

## CHAPTER 3

### RESEARCH QUESTIONS AND HYPOTHESES

Three research questions, each with its respective hypotheses, have been developed from the Stress-Coping model to examine the relationships among the variables thought to illuminate the impact upon caregivers of caring for children infected/affected by HIV/AIDS. This chapter will review each question and subsequently provide a supporting rationale for each of the hypotheses presented.

The first research question and supporting twelve hypotheses (as shown in Table 5) investigates the differences between the birth mothers and the other caregivers on the variables within each construct. This is done to examine the comparability of the two groups, as well as illuminate any potential sources of bias. Those variables with statistically significant differences will be highlighted and discussed further. The second question and its two corresponding hypotheses are examining the significance of the two stressor variables, as illustrated in Table 6. A regression equation will be used to examine the relative importance of each predictor variable on the outcome variables. As suggested by the application of the stress-coping framework, the third research question and the remaining six hypotheses (see Table 7) will investigate the buffering effect of each source of social support upon the relationship between the stressor variables and the outcome variables.

## RESEARCH QUESTIONS

The study will focus on the following research questions:

1. Are there significant differences between birth mothers and other caregivers in their reports of: personal factors (caregiver's health limits, educational level, and another sick child in the home); stressors (index child's reported health status, and level of illness management); informal social supports (family, friends, children, community connections and church/spirituality); formal social support (formal service supports); and perception of caregiver burden (stress and arousal levels)?

<b>Table 5: Hypothesized Relationships for Research Question #1</b>	
<i>Birth mothers as compared to other caregivers</i>	<i>Relationship</i>
<i>Personal Factors</i>	
Caregiver's Health Limits	More
Educational Level	Less
Another Child Ill?	More
<i>Stressors</i>	
Index Child's Reported Health Status	Less
Level of Illness Management Tasks	Less
<i>Conditioning Variables</i>	
Family Support	Less
Friends Support	Less
Children Support	More
Community Connections	No Difference
Church/Spirituality Support	No Difference
Formal Service Supports	Less
<i>Perception of Caregiver Burden</i>	
Stress Level	More
Arousal Level	Less

2. Controlling for personal factors, are the stressors (index child's reported health status, and level of illness management) significant predictors of caregiver stress and arousal levels?

<b>Table 6: Hypothesized Relationships for Research Question #2</b>		
<i>Dependent Variable</i>	<i>Independent Variables</i>	<i>Relationship</i>
<i>Stress Level</i>	<i>Stressors</i>	
	Index Child's Reported Health Status	+
	Level of Illness Management Tasks	+
<i>Arousal Level</i>	<i>Stressors</i>	
	Index Child's Reported Health Status	+
	Level of Illness Management Tasks	+

3. Does the social support provided [informal social supports (family, friends, children, community connections and church/spirituality); and formal social support (formal service supports)] significantly buffer the effects of the stressor upon the caregiver's stress and arousal levels?

<b>Table 7: Hypothesized Relationships for Research Question #3</b>		
<i>Dependent Variable</i>	<i>Conditioning Variables</i>	<i>Relationship</i>
<i>Stress Level</i>	Family Support	-
	Friends Support	-
	Children Support	-
	Community Connections	-
	Religion/Spirituality Support	-
	Formal Service Supports	-
<i>Arousal Level</i>	Family Support	+
	Friends Support	+
	Children Support	+
	Community Connections	+
	Religion/Spirituality Support	+
	Formal Service Supports	+

## HYPOTHESES

**Hypothesis 1.1:** *In comparing birth mothers to other caregivers, birth mothers will have significantly more limits on their daily living due to health concerns..*

**Results 1.1:** In their qualitative study of grandmothers who are also caregivers of HIV positive children, Caliandro and Hughes' (1998) found that many of the grandmothers minimized their own personal health needs such as high blood pressure, chest pains and asthma. This is consistent with Walker's (1998) findings on the tendency of birth mother's to attend to their children's needs over their own, often to the detriment of their health status. Nevertheless, Hansell and her colleagues (1999) found that HIV positive mothers presented with multiple and more complex problems than their HIV negative counterparts. In addition, M. Rose and Clark-Alexander (1998) discovered that HIV positive birth mother caregivers scored slightly higher than other caregivers on a nine question scale of physical health, although the amount was not significant. Thus, although other (especially older) caregivers may experience health concerns, the evidence indicates that HIV positive birth mothers have more potential health limitations.

