

CHAPTER 2

THEORETICAL FRAMEWORK: The Stress-Coping Model

This chapter will begin by exploring the conceptual origins and definitions of stress, coping and social support. The utilization of these concepts by other populations will then be examined, followed by a discussion of its applicability within the adult HIV literature. The pediatric HIV caregiving literature will subsequently be discussed and critiqued from this framework. Lastly, the study under investigation will be presented, with relevant research questions posed.

Selye (1970) was the first theorist to link stress with physical disease and ill health in human beings. This link, however, is not considered to be a direct link, but is instead affected by other social forces that allow the individual to adapt, or cope, to the stress. Rooted in the work of Durkheim, the concept of social support is now considered to be integral to this process (Waltz, 1994). As such, social support plays an important role in health and illness. Although the exact mechanism of this relationship has yet to be definitively established, social support has been correlated with increases in well-being, as well as positive increases in an individual's immunology (Broadhead et al., 1983; Leavy, 1983; Mitchell, Billings & Moos, 1982; Pilisuk, 1982; Pilisuk & Froland, 1978). Thus, it is posited that social support assists the person experiencing a stressor, such as caring for a child infected/affected by HIV/AIDS, by 'buffering' the caregiver from the potential negative influences of this stressful event. The model that puts these three concepts together – i.e. stressor, moderation by social supports, and outcome/perceived burden has become known as the Stress-Coping Model.

STRESS

The impact of stress upon humans' psychological and physiological well-being has been occurring since antiquity. Even prehistoric people must have recognized feelings such as exhaustion and fear when faced with starvation, disease or severe weather that threatened their existence. Selye (1993) writes that Hippocrates recognized the *vis medicatrix naturae* (healing power of nature) – yet stopped short of distinguishing the concept distress from stress. This is important, as distress always connotes unpleasantness; however, stress can occur from either positive or negative events (Selye). In addition, the same event can have both positive and negative factors (Selye). McCarroll (1988), although acknowledging the feelings of despair, depression and isolation an AIDS diagnosis may have, also notes the profound positive effect subsequently experienced by some women who:

transcend the limits of their previous existence. For the first time they develop deep relationships with other people, especially other women with AIDS and women who are caregivers. There is, at times, a blooming of a woman's personality that has led more than one victim to describe the months since diagnosis as a cherished time (p. 88-89).

Although Weiner (1994) suggests that Aristotle may have been the first person to clearly articulate this concept, it is only within the last few centuries that humans have begun to scrutinize and study the various facets of the stress process. One of the first recorded stress theorists was Charles Darwin, who suggested the concept of stress as an organism's struggle with the environment in competition with other organisms in order to survive. These outside forces, causing a threat or challenge to the integrity and survival

of a particular organism, have generally been understood to be the concept of stress (Weiner, 1994). In addition, Darwin (1955) believed that expressive behaviors (i.e., loud and rapid speech) resulting from a stressful event were associated with emotions (as cited in Siegman, 1993). Further, it is posited that these resultant behaviors have a biological basis and serve as communicative functions with clear-cut survival value (Darwin, 1955, as cited in Siegman, 1993). This concept later became codified into a theory through the experiments and works of Cannon (1929) and Bernard (1865). These theorists and researchers conducted a series of experiments on animals that supported their belief in the biological effects of environmental stress on an organism.

Selye (1936), while in medical school, discovered a similar process experienced by organisms when exposed to toxins, irrespective of the specific toxic source. He identified three stages through which an individual progresses, and labeled the process the *General Adaptation Syndrome* (GAS) (Selye). Attempting to maintain a level of homeostasis, an individual exposed to a noxious agent or event will enter the first stage, adaptation. An ‘alarm reaction’ calls to arms the individual’s internal and/or external defense mechanisms. Next, after the individual survives the initial reaction, comes a stage of resistance. However, this resistance is not infinite and, finally, just as a machine under stress wears out, so does an individual. The constant strain of living under stress takes its toll and the individual subsequently enters the stage of exhaustion. As the individual’s ‘adaptation energy’ becomes depleted, resistance is lowered and death eventually occurs (Selye). The GAS aptly describes the rudimentary stages of linear progression within the stress cycle, yet falls short in discussing the multi-level complexity of this topic.

Indeed, researchers have been largely unable to even agree on any one definition of the concept of stress. In fact, Selye (1993) asserts that “remarkably few people define the concept in the same way or even to bother to attempt a clearcut definition” (p. 7). To that end, Monat and Lazarus (1991) have delineated stress into three types – physiological, social and psychological. Physiological stress is concerned primarily with the disturbance of tissue and other physical systems. Social stress views the social unit as the disrupted factor. Psychological stress encompasses those threats to the individual’s psychological well-being. While these factors may be related, the nature of the relationship is not entirely clear (Monat & Lazarus). Monat and Lazarus, in their attempt to include all pertinent factors, define stress as “any event in which environmental demands, internal demands, or both *tax* or *exceed* the adaptive resources of an individual, social system, or tissue system [*italics in text*] (p. 3).

Therefore, stress can be assumed to arise when one appraises a situation (or combination of events) as threatening or otherwise too demanding and does not have an appropriate coping response (Cohen, S., & Wills, 1985). This is the type of situation in which the person perceives that it is important to respond, but an appropriate one is not available. One single event may not place great demands on an individual’s ability to cope with the situation; however, when the problem is persistent and on-going, as is HIV, it may strain the resources and problem-solving capacity of the individual (Cohen, S., & Wills). Feelings of helplessness arise because of the perceived inability to cope with the situation, taxing one’s skill and emotional levels beyond capacity. Without adequate assistance, this may subsequently lay the groundwork for maladaptive stress reactions such as illegal drug use.

COPING

Although stress and its damaging effects have been studied for over a hundred years, the concept of coping can trace its roots to the 1940s and 50s, during World War II and the Korean War, when numerous studies into the effects of stress under military combat were spawned (Lazarus & Folkman, 1984). Lazarus and Folkman posit coping as a constantly changing process involving cognitive and behavioral aspects. As such, they contend that coping is a process that it is concerned with what a person actually thinks and does in reaction to the specific stressful event (Lazarus & Folkman).

Therefore, coping is something that protects an individual from being psychologically or physically harmed by an outside force exerting stress upon the organism (Monat & Lazarus, 1991). Individuals may engage in several different forms of coping such as problem-focused coping in which the individual attempts to improve his/her concrete situation (Monat & Lazarus). Another type, emotionally-focused coping, refers to the thoughts or actions taken to relieve the emotional toil of the stressful event, yet does not actually remove the condition (i.e., it helps make a person feel better') (Monat & Lazarus). Other forms of coping include defense mechanisms such as denial, which may help a person keep from feeling overwhelmed. Unfortunately, denial can also result in an avoidance of doctors and/or medication adherence. Thus, it is recognized that all coping mechanisms may have positive and negative influences on the individual (Monat & Lazarus). In addition, coping can also be determined by the use of adaptation resources. One such coping resource that has received considerable focus, and is the one under investigation, is social support.

Social Support and the Buffering Concept

There has been a rapid growth in the literature suggesting the potential benefits of social support for various populations that Lazarus and Folkman (1984) classify as falling under the heading of coping. Social support, usually thought of as positive factor, may intervene between a stressful event and the stress reaction by attenuating or preventing a stressful appraisal of the situation, thus increasing the person's ability to respond appropriately to the situation (Maguire, 1991; Monat & Lazarus, 1991). That is, the perception that others can provide necessary resources may redefine the potential for harm posed by a situation and/or bolster one's perceived ability to handle the additional demands (Cohen, S., & Wills, 1985).

