 levels” [italics added] (p. 42). Yet, given the current study, this can not be known. Another option to ensure the validity of the questions is to check the accuracy by some objective means. However, when people are asked their perceptions and feelings there is no way of validating the answers (Fowler, 1993). Only the person has access to his or her feelings and opinions. As such, other forms of validity (i.e., concurrent or empirical) can only be determined through their correlations with other measures. Unfortunately, other comparable measures were not administered to this sample. Thus, these ‘higher’ forms of validity, although desirable, are not available.

It is impossible to determine the reliability of a single indicant (Zellar & Carmines, 1980). However, questions such as these have been utilized in several other studies (Rosenthal & Groze, 1992). In addition, closed-ended questions such as these have been found to be useful because clients find that they can 1) perform the task of answering the question when response alternatives are provided, and 2) the researcher can more reliably interpret the meanings of the alternatives (Fowler, 1993). Blythe and Tripodi (1989) assert that the tool must be understandable and easy to use. To help increase reliability, the questions were specifically written by the initial investigator to reduce any ambiguity or vagueness, and to have each question's meaning transferable to all caregiver populations (i.e., birth, foster or adoptive) regardless of educational level.

Another method of increasing the reliability of the measures is to form composite or summated scoring of questions (Zellar & Carmines, 1980). A composite score shares more of its variance with the underlying concept than does the single question (Zellar & Carmines). Therefore, the combining of two (or more) questions to form a composite score is a better approximation and is less affected by random error (Zellar & Carmines). Thus, a relatively objective, albeit rudimentary, measure may be a summary score of support (Biegel et al., 1991). Those independent variable measures below indicating subjective states will be composed of the summated score of two objective questions.

The following questions (see Tables 8-12) have been selected for inclusion in the various scales:

Personal Factors

Caregiver's Health Limits. Although it is assumed from the FaCT program criteria that all of the birth mothers are HIV positive and all of the other caregivers are

HIV negative, it is unknown whether the extent to which caregivers from either group have health issues which impact their daily living tasks. As shown in Table 9 below, caregiver health impairment will be obtained by asking the extent to which health problems, if any, impact upon their daily living activity in the home.

Table 9: Variable Questions – <i>PERSONAL FACTORS</i>	
<i>Caregiver's Health Limits on Daily Living</i>	
To what extent do you have any health problems that limit your activity around the house? (0-4) None/Hardly Ever/Sometimes/Often/Almost Always or Always	
<i>Education</i>	
Primary caregiver's education? (1-3) Did Not Complete HS/Completed HS/Some College+	
<i>Another Ill Child?</i>	
Can any other child in the home, <i>other than the index child</i> , be considered in poor health? (0-1) No/Yes	

Educational Level. As shown in Table 9, the level of caregiver education will be determined through a question asking the highest level completed.

Another Ill Child? Similar to Wiener et al. (1994), caregivers were asked whether or not there was another child in the home that could be considered to be ill. The answer will be coded as a dichotomous 'no/yes' variable.

Stressors

HIV Status. All children included in this study will be indicated within their record as either HIV negative or HIV positive as reported by their caregiver (as shown in Table 10). Those children whose status was unknown at the time the instrument was completed will not be included.

Table 10: Variable Questions - <i>STRESSORS</i>	
<i>HIV Status</i>	
Index child's health status? (1-2)	HIV-/HIV+
<i>Illness Management (I-11)</i>	
Frequency of Dr. visits in the last 6 months? (1-7)	Once in 6 months/Once every 2-3 months/Once per month/2-3 times per month/ Once per week/Several times per week/Daily
How many times has this child been hospitalized since birth/last 6 months? (0-4)	0/1/2/3/4+

Illness Management. The number of hospital visits and doctor's appointments on behalf of the child for the previous six months, as reported by the caregiver, will be determined to be the level of illness management tasks, as shown through the summated score of the two questions posed in Table 10.

Informal Social Supports

Family. The combined score of two family-related questions, as shown in Table 11, will be used to demonstrate the perceived level of family support. The first is whether or not the caregiver has a partner, that Cantor (1979) defines a *functional* spouse as "one with whom one lives" (p. 441). The second question asks the level of perceived support from the caregiver's family. The overall questionnaire specifically focuses on the infected/affected child. Therefore, although not specifically stated, this question is considered to ask about support in relation to the child (as are all subsequent support-related questions). In a previous study, Crystal and Kersting (1998) measured HIV positive subject's perception of social support utilizing two questions with three possible

responses (very satisfied, somewhat satisfied, and not very satisfied). The answers to both items were combined to form a single index of support (Crystal & Kersting).