**Hypothesis 1.2:** *In comparing birth mothers to other caregivers, birth mothers will have significantly lower education levels.*

**Rationale 1.2:** This hypothesis predicts that within the two groups of caregivers, birth mothers will have received a lesser amount of formal education as indicated by the measure. To support this hypothesis, several studies have reported higher education levels among foster parents and other caregivers over birth mothers. F. Cohen et al. (1995) reported that  $\frac{3}{4}$  of the foster parents in their study had attended some college; whereas none of birth mothers had, and only 50% had completed high school. Hansell

and her colleagues (1998) found significant differences between HIV negative and HIV positive caregivers' education level. Though not statistically significant, Black et al. (1994) also found that HIV negative caregivers in both of their studies had higher levels of education. M. Rose and Clark-Alexander (1998) reported similar findings. Thus, there appears to be sufficient evidence to support this hypothesis.

**Hypothesis 1.3:** *In comparing birth mothers to other caregivers, significantly more birth mothers will have another sick child in the home.*

**Rationale 1.3:** This hypothesis predicts that significantly more birth mothers will also be caring for another ill child in their home (although not necessarily HIV positive). This hypothesis is posited due to the numerous oppressive factors including poverty, substance abuse and prostitution impacting HIV positive women and their children's prenatal care. It is estimated that 44% of HIV positive women in the United States have been infected through intravenous drug usage (CDC, 1999e). The majority of the rest have been infected through heterosexual contact, many through prostitution. As such, these characteristics may negatively affect the growth and development of *all* their children. Thus, in addition to the index child, it is possible that the birth mother is caring for more than one ill child. This will subsequently add to the caregiver's perceived burden. Canosa (1991) posits that a new bio-psychosocial entity has emerged: the 'HIV child'. Therefore, even if the child may be HIV negative, he/she may be characterized by many of the same challenges such as low birth weight, delayed psycho-motor development, poor language development, etc. (Canosa). Although half of the children examined by Leeds (1993) were HIV positive by age two (the rest had seroconverted), almost 75% of the 195 children experienced some ailment at least once in any three

month period. Thus, the literature illustrates the increased probability of HIV positive mothers having children with various developmental and health difficulties.

**Hypothesis 1.4:** *In comparing birth mothers to other caregivers, significantly less birth mothers will have an HIV positive child in the home.*

**Rationale 1.4:** Due to the nature of the project from which the data were collected, a significantly higher proportion of other caregivers will be caring for HIV positive children. As discussed further in Chapter 4, those families (birth, foster, adoptive and kin) included in the initial project had children infected and/or affected by HIV/AIDS. The birth mothers involved in the project did not necessarily have to have a child with HIV, as their own positive diagnosis met the inclusion criteria. The foster/adoptive parents were all trained by the project staff to specifically care for an HIV positive child. Although some children may have seroconverted after placement, one of the project's goals was to place HIV positive children with appropriately trained and prepared families. Thus, due to the project protocols, it is hypothesized that other caregivers had a significantly higher proportion of HIV positive children in their care.

**Hypothesis 1.5:** *In comparing birth mothers to other caregivers, birth mothers will have a significantly lower level of illness management tasks.*

**Rationale 1.5:** HIV positive children may initially grow-up in the care of their birth mother. However, as their mother progresses through the disease process, the child is also progressing through a parallel process. Despite the overall reconceptualization of HIV as a chronic illness, infection eventually results in death. As such, time is an enemy in the fight against the virus, and as the child gets older he/she will inevitably become symptomatic. Thus, those children placed away from the birth mother due to the

mother's deteriorating health or death will be further along the illness. As the disease progresses, the responsibility for caring for an ill child becomes more complex due to medication regimes, as well as frequent health appointments and hospitalizations. In support of this hypothesis, F. Cohen et al. (1995) found that the corresponding illness management tasks were significantly more frequent for children placed with foster families (and other caregivers), who, as a group, had much sicker children living with them than those still living with their birth mothers.