One of the themes in the literature is that social support acts as a buffer to stress and its destructive consequences. It can help prevent stress by making harmful experiences seem less consequential or provide valuable resources for coping when stress does occur (Sarason, Sarason & Pierce, 1990). The case for the buffering hypothesis is still being debated (Baron & Kenny, 1986; Cobb, 1976; Cohen, S., & Wills, 1985; Thoits, 1982; Thoits, 1986; Zedeck, 1971). Blaney et al. (1991) found no statistical buffering relationship between social support, life events, hardiness and the individuals level of stress. However, Pearlin, Menaghan, Lieberman and Mullan (1981) reported mixed results in their exploration of the buffering effect of coping and social support upon stress related to job loss, with support and/or coping buffering the effect of job loss upon the respondents economic strain, self-esteem, feelings of mastery and level of depression. Other studies have also reported mixed results. For example, Bass, Noelker and Rechlin (1996) examined the moderating influence of service use upon caregivers of elderly

individuals. They found that several forms of service support (i.e. personal care, household assistance, etc.) were significant buffers of caregiver depression, social isolation and caregiver health deterioration.

One reason for the confusion is the diverse ways of defining and measuring the social support variable (Cohen, S., & Wills). Another common error has been equating social networks, the number of relationships a person has, with social support, the perception of the value of the social interaction (Lazarus & Folkman, 1984). Many studies treat the concepts interchangeably. However, inherent in this equivalence is the assumption that a larger and broader network is better than a smaller one (Lazarus & Folkman). Additionally, it is assumed that having a relationship is the same as perceiving/receiving support from it (Lazarus & Folkman). Thus, *socially supportive relationships* may serve as a buffer against the effects of stress and protecting people from some common physical/psychological reactions such as lethargy and/or guilt (House, 1981).

When assessing social support, perceived support is the most proximal feature utilized by an individual as to the level of supportiveness (Lazarus & Folkman, 1984). Vaux (1988) posits the importance of the individual's perception of supportive relationships, and asserts that this follows a long tradition of emphasizing a person's construction of the world. Citing the Roman philosopher Epictetus, Vaux writes, "Men are disturbed not by things, but by the views which they take of things" (p. 16). This has been illustrated in modern times by Gore (1978) who found that unemployed men who *felt* unsupported had higher levels of illness than those who *felt* supported. Similarly, G. Andrews, Tennant, Hewson and Schonel (1978) found that psychological impairment in a

crisis was associated with low levels of expected support from friends, relatives and neighbors. Network measures were unrelated to the impairment (Andrews, G. et al.). The basic assumption put forth by Lazarus and Folkman is that “people will have better adaptational outcomes if they receive or *believe that they will receive* social support when it is needed” [italics added for emphasis] (p. 259).

In general, social supports comprise a 2X3 matrix consisting of two modes and three functions of social support (Vaux, 1988; Zarit, Pearlin & Schaie, 1993). Modes of social support (i.e., the individual, agency, etc. providing the support) may consist of informal and/or formal sources (Zarit et al.). Informal sources of support may include partners, family, friends, neighbors and similar non-professional helping sources. Formal sources include professionally trained individuals such as social workers, nurses, and physicians, as well as larger organizational structures such as homeless shelters, drug treatment programs and respite care. A unique support form which possesses some qualities of each is the Church (or any place of worship). As such, direct interaction with clergy may be categorized within the realm of formal support, as they possess special training and knowledge. However, support from an individual’s level of spirituality (i.e., his/her personal relationship with God), or derived from interacting with other members of the congregation would be considered informal.

Although various functions of social support have been identified in the literature, three categories are most consistently highlighted. They are emotional, informational and tangible support functions (see Gottlieb, 1981 or Lin, 1986 for a typological review). It is important to note that these functions are not mutually exclusive, and all can be provided from one individual source (Lazarus & Folkman, 1984). Emotional support is provided

to an individual to enhance his/her emotional strengths, and shows that the person is accepted and valued. This has also been called expressive support and esteem support. Informational support is helping the individual to define and understand the problem in order to be better able to cope. It is also known as advice and appraisal support. Tangible support is the provision of financial aid, material resources and other concrete services. This can include respite care type services that contribute to providing the person with additional time to address the stressful event. It is also known as instrumental support.

Social support is an integral component of the Stress-Coping Model, with variations widely used to describe the coping behaviors of persons with a variety of health/mental health circumstances; including, but not limited to – aging (Costa & McCrae, 1993); cancer (Roberts, Cox, Shannon & Wells, 1994); chronic illness (Felton, Revenson, Hinrichsen & Gregory, 1984; Taylor & Aspinwall, 1993); decision-making (Janis, 1993); mental health problems (Billings & Moos, 1984; Farhall & Gehrke, 1997; Rabkin, 1993); substance abuse problems (Moos, 1992); and HIV/AIDS (Hansell et al., 1998; Hansell et al., 1999; Wiener, Theut, Steinberg, Riekert & Pizzo, 1994). It has also been used to help explain the impact of environmental stressors such as – disasters (Weisaeth, 1993); divorce (Nelson, 1989); migration (Shuval, 1993); peer pressure (Wills, Vaccaro & Benson, 1995); stressful jobs (Ramathan, 1995); war (Milgram, 1993); and the daily decisions of very young children (Kliewer, Fearnow & Walton, 1998). Proponents of the model suggest that it can be used to better understand coping under life situations that produce measurable levels of stress (Moos, 1997). However, within the pediatric HIV/AIDS literature there has been little published research that investigates the

impact of caring for a child infected/affected by HIV/AIDS (Sherwen & Boland, 1994; Taylor-Brown & Kumetat, 1994; Cohen, F., 1994; Janson & Ammann, 1994).

USE OF THE STRESS-COPING MODEL WITH OTHER POPULATIONS

Social support in one form or another is utilized by individuals of all race and ethnicities in a variety of stress situations. However, cultural differences in social support utilization patterns have been found. The importance of informal support systems among African-Americans, especially familial, is well documented in the literature (W. Hays & Mindel, 1973; Martineau, 1977; Neighbors & Jackson, 1984; Stack, 1974). Extended family members as a means of social support is a more salient structure for Black families than it is for Whites (W. Hays & Mindel; Hunter, 1997). W. Hays and Mindel report that Black families interacted with extended kin more and perceived all kin as more significant in their lives than their White counterparts, except for parents (which were considered equally important by Blacks and Whites). They contend that Black individuals rely more heavily than White individuals on a wider network of relatives as sources of support during times of crisis (W. Hays & Mindel). Other minorities such as Hispanics, Central-American Immigrants and Japanese, who may see the majority-focused external environment as hostile, also turn frequently to this natural helping system to fulfill their emotional and tangible needs (Leslie, 1992; Hanline & Daley, 1992; Koyano, Hashimoto, Fukawa, Shibata & Gunji, 1994).

One of the primary responsibilities of any family is the care and nurturance of its children. As such, there are two main types of stress experienced by primary caregivers of children; those associated with 'normative' child-related tasks (i.e., minor daily hassles), and those imposed through a major life event such as a childhood illness or

disability (Breslau & Davis, 1986; Breslau, Staruch & Mortimer, 1982; Crnic & Greenberg, 1990; Garner & Thompson, 1978; Kovacs & Feinberg, 1982; Pless & Satterwhite, 1975). Crnic and Greenberg posit that the frustration experienced by parents through daily hassles, although singularly may have little significance, can cumulatively become a meaningful stressor for the parent without appropriate social support. Spousal, friendship and community support acted to moderate the daily hassles of mothers in the study (Crnic & Greenberg). Other situational/environmental stressors that affect the parenting role may also include (but are not limited to): single parenting (Weinraub & Wolf, 1983, as cited in Crnic & Greenberg); poverty/low SES (Werner & Smith, 1982, as cited in Crnic & Greenberg); and number of children in the home (Crnic & Greenberg).