Table 11: Variable Questions – <i>INFORMAL SOCIAL SUPPORT</i>	
<i>Family Support (1-4)</i>	
Partnership status? (0-1)	Not partnered/Partnered
Are your relatives supportive of your family? (1-3)	No, not really/Yes, somewhat/Yes, very much
<i>Friend Support (1-7)</i>	
Are your friends supportive of your family? (1-3)	No, not really/Yes, somewhat/Yes, very much
How many close friends do you have? (0-4)	0/1/2/3/4+
<i>Child Support (1-9)</i>	
How do you and your child get along? (1-4)	Very poorly/Not so well/Fairly well/Very well
How often do you and your child enjoy time together? (0-5)	Less than once per month or not at all/1 per month/2-3 times per month/1 per week/2-3 times per week/Just about every day
<i>Community Connection (1-8)</i>	
How often are you (or your spouse/mate) in contact with other families similar to yours? (0-4)	Once per year or less/Every few months/1 per month/1 per week/Daily or almost daily
How active are you in your community? (1-4)	Not active at all/Not very active/Somewhat active/Very active
<i>Church/Spiritual Support (1-6)</i>	
How important is religion in your life? (0-2)	Not important/Somewhat important/Very important
How active are you in your church/synagogue? (1-4)	Not active at all/Not very active/Somewhat active/Very active

Friends. To measure perceived support from friends, the scores from the two questions shown in Table 11 will be combined. The number of friends identified, as well as inquiring as to their level of support will be indicative of the caregiver's perceived

level of support from this source. Similarly, to add a structural dimension to their measure of support, Crystal & Kersting (1998) asked about the existence of social relationships with friends.

Children. Perceived support from the child is obtained through the summed scores of the questions in Table 11. Satisfaction with the relationship and the amount of time enjoyed together will be used to operationalize this variable.

Community Connection. Self-reported contact with similar families and activity levels within the community will be combined to provide the level of perceived connection to the community.

Church/Spirituality. Asking the respondent how important religion is in his/her life provides a level of perceived support from spirituality. In addition, the frequency in which the caregiver attends services will indicate the level of perceived support from this source.

Formal Social Supports

Formal Service Supports. The receipt of formal services such as respite care and mental health counseling will be measured through a dichotomous 'no/yes' scale. The perceived support from the FaCT care worker will be assessed by the inquiring as to the services provided by the agency worker, as shown in Table 12.

Table 12: Variable Questions - *FORMAL SOCIAL SUPPORT*

<i>Formal Service Support (1-5)</i>	
Respite Care received? (0-1)	No/Yes
Mental Health services received? (0-1)	No/Yes
How would you describe the services provided by the agency worker? (1-3)	Not helpful/Adequate/Very helpful

Caregiver Response to Perceived Burden

Stress/Arousal. The majority of studies examining the occurrence of potentially stressful events use some version of a checklist where the stress score is simply the total number of items checked as having occurred (Cohen, S., & Wills, 1985). Similarly, the dependent variables in this study, stress and arousal levels, will be operationalized through the use of the Stress-Arousal Checklist (SACL) developed by Mackay et al. (1978). The 30-item SACL consists of adjectives commonly used to describe one's psychological experience to stress. The SACL was originally tested with a sample of undergraduate students (Mackay et al.). It has since been utilized with a variety of populations; for example - nurses (Hirosawa, Hatta & Yoneda, 1998), computer entry workers (Sharit, Czaja & Nair, 1998), and pilots (Cooper & Sloan, 1987). However, it has never been utilized on caregivers of children infected/affected by HIV/AIDS.

Each respondent utilizing the SACL (see sample instrument in Appendix A) will rate each adjective in terms of the intensity of his/her feelings toward each. Each sub-scale consists of positive and negative adjectives used to describe stress and arousal. For the positive adjectives, the ++ and + ratings are scored 1, and the ? and - are scored 0.

The opposite scoring is used for the negative adjectives (i.e., ++ and + score 0, and ? and – score 1). For the stress sub-scale, the positive adjectives are items 1, 5, 6, 9, 10, 11, 12, 13, 18, 23; and the negative items are 2, 3, 15, 21, 22, 25, 27, 28. The adjectives for the arousal sub-scale are: positive = 4, 7, 14, 19, 20, 29; and negative = 8, 16, 17, 24, 26. Thus, the stress score can range from 0-18 and the arousal score can range from 0-12.

There are no reports on the reliability of the SACL (J. Fischer & Corcoran, 1994). However, the SACL has been subjected to factor analyses by several researchers to determine its internal consistency (D. Fischer & Donatelli, 1987; Mackay et al., 1978). Factor analysis has identified a two-factor structure, subsequently labeled stress and arousal. The SACL has known groups validity showing, for example, that scores increase as a consequence of a stressful situation (Burrows, Cox & Simpson, 1977; King et al., 1983). In addition, the SACL has also been shown to have concurrent validity, with scores correlating with various physiological measures (Burrows et al.; Mackay, 1980).

DATA ANALYSIS PLAN

All quantitative data will be analyzed using SPSS statistical software. Data will be examined for any conflicts against the original surveys. Several types of statistical tests will be utilized to analyze the data and make decisions about the hypotheses: diagnostics and missing values, reliability and validity, as well as descriptive, bivariate, multivariate and interactional analyses.