**Hypothesis 1.6:** *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from family.*

**Rationale 1.6:** Several factors serve to isolate birth mothers from many sources of support, including their families. The stigma associated with HIV, as well as the mode of acquisition for the birth mother and source of transmission to the child, have alienated many families (McCarroll, 1988). Thus, fear of disclosure has prevented many HIV positive mothers from obtaining support from family. Walker (1998) writes that, "for them, the price of disclosure exceeded the benefit of potential support" (p. 83). Stories abound of families rejecting their HIV positive members (Walker). M. Rose (1993) reported that rejection from family was a major concern among women, and that rejection was more common from family members if the member had children, fearing their children may contract the virus.

Although not source specific, Hardy and her colleagues (1994) noted that the parents in their HIV positive group scored lower on social support than either the cancer or control groups. They were also the group with the most single parents and least married parents (Hardy et al.). Black et al. (1994) reported similar findings. Hansell and

her co-authors (1998) reported that while 41% of the HIV negative caregivers were partnered, only 29% of HIV positive caregivers were. Hughes and Caliandro (1996) found that their respondents scored at the high end of the low social support range. In addition, Mayers & Spiegel (1992) found isolation from family, as well as friends and the medical staff, to be a recurrent theme for birth mothers. M. Rose and Clark-Alexander (1998) also found that alternative caregivers had significantly more support from family, with birth mothers not reporting support from family. Thankfully, not all birth mothers experience such isolation, as Black et al. found that out of the four study groups, HIV positive mothers receiving the intervention scored highest on informal support, although not statistically significant from other groups. As overwhelmingly demonstrated in the literature, lack of support from family is not uncommon among HIV positive caregivers, who describe being held hostage by the disease (Koehn, as cited by Mayers & Spiegel).

**Hypothesis 1.7:** *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from friends.*

**Rationale 1.7:** Lichtman et al. (1987) found that when provided, high support from friends, breast cancer survivors improved in their psychological adjustment. Unfortunately the social isolation of HIV positive birth mothers permeates the literature, with the need for social support cited as one of the top concerns of caregivers of children infected/affected by HIV/AIDS (Hackl et al., 1997; Heath & Rodway, 1999; Mayers & Spiegel, 1992; Wiener, 1998). Mayers & Spiegel found isolation from friends, in addition to other sources, to be an important issue for birth parents in their support group.

Friends are often the main source of social support for women with HIV, as family relationships may have been severed (McCarroll, 1988; Namir et al., 1989).

Friends can offer empathy and shared values, and have been associated with improved psychological adjustment in individuals with HIV (R. Hays et al., 1990). However, M. Rose and Clark-Alexander (1998) found that alternative caregivers had significantly more support from friends; which they described as ‘dramatic’. Indeed, the lack of support from friends is characteristic of AIDS patients and of their caregivers who are often held hostage by the disease (Koehn cited by Mayers & Spiegel, 1992, p185). For example, even though friends may offer support to HIV positive caregivers, almost all of the birth mothers participating in F. Cohen et al.’s (1995) study reported expressing caution and reserve when choosing whom to tell. This indicates a heightened awareness of the potential rejection from this source of social support.

**Hypothesis 1.8:** *In comparing birth mothers to other caregivers, birth mothers will have significantly more support from children.*

**Rationale 1.8:** S. Andrews et al. (1993) reported that many birth mothers in their study reported receiving support from their children. Many HIV positive mothers described having a very special relationship with their child, with this special bond acknowledged throughout the literature (Andrews, S. et al.; Caliendo & Hughes, 1998; Cohen, F. et al., 1995). The mothers revealed that the child’s presence decreased their feelings of isolation and gave them a reason to live (Andrews, S. et al.). Walker (1998) posits that when the danger of losing a loved one exists, an intense bond may form. She contends that caregivers grapple with the traumatic nature of the illness through this attachment (Walker). Birth mothers felt that the anticipated loss of their child, coupled with the fact that they shared the same illness, intensified the bond between them (Walker). Further, women expected children (8 years old and older) to assist with

household tasks, including caring for their younger siblings (Walker). Thus, as posited in the literature, due to the bond formed by their illness and their isolation, birth mothers rely to a greater degree on the support of their children.