Despite the love and affection felt for a child, caregivers of children with a chronic and/or terminal illnesses continue to face an onerous task. As treatment protocols have advanced, once life-threatening and debilitating illnesses such as cancer and diabetes have resulted in longer life expectancies for afflicted children. Unfortunately, the child's health improvements may not be complete. Thus, parents may be faced with on-going therapeutic responsibilities, concerns about the child's future, and the new unknown course of the illness (Avison, Turner, Noh & Speechley, 1993). For children with cancer, perceived social support by parents was an "extremely important predictor of distress" (p. 91), and, although a moderating effect was not found, "these resources do seem to play some role in reducing the effects of the chronic strains associated with giving care" (Avison et al., p. 92).

Although there are important differences, living with cancer has several similarities to an AIDS diagnosis (which many times includes cancer). There are fears of

contagion, appearance changes, associated stigma and other stressors (DiMatteo & Hays, 1981; Revenson, Wollman & Felton, 1983). This is especially true for women with breast cancer, with the “emotional trauma that results from the diagnosis and treatment...as potentially damaging as the disease itself” (Roberts et al., 1994, p. 158). Post-operative breast cancer patients with higher levels of perceived support had fewer reported adjustment problems than those with lower levels of support (Northouse, 1988). In addition, Peters-Golden (1982) and Funch and Mettlin (1982) also found that social support was positively related to psychological adjustment in breast cancer survivors.

Another area that has explored the stress-social support relationship is the mental health field. Erickson (1968) explained similarities he found between MMPI profiles of parents of persons with emotional disturbances and parents of persons with mental retardation. This was the first time someone had used a stress-related concept to explain the impact of mental illness on family caregivers. This development was significant, as it demonstrated that the problems that caregivers develop are a direct result of stress caused by the impact of the care recipients’ mental health problems. Research in this vein has gone a long way in reducing stigma and blame for caregivers and in improving services for mental health consumers and their families (Biegel, Farkas & Flint, 1989; Biegel, Milligan, Putnam & Song, 1994; Biegel, Sales & Schulz, 1991; Bulgar, Wandersman & Golman, 1993; Friesen, 1996; Potsazanik & Nelson, 1984).

Although families have been the first line of support for ill members since antiquity, they were often thought of by professionals as part of the problem rather than as part of the solution. For example, the concept of the schizophrenogenic mother (i.e., that a particular pattern of bad mothering causes schizophrenia) has no basis in fact.

Indeed, parents/caregivers may relate to the schizophrenic child differently, but this is probably a reaction to the child's disorder. Parenting style is not a fundamental cause of schizophrenia. However, as a result of the body of research outlined, families are now seen as a source of strength and support for individuals suffering from a variety of maladies rather than as a casual factor in the development or exacerbation of the illness (Solomon, 1994). In addition, as medical budget strains have occurred, the focus has shifted to have caregivers provide care for their family members; however, these duties have brought additional stress and burden on these families members as they provide this care. It is this “caregiver burden” and its impact on the caregiver that is now the focus of study – albeit with the child and caregiver’s HIV status as the stressor.

USE OF THE STRESS-COPING MODEL WITH THE ADULT HIV/AIDS

POPULATION

Within this literature base, various permutations of stress-based coping models have been used to conceptualize the impact of becoming HIV positive or receiving an AIDS diagnosis on either the infected individual or other family members, as well as the effects of social support upon the caregiver and/or the afflicted individual. Many phenomenon often associated with burden are incorporated into these studies - issues such as financial problems, increased stress, social stigma, depression, anxiety, and even tobacco use are measured and discussed.

A diagnosis of AIDS can have a devastating effect on an individual’s support system, precisely at the time when stress is greatest. In addition to alterations to one’s life due to medical regimes, bodily changes and potential ostracism, feelings of guilt, loss, fear of death and rejection are a few of the stressor experienced (Macks, 1987). The

disclosure of AIDS may serve to destroy previously supportive relationships. Gay individuals may have to 'come out' to parents and other family members, and partners/spouses of HIV positive individuals may themselves be positive through exposure by their loved one. Therefore, "the couple must deal with the impact of AIDS on their relationship as well as the uncertainty of the partner's or spouse's future health" (Macks, p. 33).

One of the earliest looks at the application of the stress-coping model to the AIDS population was conducted by Zich and Temoshok (1987). They found the diagnosis of AIDS to be a significant stressor. However, all types of social support were inversely correlated to the HIV positive individual's level of hopelessness and depression, such that the more social support received the less hopeless and depressed the individual may be (Zich & Temoshok). It is reported that study participants found social supports helpful throughout the entire process, with lovers, family and friends critical in maintaining functionality (Zich & Temoshok). Similar results can be found throughout the AIDS literature (Hall, V., 1999; R. Hays, Turner & Coates, 1992; Ingram, Jones, Fass, Neidig & Song, 1999; Leserman et al., 1999; Namir, Wolcott, Fawzy & Alumbaugh, 1987).

It is important to note a significant limitation when reviewing the social support literature on adults infected by HIV/AIDS. Thus far, the emphasis has been on White, middle class, gay males (Barbee, Derlega, Sherburne & Grimshaw, 1998). Barbee and colleagues only found two studies examining Black gay men and one that included women in the sample. This investigator was able to locate two additional articles either focusing solely on Black gay men or comparing them to their White counterparts (Gant & Ostrow, 1995; Ostrow et al., 1991). However, to date, it appears that there are still no

articles that have focused solely on women within a stress-coping paradigm outside of their roles as caregiver. Nor is there any research solely focusing on other groups such as Hispanics and straight men. Given the literature citing the importance of family support among African-Americans, Gant and Ostrow were surprised to find only a weak, nonsignificant relationship between family support and mental health. They posit that one explanation may be that traditional measures may not be sensitive to the various dimensions of familial support utilized by African-Americans (Gant & Ostrow). Therefore, it may be found that different stress-social support relationships exist for people of color, people from lower SES, heterosexuals and women.

Although differences exist due to culture, gender, SES, sexual orientation and other factors, there may be challenges that are common to all caregivers. In a recent study of caregivers of persons with AIDS (PWA's), decreases in work performance and economic burden were common stressors that were not unusual for many caregiving experiences (Raveis & Siegel, 1990). Caring for an individual infected with HIV/AIDS also possess several unique characteristics such as uncertainty, multiple premature losses and stigma by association (Brown & Powell-Cope, 1991) that Goffman (as cited in Turner, Pearlin & Mullan, 1998) terms "courtesy stigma" (p. 138). Unfortunately, because of these stressors, both common and unique, the acquisition and use of social support for AIDS caregivers may prove difficult. Indeed, Turner and her colleagues found that close to half of their respondents received no informal assistance with caregiving tasks, and over 14% felt that they had no confidant to turn to when feeling overwhelmed. Interestingly, HIV positive caregivers perceived greater support from family and friends than those caregivers that were HIV negative.