Diagnostics/Missing Values

First, the data ranges and distributions will be checked to ensure it was appropriately entered. Next, to ensure the appropriateness of the data for analysis,

regression diagnostics will be conducted to explore any potential problems that may compromise the assumptions imbedded in the statistical model. Calculations will be conducted to identify any influential data, as well as any violations of multicollinearity or normality. Also, given the sensitive nature of the topic, missing data may occur. However, missing data may reduce the precision of the calculated statistics because of the decrease in available data (Hill, 1997). In addition, many statistical procedures are based upon complete cases, and missing values can complicate the findings (Hill). To correct for this, SPSS Missing Values Analysis will be utilized to impute values for those variables with missing data. To determine if a variable will be kept and missing values imputed, the missing values must be random and less than 20% of the total responses. Little's chi-square test for variables missing completely at random (MCAR) will be utilized (Hill). As such, a non-significant p-value is indicative of randomness (Hill). Conversely, a significant p-value ($p < .05$) illustrates data that is missing non-randomly (Hill). A further analysis of the missing values patterns will be conducted to determine any relevant significance from the missing values, with appropriate tables generated.

Reliability and Validity Issues

All questions used in this study, or variants thereof, have either been found to be reliable in previous research with similar samples or are assumed to be reliable because they are based on scales that have been found to be reliable in previous research. However, statistical tests will be utilized to insure the reliability of the use of all scales with this particular sample. Cronbach's alpha will be used to assess the internal consistency of data generated by measures used in the study.

The SACL has been utilized in numerous previous studies and has acceptable levels of validity, with King et al. (1983) reporting Cronbach's alpha for a modified version at .86 (stress) and .74 (arousal). However, because the scale has not been validated with a primarily African-American, female population factor analysis will be conducted to assess the validity of the scale. Therefore, after factor analyzing the data to discern the patterns, minor revisions of the scale may be done for application to this study.

Descriptive Statistics – Characteristics of the Sample

Descriptive analyses will be used to assess the characteristics of the data both in terms of the overall sample, and in terms of the two caregiver groupings. All collected data will be analyzed in this manner, including the results of the social support questions and SACL, as well as any collected demographic information. Demographic information will include the caregivers relationship to the child, gender, age, race/ethnicity, income, number of other children in the home, employment status and effect of the child. Child demographics (i.e., gender, age and race/ethnicity) will also be highlighted. Statistical tests that will be used in this level of analysis will include frequencies, percentages, distributions, ranges and measures of variability and central tendency. All findings will be summarized in tables.

Analyses – Research Question #1

Once the data has been described and the scales have been found to be reliable, a series of bivariate analyses will be conducted to test the hypotheses associated with the first research question comparing birth mothers and other caregivers. T-tests will be used to compare the means of the variables identified in the associated hypotheses. T-tests

will also be utilized to compare the means of the stress/arousal sub-scale measure and applicable demographic categories. The significance or non-significance of these tests will be noted in the descriptive tables.

Analyses – Research Question #2

For the second question a series of regression analyses will be utilized to examine and test the relationships between the independent and dependent variables outlined. The predictive value of each of the two stressors on the caregivers' stress and arousal levels will be used to assess the importance on these dependent variables to the model after the personal factors have been included. Thus, the first set of predictors used in the application of this model will include the personal factors. This will be followed by the stressor variables. This will be run for the stress sub-scale, as well as the arousal sub-scale. The subsequent values of the R^2 's will be noted with the significance to determine the decision rule in testing the hypotheses.

Analyses – Research Question #3

For question #3, twelve multiplicative regression models with interactions will be conducted. One for each permutation of support source (5 informal, 1 formal) for the two dependent variable sub-scales. Thus, taking the regression equations from question #2 a social support source (for example, family support) will be added, as will the relevant multiplicative terms (family support X child's HIV status, and family support X level of illness management tasks). Therefore, in each regression analysis the personal factors will be entered first, followed by the stressor variables and single conditioning variable, with the multiplicative interaction variable entered last. Main effects from the conditioning variable upon stress and arousal levels will be examined. In addition, the

hypothesized moderating effects will be indicated if the added interaction term significantly increases the model's R^2 beyond the main effects, as identified by significant regression coefficients. Lastly, a decomposition analysis will be performed on any significant interaction term to determine the significance of the slope of perceived levels of support on stress at low and high levels.

ETHICAL CONSIDERATIONS

All data will be kept in strict confidence, without any identifying information from the respondents noted in the record. Due to the sensitive nature of the subject, only an identification number will identify caregivers' surveys. Data from the original study was individually coded to ensure the anonymity of the respondents. For example, the code used the following designations – 08H112B [08 = county; H = HIV infected/affected; 112 = client ID number; B = birth family]. This research will utilize the same coding procedure to maintain this level of confidence. In addition, respondents in the original project were not denied treatment, nor given any additional treatment, to participate in the study. For purposes of this study, informed consent can be assumed to have been provided through the completion of the information requested. Those families not wishing to participate will have selected themselves out from the earlier study. There were no known risks to involvement in the original project, nor are any known at this time. Lastly, to ensure that study subjects are protected a Case Western Reserve University Institutional Review Board (IRB) application was submitted, with subsequent approval granted on April 10, 2000 (see Appendix B for a copy of the IRB approval).