**Hypothesis 1.9:** *In comparing birth mothers to other caregivers, there will be no difference between birth mothers and other caregivers' level of connection to the community.*

**Rationale 1.9:** There is a small, but growing body of literature demonstrating the therapeutic effects of support groups for people caring for children and adults with HIV (Grief & Porembski, 1988; Kelly & Sykes, 1989; Mayers & Spiegel, 1992; Pearlin et al., 1988; Wiener, 1998). One of the earliest articles focusing on the stress of caring for a child infected by HIV/AIDS describes a parental support group to prevent social isolation due to the lack of available social support (Mayers & Spiegel). Through the commonality of experiences, meeting with others who are caring for children infected/affected by HIV/AIDS can allow the caregiver the opportunity to reflect, express and reconcile feelings in a supportive community format. Through the group, caregivers are sustained in fulfilling their roles. HIV positive women often report on the benefits of universality and companionship found in support groups to deal with depression, hopelessness and anxiety surrounding the disease (Hackl et al., 1997; Wiener). Additionally, in a study of professional caregivers of HIV positive clients, George et al. (1993) found that supportive groups effectively buffered stress and improved the quality of the care provided. It appears that this source of support is beneficial to both HIV positive and HIV negative caregivers, and, since all participants are affected by HIV, there are

minimal barriers to group entry. Thus, it is hypothesized that there will be no difference between birth mothers and other caregivers.

**Hypothesis 1.10:** *In comparing birth mothers to other caregivers, there will be no difference between birth mothers and other caregivers' level of support from church/spirituality.*

**Rationale 1.10:** Although individuals infected by HIV met with opposition by many traditional religious institutions during the early stages of the pandemic, church/spirituality have been found to be a positive coping support used by all types of caregivers (Leserman et al., 1992; Warner-Robbins & Christiana, 1989; Weitz, 1989). M. Rose and Clark-Alexander (1998) found that 80% of their sample (70% of who were birth mothers) used prayer as a method of coping with the stress of caring for an HIV positive child. The role of religion as a coping strategy has also been highlighted by Mellins and Ehrhardt (1994), stating that its role within their sample of HIV positive and negative inner-city family caregivers could not be 'overemphasized'. Many grandmothers expressed a realization of their personal limits, and found comfort in placing faith that the health of the child was in 'higher hands' (Caliandro & Hughes, 1998). Caliandro and Hughes assert that "being strong and able to cope with problems were clearly linked to their strong spirituality" (p. 110). This theme was also present in Heath and Rodway's (1999) findings, with the issue of spirituality emerging from the qualitative data and two respondents describing a deepening of their beliefs since diagnosis. Boyle, Ferrell, Hodnicki & Muller (1997) found that among African-American mother-caregivers of adult children with AIDS, two of the greatest sources of support were spiritual beliefs and participation in church. Therefore, it is clear that as a

method of coping with the stress produced by caring for a child with AIDS many caregivers turn to their faith and church for support. The literature does not clearly identify which group may derive more support from this source. Thus, it is hypothesized that there is no difference between birth mothers and other caregivers in their level of perceived support from this source.

**Hypothesis 1.11:** *In comparing birth mothers to other caregivers, birth mothers will have significantly less support from formal service supports.*

**Rationale 1.11:** In a study of social workers' attitudes toward people with AIDS, it was found that 80% of respondents would refuse the assignment of an AIDS case if they were a hospital social worker, with an additional 9% undecided (Dhooper, Royse & Tran, 1988). Although physicians profess the need to treat all patients, similar findings have been reported (Rose, L., 1994). Even though some practitioners still admit to being very fearful and uncomfortable working with PWAs, many HIV negative caregivers report satisfaction with their relationships with professionals. However, some birth mothers feel blamed by professionals for their child's illness. This is an especially sensitive area since they *are* the agents of infection for the majority of children. Surprisingly, in their first study, Black et al. (1994) found that out of the four groups, HIV positive caregivers in the comparison group scored highest on formal support (although not statistically significant from other groups). Nevertheless, respite and childcare availability is a problem for seropositive mother-caregivers of HIV positive children (Andrews, S. et al., 1993). Communicating with health care providers and social service agencies also proved to be difficult for caregivers, especially for HIV positive birth mothers (Mellins & Ehrhardt, 1994). Foster and adoptive families reported turning