It is clear that HIV positive individuals, as well as their caregivers, are under an enormous burden due the variety of stressors present. As such, within this model, the positive diagnosis and the subsequent care-related behaviors by the caregiver serve to increase the caregiver's stress. This stress, in turn, has an impact on the caregiver - both in the behaviors they use to cope with their loved one's illness and through direct impacts to their own physical and mental health. Social support, encompassing the source and functional range, can assist in alleviating feelings of helplessness, depression and isolation. However, many of these stresses may be heightened when caring for an infected/affected child. Mothers and other caregivers must face challenges parenting children who may lose, in addition to their own life, multiple family members. Family placement decisions must be considered, as well as school issues and developmental milestones. Events such as childhood playdates, which other families take for granted, can be impossible for those families isolated due to societal fear. The next section will review the relevant literature addressing the experiences of those individuals caring for a child infected/affected by HIV/AIDS, as well as their methods of coping with the multitude of stressors present.

USE OF THE STRESS-COPING MODEL WITH THE PEDIATRIC HIV/AIDS POPULATION

Although pediatric HIV/AIDS had been acknowledged as early as 1982, psychosocial research examining the effect upon caregivers of children infected/affected by HIV/AIDS did not emerge in the literature until 1992 – ten years later (Caldwell & Rogers, 1991; Mayers & Spiegel, 1992). Since that time, the literature has averaged one

qualitative journal article per year (n=9), and less than one quantitative article (n=6) each year (the first published in 1994).

Given the immensity of this problem for thousands of families, it is difficult to imagine such a lack of attention by the professional community. However, Dr. Phyllis Hansell, Professor and Acting Dean of the College of Nursing has confirmed this paucity of research at Seton Hall University. In a personal communication (December 3, 1999), Dr. Hansell, who has authored or been affiliated with 4 of the 15 published articles, acknowledged the lack of, and further need for, research on this topic area.

Initial research focusing on caregiver's of children infected/affected by HIV/AIDS followed the logic of the Stress-Coping theory and discussed stress in terms of a reaction to a positive diagnosis, with more recent literature integrating the concept of social support. However, due to the statistical models utilized, only the main effect of social support upon the caregiving relationship has been explored, with none having done so in a moderating capacity. Some critics of the theory's utilization with the HIV positive population posit that the stressful impact of caregiving is not being caused by the stress of caring for an ill child, but instead uses the concept of race, poverty and other stressors to describe a pre-existing condition that is exacerbated by this disease (Kalichman, 1998). Kalichman highlights studies that have found that a diagnosis of HIV is not listed as the top stressor for infected adults, and that other more pressing needs must first be met such as housing, food, etc. F. Cohen, Nehring, Malm and Harris (1995) posit that, "it is *possible* that the extent of further family disruption caused by HIV disease may not be as readily apparent or is experienced differently because of other concomitant stresses and disruptions due to the conditions and struggles of everyday

existence” [italics added] (p. 253). However, they argue that without further research into this area focusing on the mother (caregiver)-child relationship, as well as the entire family system, these questions will go unanswered (Cohen, F. et al.). In an attempt to address the various questions regarding the effect of caring for a child who is infected/affected by HIV/AIDS, the existing qualitative and quantitative studies will be examined, with relevant findings highlighted and the strengths and limitations discussed.

Caregivers of Children Infected and/or Affected by HIV/AIDS - Qualitative Studies

The first article focusing on the stress of caring for a child infected by HIV/AIDS, a qualitative article published in *Health and Social Work*, described a parental support group to prevent social isolation due to the lack of available social support (Mayers & Spiegel, 1992). The authors found isolation from family, friends, and even the medical staff to be a recurrent theme throughout the group meetings. In addition, during those times when support could be found, topics such as death were off-limits “...consequently [the mother] avoided these friends to keep from burdening them” (Mayers & Spiegel, p. 189). This sense of isolation 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; Wiener, 1998).

For many HIV negative caregivers, the task of caring for an infected child is a new experience requiring substantial role redefinition and adjustment (Hansell et al., 1999). However, when compared with uninfected caregivers, HIV positive mothers reported higher incidences of isolation, as well as fewer financial and support resources (Hackl et al., 1997; Mellins & Ehrhardt, 1994). Hansell and her colleagues also found

that HIV positive mothers presented with multiple and more complex problems than their HIV negative counterparts.

In an examination of the mother-child relationship, S. Andrews, et al. (1993) reported that one-third of the respondents to their qualitative interview relied on their children (16+ years old) as a source of support (Andrews, S. et al.). Eight percent stated that they also relied on their younger children (under 16 years old) (Andrews, S. et al.). As such, children not only take but are also good at offering affection to their caregivers. One mother states, "If I didn't have my kids, I'd be dead by now"...another tells of her son, "If I'm crying, he'll come up to me and ask me 'What's wrong mommy?'" (Andrews, S. et al., pp. 195 & 196). 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.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). At the same time, several HIV positive mothers viewed the role of motherhood as burdensome, whether or not the child was HIV positive (Andrews, S. et al.).

Illness management was listed as a major stressor, including multiple hospitalizations and juggling outpatient visits (Caliandro & Hughes, 1998; Mellins & Ehrhardt, 1994). This was especially burdensome for children placed with foster families, who, as a group, were much sicker than children still living with their birth mothers (Cohen, F. et al., 1995). Communicating with health care providers and social service agencies proved to be stressful, with "health care providers that are supposed to know about [AIDS] and are in the field giving services... Well, they turn their noses up at us and they're insensitive to our needs and to what the sickness can do" (Mellins & Ehrhardt, p. s56).

Subsequent qualitative articles have identified respite care to be an important source of support for caregivers attempting to juggle medical appointments. In addition, managing multiple medical appointments was identified as “a problem for seropositive mothers, especially when the child is also seropositive” (Andrews, S. et al., 1993, p. 197; Mellins & Ehrhardt, 1994). It was the most frequently cited need, with parents having very little time to meet their own needs (Mellins & Ehrhardt).

Mellins and Ehrhardt (1994), stating that its role within their sample of inner-city families could not be 'overemphasized', highlighted the role of religion as a coping strategy. Many grandmothers expressed a realization to their 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.

It is important to acknowledge the limits of these studies. Several of the samples were quite small, ranging from 3 to 80 people, as listed in Table 3 below. However, the recurrent themes among the articles help lend strength to the overall findings of the articles. The studies profiled illuminate the many challenges faced by caregivers, as well as provide some insight into ways to alleviate some of the stress. The sense of isolation and need for support ties this body of work together in a tapestry that shows the burden perceived by all caregivers, whether foster/adoptive parent, grandparent or birth parent. Despite the rich information provided, none of the studies utilized comparative data to

determine if these stresses were truly a result of caring for an HIV positive child, or an artifact due to other factors. Also, the studies as a group did not clearly explain the ‘researcher/interviewer as instrument’. As such, the researcher’s own reference frame (i.e. gender, race, etc.) should be discussed, as well as any special training received, to explain and reduce the potential influence of personal bias. To that end, there is no mention made regarding the interviewers utilized to conduct the semi-structured interviews in 6 of the 9 studies. Lastly, although several of the studies alluded to the potential moderation of stress through the provision of social support, Hansell and her colleagues (1999) assert from their findings that “stress...for the seropositive caregiver of a child with HIV/AIDS is not significantly buffered by the increased levels of social support” (p. 301). However, this overgeneralization is not warranted from the type of analysis provided.

Table 3: Qualitative Studies – 1992 to Present			
#	<i>Author(s)</i>	<i>Year</i>	<i>Methodology</i>
1	Mayers & Spiegel	1992	Overview of support group for parents and caregivers of HIV infected children. (n=30 families with 35 infected children)
2	Andrews, Williams & Neil	1993	Two semi-structured interviews. HIV positive mothers who have had at least one pregnancy while seropositive. (Interview #1, n=80; Interview #2, n=20)
3	Mellins & Ehrhardt	1994	Semi-structured interviews of caregivers, siblings and HIV infected children. (n=52 participants comprising 25 families)
4	Cohen, F., Nehring, Malm & Harris	1995	Semi-structured interviews of caregivers of an HIV positive child under 3 years of age. (n=8, 4 birth families and 4 foster families)
5	Hackl, Somlai, Kelly & Kalichman	1997	Semi-structured interviews of HIV positive women. (n=8; 7 of the 8 were mothers)
6	Wiener	1998	Overview of telephone support group for mothers whose children have died from AIDS. (n=5)
7	Caliandro & Hughes	1998	Phenomenological interviews of grandmothers caring for an HIV positive grandchild. (n=10)
8	Heath & Rodway	1999	Open-end questionnaire (n=12) and semi-structured interviews (n=6) of HIV positive women. (9 of the 12 were mothers)
9	Hansell, Hughes, Caliandro, Russo, Budin, Hartman & Hernandez	1999	Case examples described to profile social support program. (n=3)

Caregivers of Children Infected and/or Affected by HIV/AIDS - Quantitative Studies

Utilizing a non-random sample, Hardy and her colleagues (as shown in Table 4 below) examined the coping strategies of parents with children who were either HIV positive, diagnosed with cancer, or healthy (Hardy, Armstrong, Routh, Albrecht & Davis, 1994). The researchers used a cross-sectional, comparison/control group design, with 20 children in each group. Social support was found to be non-significant across groups utilizing ANOVA and multiple regression analyses, although the social support variable utilized had no distinction made for the range of potential support sources and functions.

In fact, the only significant finding was that the caregivers of HIV positive children exhibited significantly more wishful thinking than members of the other groups (Hardy et al., 1994). However, it is important to note that the groups contained some significant differences which may have confounded the findings such as ethnicity (more White caregivers in the cancer group), partnered (more married people in the cancer group), SES (higher SES in the cancer group), and foster care status (half of the children in the HIV group were in foster care, while none of the others were) (Hardy et al.). Other potential limitations included a moderate sample size with no mention of statistical power, potential violations of the underlying assumptions of the analysis or the psychometric properties and applicability to this population.

Similar findings were reported by Wiener et al. (1994), with no significant differences found on scores of depression or self-blame in their sample of 101 HIV positive and negative caregivers of HIV positive children. Significant differences were noted for HIV negative caregivers who had higher anticipatory grief scores, and HIV positive caregivers who reported higher anxiety scores. The authors believe that this may be due to the non-infected caregivers accepting the idea of having to live without the child, while the infected parents experience heightened anxiety as they may have to face placing the child due to their own failing health (Wiener et al.). Surprisingly, no relationship was found between parents scores and the child's degree of debilitation, until the child was extremely ill (Wiener et al.). It is hypothesized that this may be due to the illness/recovery pattern experienced by the parents, and the defense mechanism which protects them from this 'emotional roller-coaster' until death is imminent (Wiener et al.). Social support was not examined in this study. The article did not state if the measures

utilized were standardized on this population or diagnostic calculations were conducted to determine the appropriateness of the data.

In their first study, Black, Nair and Harrington (1994), compared four groups of caregivers (HIV positive with intervention, HIV negative with intervention, HIV positive with no intervention, and HIV negative with no intervention) and reported no main effects for child abuse potential, stress, support or functioning related to the child's HIV status. The study only identified support as informal or formal, with no descriptions as to specific sources or support tasks needed. In addition, as illustrated in Table 4, the study utilized a relatively small sample and made no mention of potential statistical violations such as homogeneity of variance. Their second study examined social support and maternal HIV status. Support was dichotomized as high/low, with no consideration of source or function, and there were no main or interaction effects noted for the measures. However, utilizing videotaped mother-child interaction sessions, the authors found that HIV positive mothers with higher support were more involved with their infants during feeding (Black et al.). The researchers acknowledge the limitations of their study, stating that they "cannot be sure that the scales were valid measures of the constructs under consideration" (Black et al., p. 610). They further assert that future studies should examine support more carefully (Black et al.).

The theoretical framework utilized by Hughes and Caliandro (1996) was a melding of Lazarus and Folkman's work on stress theory, Vaux's theory of social support, and the theory of caregiver appraisal posited by Lawton, Kleban, Moss, Rovine and Glickman. The study's purpose was to examine the effect of caregiver stress, social support, and level of child illness on the caregiver's appraisal of the situation (Hughes &

Caliandro). No differentiation of social support was made for sources and/or functions, although its global identification was a significant predictor of caregiver appraisal. Surprisingly, the child's level of illness (according to the CDC guidelines) was not significant (Hughes & Caliandro). The authors contend that children, even though classified as asymptomatic, may have a spectrum of health-related difficulties, and, conversely, a child classified as symptomatic may not be perceived to be ill within the caregiver's perception (Hughes & Caliandro). They believe that children identified by the CDC's classification schema are not properly categorized due to these spurious influences that may have skewed the results. Lastly, the researchers make no mention of potential limitations such as the utilization of a small sample, no mention of statistical power, potential violations of the underlying assumptions of the regression analysis, or the potential interaction effects of the variables posited by the theories used.

Utilizing a convenience sample of HIV positive and negative caregivers of infected children, Rose and her colleagues attempted to examine their coping styles within the Lazarus and Folkman framework (Rose, M., & Clark-Alexander, 1998). Social support was measured using a seven question scale with questions such as, "How lonely are you?" (p. 60). These questions were further divided into measures of support from family and friends, with HIV negative caregivers perceiving significantly stronger support from both sources (Rose, M., & Clark-Alexander). In addition, 80% of the sample used prayer as a method of coping with the stress of caring for an HIV positive child (Rose, M., & Clark-Alexander). The authors, citing Lazarus and Folkman's theory, conclude that improved coping skills, including increased social support, will affect healthy outcomes (i.e., buffer the stressful events) (Rose, M., & Clark-Alexander).

However, interactions were not utilized, nor was there evidence of having tested the potential violation of statistical assumptions, such as normality and equality of variance for the ANOVA model used. As a result, it is unknown whether harmful problems were present which may have led to biased findings. Lastly, bivariate analyses can demonstrate significant differences on the measures between groups, yet can not prove the causality inferred (Rose, M., & Clark-Alexander).

A subsequent study also exploring the relationship of social support to caregiver outcomes utilized an intervention to ‘boost’ the availability and utilization of social support. This intervention, which was found to be partially effective, used a modified case management approach to reduce stress by enhancing the social support network (Hansell et al., 1998). Utilizing a four group design (HIV positive with intervention, HIV negative with intervention, HIV positive with no intervention, and HIV negative with no intervention), the researchers examined the effect of the intervention on levels of stress, coping and social support over a 6 month period.

After conducting the appropriate diagnostics tests to ensure the appropriateness of the data, repeated measures MANOVA revealed no statistical differences on levels of stress and coping. However, there was a statistically significant increase over time in the HIV negative experimental group’s scores. Although the stress, coping and social support scores for both HIV positive groups were worse than both HIV negative groups at both time points, the HIV positive experimental group’s social support score dropped to the lowest of all four groups after the intervention (Hansell et al., 1998). This confounding effect has led to criticism of their conclusions (Eldredge, 1998). Lastly, the authors conclude that the “results are not conceptually congruent with the work of

Lazarus and Folkman (1984) relative to the interactive theory of stress as to the buffering effect of social support on stress by enhancing coping” (Hansell et al., p. 85). Yet, this conclusion is not possible given the lack of testing for possible interactions.