to professionals for support more frequently, with birth parents less frequent (Mellins & Ehrhardt). They hypothesize that this may be due to the already existing alliance between foster/adoptive parents and social service agencies (Mellins & Ehrhardt). Lastly, HIV positive women in two studies reported health care professionals to be hostile, fearful and lacking in knowledge (Chung & Magraw, 1992; Florence, Lutzen & Alexius, 1994). Thus, the literature suggests that HIV positive birth mothers will perceive less support from formal support services when compared to other caregivers.

**Hypothesis 1.12:** *In comparing birth mothers to other caregivers, birth mothers will have significantly higher stress levels.*

**Rationale 1.12:** It is hypothesized that the combination of factors impacting birth mothers (i.e., poverty, race/gender biases, their own illness status, and the emotions experienced from transmitting the illness to their child) will result in this group having significantly higher stress levels than their HIV negative counterparts. Throughout the literature, HIV positive parents have been shown to experience higher levels of depression, anxiety and anticipatory grief than have foster or adoptive parents or extended family members (Hansell et al., 1998; Hughes & Caliandro, 1996; Wiener et al., 1994). Hughes and Caliandro also reported that their study subjects were less able to relax and find diversion from typical daily routines. In addition, HIV positive mothers also reported above average stress in their family relationships (Hughes & Caliandro). Although not at the highest levels, M. Rose and Clark-Alexander (1998) found mothers to be more depressed than other caregivers. Birth mothers have almost unanimously reported higher levels of stress and stress-related issues; therefore, it is hypothesized that birth mothers in this study will also report higher levels of stress than other caregivers.

**Hypothesis 1.13:** *In comparing birth mothers to other caregivers, birth mothers will have significantly lower arousal levels.*

**Rationale 1.13:** Hardy and her colleagues (1994) found that birth mothers of HIV positive children exhibited higher amounts of wishful thinking than caregivers in the other study groups. Hughes and Caliandro (1996) also reported that HIV positive subjects' feelings of mastery were lower than the normative group, although still in the upper half of the possible range. M. Rose and Clark-Alexander (1998) found that alternative HIV negative caregivers used confrontative coping that focuses on constructively handling the stressful situation and directly confronting the problem. The alternative caregivers utilized the more active strategy significantly more than HIV positive birth mother caregivers, who utilized a more passive coping style that is depicted through the modulation of tension by reframing the situation without directly confronting it (Rose, M. & Clark-Alexander). Because of this, alternative caregivers also felt more in control of their lives (Rose, M., & Clark-Alexander).

Lastly, HIV positive birth mothers, in addition to caring for their child, are fighting the illness themselves. Many women experience the extreme physical exhaustion that is characteristic of AIDS (Hansell et al., 1998; Walker, 1998). However, as indicated in the literature, birth mothers will have significantly lower arousal (i.e., active behavioral) levels when compared to the other caregivers.

**Hypothesis 2.1:** *Controlling for personal factors, the index child's illness status will be a significant predictor of; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 2.1:** After entering the personal factors into the regression equation, the two stressor variables will be entered. This hypothesis predicts that an HIV positive diagnosis for the index child will be a significant predictor of caregiver (a) stress and (b) arousal levels. The qualitative literature clearly illustrates that an HIV positive diagnosis for a child is a stressful event. Women state that they experienced far greater distress when their child was diagnosed with AIDS than when they themselves were diagnosed (Walker, 1998). However, this stressor variable is absent from the empirical literature, as all of the children studied are HIV positive. Nevertheless, the chronic illness literature has long documented the immense stress experienced by the parents upon learning of their child's prognosis (Eisenberg, Sutkin & Jansen, 1984; Love, 1970; Solnit & Stark, 1961). MacKeith (1973) points out that, in addition to the stress caused by the child's illness, there is an accompanying wish to protect and help the child. It is common for caregivers to focus on the needs of the child, even at the expense of their own needs (Walker). Thus, a positive HIV diagnosis will cause significant elevations in both the caregiver's stress and arousal levels.