Table 4: Quantitative Studies - 1994 to Present			
#	Author(s)	Year	Methodology
1	Hardy, Armstrong, Routh, Albrecht & Davis	1994	Examined parental coping strategies using comparison/control groups. (n=20 HIV positive children; n=20 child with cancer; n=20 healthy children) Analysis: ANOVA, multiple regression (no interactions)
2	Wiener, Theut, Steinberg, Riekert & Pizzo	1994	Psychological adaptation of caregivers of HIV positive children. (n=101) Analysis: t-test, ANOVA
3	Black, Nair & Harrington	1994	Two studies Examining whether support could offset stress of HIV positive mothers (n=43; n=199) Analysis: t-test, MANCOVA, Repeated Measures MANCOVA (with interactions)
4	Hughes & Caliandro	1996	Relationship between social support, stressors and burden for caregivers of children with AIDS (n=49) Analysis: correlations, multiple regression (no interactions)
5	Rose, M., & Clark-Alexander	1998	Coping and quality of life of caregivers of children with HIV/AIDS. (n=79) Analysis: ANOVA
6	Hansell, Hughes, Caliandro, Russo, Budin, Hartman & Hernandez	1998	Effect of social support ‘booster’ on levels of stress, coping and social support (n=70) Analysis: Repeated Measures MANOVA (no interactions)

Overall, these studies demonstrate the various strains experienced by caregivers of children infected by HIV/AIDS and lay a foundation for further research into this area. However, each possessed numerous flaws which make the findings questionable such as the use of measures not created or standardized for this population, not conducting factor

analysis to determine validity of the measures with the samples, small to moderate sample sizes that may impact the power of the statistical analyses and introduce potential bias, findings regarding the value of social support are mixed and differ from those found in the qualitative research, limited utilization of the various sources and functions of support as an independent variable, discussing (or alluding to) the buffering effect of social support without using the appropriate analytical techniques for testing, and, lastly, one-third of the studies only used bivariate statistics in their analyses.

As discussed, there have been several common streams of research within HIV/AIDS and its impact on children and families. However, the available literature lacks well-developed empirical studies regarding the child's infection status and illness management tasks upon the caregiver's stress and coping responses, and the subsequent effect of various social support mechanisms (Sherwen & Boland, 1994; Sherwen & Tross, 1995). The majority of the empirical studies have not adequately tested this theory stream, and many others are based more on anecdotal clinical experience and semi-structured interviews. The Stress-Coping model appears to be relatively elastic and have a multitude of applications. It speaks specifically to the issues of this study, examining the stress factors impinging upon those caring for children infected/affected by HIV/AIDS, and the moderating effects of social support upon those factors. The numerous qualitative and quantitative studies within the literature utilize variants of the Stress-Coping framework to explain the stressful impact of caring for a child infected/affected by HIV/AIDS upon the caregiver. The study proposed will attempt to fill in some of the many gaps remaining in the literature.

USE OF THE STRESS-COPING MODEL IN THIS STUDY

Even though the documented problems of children with HIV/AIDS would appear to have obvious impacts for their caregivers, the specific burden related to the illness management tasks of the child and his/her HIV status, as well as the potential buffering effect of social support, has not been fully researched (Cohen, F., 1994; Sherwen & Boland, 1994; Sherwen & Tross, 1995; Taylor-Brown & Kumetat, 1994a; Taylor-Brown & Kumetat, 1994b). The limited research in this area lacks an appropriate theoretical framework, multivariate analysis, and adequate sample sizes (Cohen, F.; Sherwen & Boland; Sherwen & Tross; Taylor-Brown & Kumetat; Taylor-Brown & Kumetat). This study will build upon the previous body of work by providing a larger more representative sample, investigating additional variables not included in prior studies such as various sources of support, using the Stress-Coping model as a single theoretical explanation, and testing relationships among the variables used through the utilization of a multiplicative interaction regression model.

This study will focus on the caregivers of children infected/affected by HIV/AIDS. The purpose of this study is to explore the effects caring for an infected/affected child has on the stress and coping levels of the caregiver. Prior research in this area suggests that these caregivers are subject to burden due to the physical and psychological costs of caring for the infected/affected child. By filling this gap in the literature, this research will lead to a better understanding of caregiver needs and improvements in services to both the families and their ill family members.

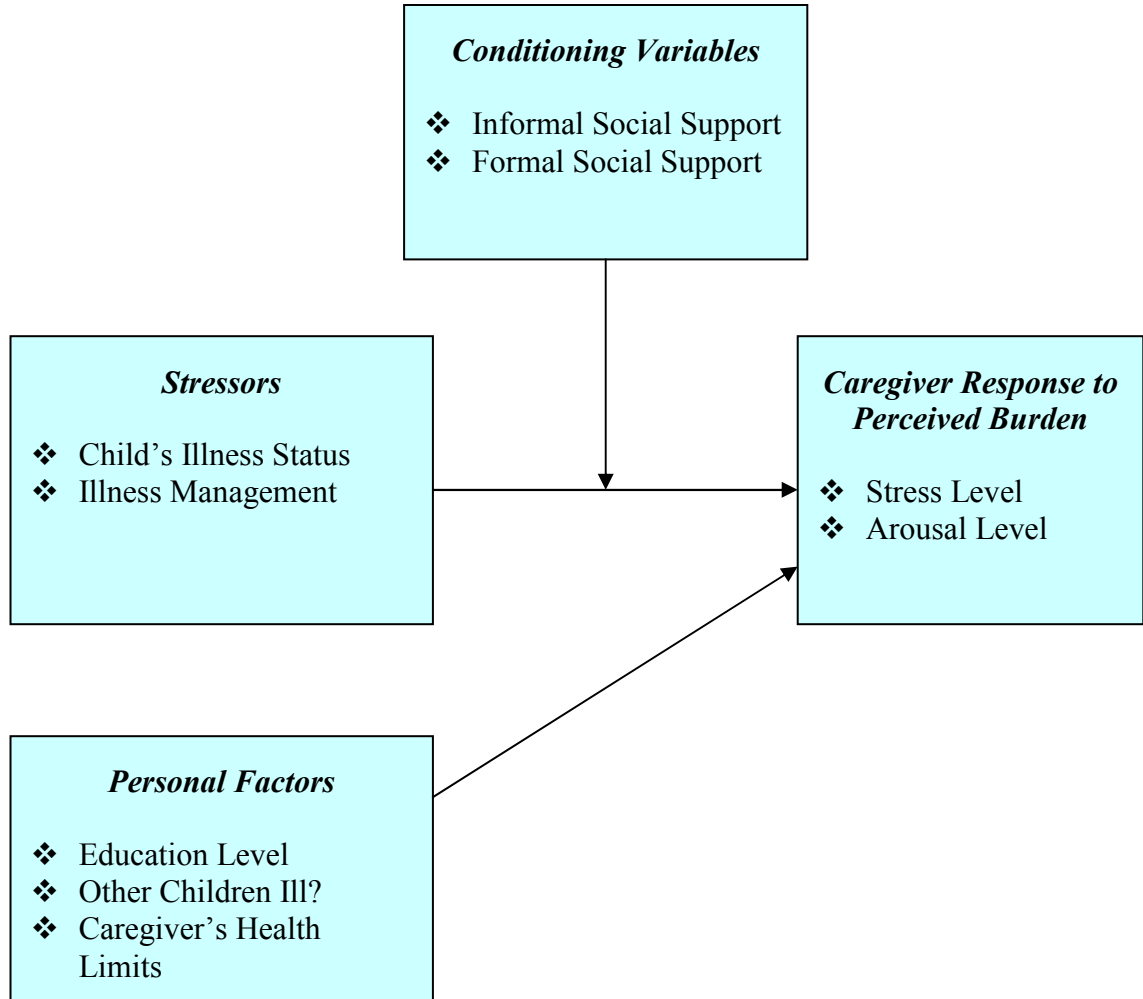
The specific Stress-Coping model used in this study is a variation based on the work of Schulz, Tompkins, Wood and Decker (1987). This model is based on their

review of the theoretical and empirical literature on caregiving in chronic illness, and encompasses adaptations of this model from the caregiver Stress-Coping models posited by House (1974) and George (1980) (as cited in Schulz et al.). Within the Schulz et al. model, the stressor of the child's illness diagnosis and caregiver illness-related tasks will be used. The impact of the perceived stress will be understood in this study as the level of perceived burden on the family caregiver. This application will also include the conditioning variable of social support, which will buffer the impact of the stressors on the perceived caregiving burden.

Although there are some variants of the Stress-Coping model, due to their common origins there exists consensus regarding the central variables relevant to understanding the phenomenon (Biegel et al., 1991). The central concept of this framework is that the existence of stressors, such as HIV/AIDS in a young child, serves as a source of stress to the caregiver. Within this framework (see Figure A) the independent variables, or stressors, impact the dependent variable of perceived stress. This model also provides for the inclusion of conditioning variables, which can affect the various processes.

Figure 4: Conceptual Model

A variation of the model utilized by Schulz et al. (1987)



Stressors

The underlying assumption of this model is that patient illness and disability represents an objective stressor to the caregiver (Biegel et al., 1991). The illness is typically characterized on any number of dimensions. For example, for caregivers of children infected/affected by HIV/AIDS, it may be on the medical regime and stigma

associated with a positive diagnosis. Therefore, the objective factors that evoke the patterned response are referred to as stressors (Selye, 1993). As such, the adaptive response to these objective factors can break down or go wrong because of psychological mismanagement (Selye). The independent variables, or stressors, in this study's model are the child's illness status and amount of illness management tasks. Johnson (1994), examining family's coping, reported that, "There is one common feature [to stress research] the extent and degree of burden appears to be related to the amount of patient dysfunction" (p. 312). Some of the factors that are likely to play a role in creating caregiver stress are the illness prognosis (i.e., terminal) and visibility (i.e., stigma associated with the illness), as well as the level of duties needed to care for the individual (Schulz et al., 1987).

The results of research on the caregivers of HIV positive children, loosely based on the Stress-Coping model, have borne out the tremendous burdens placed on caregivers (Black et al., 1994; Caliandro & Hughes, 1998; Hansell et al., 1998; Hansell et al., 1999; Hughes & Caliandro, 1996; Rose, M., & Clark-Alexander, 1998; Wiener, 1998). Within the Stress-Coping framework, the impact on caregivers is usually conceptualized as a reaction to the stress of caring for the sick child, as well as the additional burden of self-care – as in the case of infected mothers. Further, for many HIV negative caregivers the task of caring for an infected child is a new experience requiring substantial role redefinition and adjustment (Hansell et al.).

In addition, 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). This was especially burdensome for children placed with foster families, who, as a group, were much sicker than children still living with their birth mothers (Cohen, F. et al., 1995).

Thus, as discussed above, the association between these two factors and perceived caregiver burden has been documented in the literature - with a clear and strong positive relationship between the stressor and response to the perceived burden. However, it is important to note that, as posited by the theory, conditioning variables can moderate this stress and assist in supporting coping behaviors (Cobb, 1976; Cohen, S., & Wills, 1985).

Conditioning Variables

Conditioning variables are contextual or situational variables that moderate the caregiver response to the perceived burden (Biegel et al., 1991). Social support has always been a part of this equation, having its earliest roots in the work of Durkheim (as cited in Waltz, 1994). As such, social support variables have an indirect effect on caregiver well-being in that they influence the individual's perception of the burden (Schulz et al., 1987). Within this study, social support will be defined as interactions, either emotional, task or informationally oriented, with other individuals and/or groups that provide assistance and validation (Selye, 1993).

The social support variables discussed below will be utilized as buffers to the effects of the stressors on the response to the caregiver's perceived burden. There is some evidence of the power of social support as a conditioning variable for the burden of caring for a child infected/affected by HIV/AIDS (Hackl et al., 1997; Hansell et al., 1998; Hughes & Caliandro, 1996; Mayers & Spiegel, 1992). Social support variables have

been found to alleviate some of the burden placed on caregivers, although the buffering effects of these variables may not be as available to birth mother caregivers due to the stigma sometimes placed upon them by traditional sources of support. As such, two social support variable groups in this model will be explored as potential buffers to the effects of the stressor – informal and formal social supports, with the contributions of various sub-sources examined.

The first group of conditioning variables, informal social supports, includes those factors traditionally sought out as the primary line of defense against stressors (Gottlieb, 1988). Sources included are family, friends, children, community connections and church/spirituality.

Family. Emotional support, in particular, is provided primarily by those individuals possessing qualities such as trust and intimacy. Pearlin et al. (1981) posit that this is commonly found in married (or partnered) relationships. Although recognizing that this is not always the case, they argue that “marriage is an institution distinguished by its potential for being a continuous reservoir of emotional support, and, consistent with the findings from other research, we have sought to incorporate [this]...in our measure of support” (Pearlin et al., p. 347). Generally, spousal support for breast cancer patients is positive and beneficial, with the patient's husband the most pivotal person in the support network (Funch & Mettlin, 1982; Lichtman, Taylor & Wood, 1987; Roberts et al., 1994). Support from other family members has also been shown to contribute to the adjustment of individual's caring for individuals with HIV (Greif & Porembski, 1988). In addition, Lichtman et al. found high support from family correlated positively with psychological adjustment of cancer patients.

Friends. Social isolation 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 family, friends, and even the medical staff to be a recurrent theme throughout the group meetings. However, when available, Lichtman et al. (1987) found that when provided, high support from friends for breast cancer survivors assisted in improving patient psychological adjustment. In fact, Roberts et al. (1994) found that single women with strong support from friends fared as well as married women with support from husbands. Friends are often the main source of social support for women with HIV, as family relationships may have been severed (McCarroll, 1988; Namir, Alumbaugh, Fawzy & Wolcott, 1989). Friends can offer empathy and shared values, and have been associated with improved psychological adjustment in individuals with HIV (R. Hays, Catania, McKusick & Coates, 1990).

Child. S. Andrews et al. (1993) reported that many caregivers 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.; Caliandro & Hughes, 1998; Cohen, F. et al., 1995). 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). Further, women expected children (8 years old and older) to assist with household tasks, including caring for their younger siblings – some with AIDS (Walker).