**Hypothesis 2.2:** *Controlling for personal factors, the level of illness management will be a significant predictor of; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 2.2:** Within this framework the ill child's symptomatology has an effect on the caregiver, which in turn leads to the outcomes of stress and/or coping. These

illness management tasks, including multiple hospitalizations and juggling out-patient visits, were listed as a major caregiver stressor (Caliandro & Hughes, 1998; Mellins & Ehrhardt, 1994). Individuals dealing with caring for a child with a complex medical regime have a great deal of stress with which they need to cope (Rose, M., & Clark-Alexander, 1998). Juggling outpatient visits was identified as especially stressful for caregivers of HIV positive children (Mellins & Ehrhardt). HIV positive caregivers also have to cope with their own illness in addition to managing the child's medical tasks, which is especially stressful when appointments are in different locations (Mellins & Ehrhardt). However, despite the resultant stress caregivers continue to try to find the energy to do the tasks that will benefit their child (Caliandro & Hughes; Walker, 1998). Therefore, it is hypothesized that as the level of illness management tasks increase so will both the caregiver's level of stress and arousal.

**Hypothesis 3.1:** *Controlling for personal factors, the level of support from family significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 3.1:** There is some evidence to support the buffering effect of family support on the effects of the stressors. Roberts et al. (1994) found that spousal support had some buffering effect for breast cancer patients. Additionally, in Black et al.'s (1994) second study it was reported that social support, although not source specific, clearly buffered the amount of stress experienced by all groups – HIV negative, positive and comparison caregivers. The groups were all dichotomized into low and high support segments. The HIV negative and comparison (also HIV negative) low support groups both had reductions in stress, but not to the level of their high support counterparts. In

addition, the HIV positive low support group's stress level actually increased, whereas the high support segment reduced stress 76%. It is clear that HIV positive women benefit from support (Black et al.). Lastly, they reported that those HIV positive mothers benefiting from social support exhibited a more positive attitude, decreases in child-related stress, and more positive involvement with their children (Black et al.).

Hughes and Caliendo (1996) reported that high levels of social support contributed significantly to the perception of minimal impact on one's lifestyle. There is also evidence demonstrating that the lack of social support can increase distress within a family (Hughes & Caliendo). Furthermore, M. Rose and Clark-Alexander (1998) found a clear association between social support and the caregiver's level of coping (+) and stress (-). Efforts to boost *all* forms of social support among caregivers of children infected with HIV showed improvement for those individuals who were not HIV positive (Hansell et al., 1999). Thus, it is hypothesized that support from family will significantly reduce the amount of stress perceived, as well as significantly increase the amount of reported arousal.

**Hypothesis 3.2:** *Controlling for personal factors, the level of support from friends significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 3.2:** Lichtman et al. (1987) reported a moderate correlation between perceived social support from friends and psychological adjustment among cancer patients. Similarly, Roberts et al. (1994) found that the support of friends buffered the stress of breast cancer for single women comparable to that experienced by married women's spouses. Friendship was also consistently seen as a moderator of a mother's

experiences of daily parenting hassles (Crnic & Greenberg, 1990). In a sample of male hemophiliacs with HIV, support from friends was related to lowered depression levels (Dew, Ragni & Nimorowicz, 1990). Other study participants noted that the support of friends, as well as family, was crucial in regaining and maintaining equilibrium (Zich & Temoshok, 1987). In another study, contact with friends was cited as the greatest support source (Turner et al., 1998). Friends were a crucial source of support for both foster and birth families caring for an HIV positive child (Cohen, F. et al., 1995). Thus, as indicated in the literature, it is hypothesized that as the perceived support from friends increases, so will caregiver arousal levels. Conversely, caregiver stress levels will decline.

**Hypothesis 3.3:** *Controlling for personal factors, the level of support from children significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 3.3:** Several of the women in Walker's (1998) study identified children as a source of support. This appears to be a surprising, but common, occurrence (Andrews, S. et al., 1993; Walker). S. Andrews and her colleagues reported that many caregivers in their study reported receiving support from their children. They described having a very special relationship with their child, with this special bond acknowledged throughout the literature (Andrews, S. et al.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). Walker posits that when the danger of losing a loved one exists, an intense bond may form. She contends that caregivers grapple with the traumatic nature of the illness through this attachment (Walker). Further, women expected children (8 years old and older) to assist with household tasks, including caring for their younger siblings – some with AIDS (Walker). Thus, as the perceived support from the child increases, caregiver

perception of the burden (as evidenced by their stress scores) will decrease. Caregiver arousal will significantly increase due to the buffering effect of higher levels of support from children.

**Hypothesis 3.4:** *Controlling for personal factors, the level of connection to the community significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 3.4:** Several women in Heath and Rodway's (1999) study reported attending support groups, and found it helpful for alleviating stress. Crnic and Greenberg (1990) reported that community involvement/support significantly buffered daily parenting hassles. In addition, there is a small body of literature examining the buffering effect of support groups for caregivers of individuals with HIV/AIDS (Greif & Porembski, 1988; Kelly & Sykes, 1989; Mayer & Spiegel, 1992; Pearlin et al., 1988; Wiener, 1998). Groups are especially powerful sources of support in that everyone has the common experience of loss due to HIV (Kreibick, 1995). As such, a solidarity may be established among the caregivers which can assist in augmenting or replacing other damaged sources (Kreibick). McCarroll (1988), describing a support group for caregivers of HIV positive children, explains, "People who have escaped the loneliness of parenting a special child tend to value close times together...[to] face whatever problems emerge: trouble from neighbors or bureaucrats, diaper rashes, the need for a crib or help with housework, lack of sleep" (p. 87). Therefore, the fear of ostracism many caregivers experience can be overcome through this source (Hackl et al., 1997). Thus, it is hypothesized that an increased connection to similar families in the community will reduce caregiver stress and increase one's ability to actively respond to the situation.

**Hypothesis 3.5:** *Controlling for personal factors, the level of support from church/spirituality significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 3.5:** Several of the women in Walker's (1998) study identified God as a source of support. Families dealing with HIV have exhibited a strong sense of spirituality. One grandmother stated, "God never gives you more than you can bear, and I can do all things through God, who strengthens me" (Boyd-Franklin, Alemán, Steiner, Drelich & Norford, 1995, p. 125). When faced with HIV/AIDS, many minority families described how their spirituality buffered the stressful experience and allowed them to cope (Boyd-Franklin, Alemán, Steiner, Drelich & Norford). Although some families may have withdrawn from their 'church families' due to the stigma associated with HIV/AIDS, ministers and other religious leaders can be valuable supports for caregivers (Boyd-Franklin, Alemán, Steiner, Drelich & Norford). Thus, it is hypothesized that one's level of spirituality and involvement in a religious community will reduce the level of stress and increase one's arousal level.

**Hypothesis 3.6:** *Controlling for personal factors, the level of formal service supports significantly will buffer the effects of the stressor upon; a) caregiver stress levels, b) caregiver arousal levels.*

**Rationale 3.6:** It is hypothesized that increased support from formal service providers (i.e., case workers, respite care and mental health services) will buffer the effects of the stressor and result in a corresponding decreasing in caregiver stress, as well as an increase in caregiver arousal. This source has only been examined in one empirical study, with no significant findings noted (Black et al., 1994). However, Heath and

Rodway's (1999) subjects identified counselors, health care workers and social workers as being the most significant social supports (after family and friends). In addition, because of the perceived burden of caring for a child infected/affected by HIV/AIDS, respite care is utilized as a supportive service to reduce the demands placed upon the caregiver (Boyd-Franklin & Boland, 1995). As such, caregivers of children infected/affected by HIV/AIDS have very little time for their own needs; thus, respite care is one of the most frequently cited support services needed (Mellins & Ehrhardt, 1994). Lastly, in support of this hypothesis, mental health services can provide the caregiver the opportunity to address various needs in a safe environment, as well as work with the therapist to identify strengths and other potential sources of support (Boyd-Franklin, Alemán, Steiner, Drelich & Norford, 1995).