Community Connections. There is a small, but growing body of literature demonstrating the therapeutic effects of support group for people caring for children and adults with HIV (Grief & Porembski, 1988; Kelly & Sykes, 1989; Mayers & Spiegel, 1992; Pearlin, Semple & Turner, 1988; Wiener, 1998). One of the earliest articles focusing on the stress of caring for a child infected by HIV/AIDS described 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 support community format. Through the group, caregivers are sustained in fulfilling their roles. In a study of professional caregivers of HIV positive clients, George, Reed, Ballard, Colin & Fielding (1993) found that supportive groups effectively buffered stress and improved the quality of the care provided.

Church/Spirituality. Although HIV infection has been met with opposition by many traditional religious institutions, religion/spirituality have been found to be a positive coping support (Leserman et al., 1992; Warner-Robbins & Christiana, 1989; Weitz, 1989). M. Rose and Clark-Alexander (1998) found that the vast majority of their sample used prayer as a method of coping with the stress of caring for an HIV positive child. Mellins and Ehrhardt (1994), stating that its role within their sample of inner-city families could not be 'overemphasized', have also highlighted the role of religion as a coping strategy. Many grandmothers expressed a realization to their 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.

The second conditioning group of variables is formal social support provided by professionals such as doctors, social workers and home health aides, that have also been shown to be important to this process.

Formal Service Support. Although some practitioners still admit to being very fearful and uncomfortable working with PWAs, many caregivers report satisfaction with their relationships with professionals. However, a significant minority has voiced concerns about these relationships (Biegel, Song & Milligan, 1995). Concerns about these relationships are both attitudinal (i.e. caregivers do not want to be stigmatized) and behavioral (caregivers strongly desire a mutual working-partnership with professionals and are dissatisfied when these do not occur) (Solomon, 1994). Some often feel blamed by professionals for their relative’s illness – which is an especially sensitive area when working with birth mothers, who *are* the agent of infection for the majority of children. Other caregivers complain about the lack of practical information provided about their relatives’ illness and care (Biegel et al.; Francell, Conn & Gray, 1988; Solomon, 1994).

Caregiver Response to Perceived Burden

The most frequent outcome measure utilized in Stress-Coping research is the level of perceived burden by the caregiver in response to the stressors (Biegel et al., 1991). Burden, as defined by Webster’s Dictionary (2000), is “that which is borne or carried; a load” (p. 1). Applied to this study, it can be translated to indicate the caregiver response

due to the impact of the child's positive HIV diagnosis and the time spent in illness-related tasks. This response can take two co-existing forms: stress – the internal response (positive/negative) to the perceived favorability of the external environment; and, arousal – the active response (positive/negative) to the perceived favorability of the external environment (Cox & Mackay, 1985; King, Burrows & Stanley, 1983; Mackay, 1980; Mackay, Cox, Burrows & Lazzerini, 1978). Thus, the perceived caregiver burden is defined as the cognitive (internal) and behavioral (active) responses caused by caring for a child infected/affected by HIV/AIDS.

The Stress-Coping model suggests that the stressor of child's health status, as well as the level of illness management tasks, will lead to the elevation of stress and arousal levels among caregivers. King et al. (1983) posit that, although distinct factors, stress and arousal tend to be raised in unison. This relationship is both direct and positive (i.e., the higher the level of given stressors, the higher the level of stress among caregivers). It is further posited that as the stressors increase there will be an increase in the caregiver's active coping response, sometimes referred to as their 'fighting spirit', that has been correlated with improved health and self-esteem (Leserman et al., 1992). This active response has also been shown to be strongly associated with perceived satisfaction with social support (Namir et al., 1987). This relationship is also direct and positive (i.e., the higher the level of stressors, the higher the level of arousal among caregivers).

Personal Factors

Figure 1 has an additional feature not directly derived from the Schulz et al.'s (1987) Stress-Coping model. It includes personal factors, or covariates, shown in prior

research to impact the caregiving context. These characteristics of caregivers have been recognized as contributing to outcome measures.

Caregiver's Highest Level of Education. 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 had attended some college; whereas none of birth mothers had, and only 50% of birth mothers 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) found that HIV negative caregivers in both of their studies had higher levels of education. M. Rose and Clark-Alexander (1998) reported similar findings.

Although there have been mixed results, some studies have demonstrated that education may play a role in medication adherence due to the often complex drug treatment regime (Hecht & Chesney, 1999; Moloney, Damon & Regan, 1998; Singh et al., 1996). Hecht and Chesney, in a review of the adherence research, found that demographic characteristics such as race/ethnicity, sex, occupation and income are poor predictors of treatment adherence. They found one study that indicated a significant relationship between low education levels and lower adherence rates. Mastering the administration of medicines for the child can be a very complex task. The cognitive ability of the caregiver plays an important role in successfully implementing the intervention (Moloney et al.). Missed doses reduce the efficacy of the medication, thereby allowing drug-resistant mutations to develop; this places the infected child at greater risk (Hecht & Chesney).

Another Child Ill? HIV infected mothers are often affected by numerous oppressive factors including poverty, substance abuse and prostitution. An estimated 44% of women in the United States have been infected by 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 individual 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. It is important to control for the potential effects of this additional stressor.

Caregiver's Health Limits. Differences between HIV positive and HIV negative caregivers are prevalent in the literature. Hansell and her colleagues (1999) found that HIV positive mothers presented with multiple and more complex problems than their HIV negative counterparts. However, dichotomous measures of caregiver illness status (i.e., HIV positive vs. HIV negative) have not been found to significantly predict caregiver burden (Hughes & Caliendo, 1996). Conversely, one of the findings in Caliendo and Hughes' (1998) qualitative study of grandmothers who are also caregivers

of HIV positive children was that of minimizing their own personal health needs. 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. In support of the impact of health concerns among both caregiver groups, M. Rose and Clark-Alexander (1998) discovered that HIV positive birth mother caregivers, while differing significantly on a number factors, did not score significantly higher than other caregivers on physical health. Therefore, due to the potential stressors placed on caregivers due to their own potential health limitations, whether HIV positive or not, this variable will also be examined.

SUMMARY AND RESEARCH QUESTIONS

From all of this literature several broad ideas become clear. First, the Stress-Coping Model appears to be an adequate framework to conceptualize the impact of caring for a child infected and/or affected by HIV/AIDS on caregivers. Secondly, this framework provides specific factors whose relationships can be measured.

It is clear that the challenges faced by caregivers of children infected and/or affected by HIV/AIDS are stressful. However, in addition to the familial stress, the pervasiveness of issue is also having adverse effects upon other systems such as child welfare, as well as society-at-large. Further exacerbating these problems are issues related to the inadequacy of service delivery and support systems to meet their needs. Although there has been some exploratory research on the impact of caring for a child infected/affected by HIV/AIDS on the family of these individuals, it has yet to be fully explored.

As discussed, there have been several empirical studies within the HIV/AIDS literature utilizing stress-related theories – with many of the independent, dependent,

moderating and control variables chosen for this study having been tested in prior research with various samples of HIV/AIDS infected individuals and/or their family members. However, none of the studies have attempted to examine each of the variables in the same model. As such, there is evidence for the inclusion of each of the individual variables and the model as a whole.

Some initial research in this area has been completed. However, a larger scale evaluation of the impact on caregivers of children infected/affected by HIV/AIDS should be conducted. Caregivers for children either infected or affected by HIV/AIDS are at increased risk of involvement with the child welfare system due to increased levels of stress associated with caregiver tasks such as frequent doctor visits and the associated health needs of the children. These stressors are in addition, in the case of birth mothers, to their own HIV/AIDS status. This study will utilize questions that have been used on similar populations, or based closely on such instruments, thus allowing for some comparisons to other groups of caregivers. This research will attempt to answer the following 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)?

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?
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?