

CHAPTER 6

DISCUSSION

This final chapter will dissect the results presented in Chapter 5 and discuss the potential of the findings to help families living with HIV/AIDS. Next, to further the development of applicable theory, the findings will be examined within the Stress-Coping model. Significant findings will be placed within the theoretical context and a final model consistent with the findings will be presented. Implications for future practice and program creation will be proposed in light of the findings. To that end, new ways to support families and caregivers through legislation and policy development will be discussed. The limits of the study will also be listed, with their potential influence on the findings examined. Lastly, avenues for future research will be put forth, as well as specific questions posed highlighting the further need to explore the important relationship between social support and caregiver stress throughout the HIV/AIDS illness trajectory.

Discussion of the Findings

A sample of 212 caregivers of children infected and/or affected by HIV/AIDS was obtained to explore the relationship of various sources of social support upon their levels of stress and arousal. This section will place the findings within the context of the existing literature. It will highlight the similarities and differences between this and other studies, as well as suggesting possible reasons for both as indicated by the results. Utilizing this criteria, the sample characteristics will be examined to provide a profile of the caregivers and children. In addition, significant differences found between birth

mothers and other caregivers will be illuminated with implications drawn for each. Lastly, the relative influence of the personal factors, stressors, and conditioning and interaction variables upon the dependent variables of stress and arousal will be discussed.

The majority (67.5%) of caregivers in the study were birth mothers, which is consistent with samples found in other studies of caregivers of children with HIV/AIDS (Hughes & Caliandro, 1996; M. Rose & Clark-Alexander, 1998). In addition, the overwhelming majority (93.8%) of the caregivers within both groups were female. In a study of caregivers, Mellins and Ehrhardt's (1994) sample also consisted of primarily (84%) female subjects. This finding permeates the caregiving literature, with M. Rose and Clark-Alexander having an all female sample, and Hughes and Caliandro reporting an 83.7% female sample. The consistency of these findings across studies spanning over a decade illustrate the overwhelming responsibility placed upon women, many (60.8% in this study) of whom are single parents.

Many of the caregivers must also cope with stressors due to their minority status, with 92% of this sample identified as African-American. Although not as high, this majority is consistent with Hansell and her colleagues (1998), who had a sample which included 74% African-Americans. M. Rose and Clark-Alexander (1998) had 68%, Hackl et al. (1997) had 63%, and S. Andrews et al. (1993) also had a majority (56%) of African-Americans in their sample.

This lack of heterogeneity throughout the literature may be attributable to a variety of factors, particularly sampling, yet this study's sample may actually be more representative of its investigative jurisdiction than the other studies. As of July 1999, Maryland had the 6th highest concentration of African-Americans in the United States,

accounting for 28.1% of the state's population (U.S. Census Bureau, 2000b). The other studies have taken place in areas that have a much smaller percentage of African-Americans. For example, Hackl et al. (1997) study was conducted in Wisconsin, which ranks 30th with only African-Americans representing only 5.6% of the state's peoples. Similarly, Hansell et al. (1998) conducted their examination in New York and New Jersey which rank 11th and 16th respectively, with an average representation of 16.2% African-Americans. Neither S. Andrews et al. (1993) nor M. Rose and Clark-Alexander (1998) specified their location enough to estimate the representativeness of their samples. Thus, African-Americans in this study were 3.27 times more likely to be included in the sample than individuals of other race/ethnicities.¹ However, African-Americans in Hackl et al.'s study were 11.25 times more likely to be included, and those in Hansell and her colleagues' study were 4.57 times more likely. Therefore, when examining the racial/ethnic dispersion of this study in relation to the others, and also considering the disproportionate amount of HIV positive African-American women found throughout the country, the sample contained herein appears to capture an important and representative segment of affected families.

The mean age of the caregivers was 34 ½ years old. However, birth mothers averaged 31 (SD=6.85) while other caregivers averaged 45 (SD=9.33), which is a significant difference in their respective ages ($t=11.105$; $p<.001$). This overall mean age is consistent with Hackl et al. (1997), whose participants had an average age of 35.6 years

¹ This calculation was obtained by dividing the overall percentage of African-Americans in the sample (92%) by their representation in the population-at-large within the respective state, Maryland (28.1%). For example: $92/28.1=3.27$. Similar calculations were made for the other available studies' samples.

old. S. Andrews et al. (1993) reported similar findings, with subjects' having a mean age of 30.3 years and an overall range of 19-43 years old. Respondents in Hansell et al.'s (1998) research had a mean age of 36, with HIV negative caregivers significantly older (mean = 42) than birth parents (mean = 32). M. Rose and Clark-Alexander (1998) also found that alternative caregivers were older than birth mothers, averaging 47.4 years of age (SD=13.0) and 27.4 years old (SD=5.2), respectively. They reported that this was due to many of the alternative caregivers being grandmothers. This was also true for many of the other caregivers within this study. In addition, other caregivers consisted of other female relatives (primarily aunts), as well as foster/adoptive parents who may have waited years to complete their education or attain career goals before choosing to care for a child infected and/or affected by HIV/AIDS.

As hypothesized, other caregivers had more formal education than did the birth mothers. Similarly, S. Andrews et al. (1993) found that 51% of birth mothers had not completed high school, with only 24% graduating high school and another 25% progressing beyond high school. M. Rose and Clark-Alexander (1998) also found that neither group of caregivers in their sample had a mean over the 12th grade (although some had completed high school). Hansell et al. (1998) reported that birth parents had less formal education than others, with half of the birth parents not completing high school. The significantly less formal education found among birth mothers may be a consideration when working on issues such as treatment adherence, understanding complex medical regimes, transportation schedules, program availability and eligibility, and other life sustaining necessities. Social support, if available, must be mobilized to assist in completing these tasks.

Unfortunately, birth mothers had significantly less support from their relatives and friends than did other caregivers. This finding is consistent with the existing literature, with M. Rose and Clark-Alexander (1998) reporting that alternative caregivers in their study had higher family support. They found the same results among support from friends, with alternative caregivers reporting significantly more support (M. Rose & Clark-Alexander). A confounding factor may be that neither caregiver group in this study were asked if their family, friends or other supports were aware of the HIV status of either themselves or their child. Thus, the difference may be due to the perceived or real stigma and fear of rejection associated with telling family and friends about their HIV status. In fact, many women, fearful of losing what support they may have, have not told their family and/or friends about their (and/or their child's) HIV status, resulting in a 'conspiracy of silence' (Walker, 1998).

As hypothesized, birth mothers scored lower than other caregivers on their level of support from family and friends. However, contrary to expectations, there was no difference between caregiver groups in the level of support obtained from the index child. It was thought that birth mothers would have stronger support from the index child due to the strengthening of the mother-child bond through the illness and social isolation process (Andrews, S. et al., 1993; Walker, 1998). Yet, it was found that both caregiver groups in this study had very high levels of support from their child, with three-fourths of all caregivers feeling that the child had had a mostly/very positive effect on the home. This finding is consistent with Hughes and Caliandro (1996), who, in a study of 29 biological parents and 22 other caregivers, reported that caregivers' satisfaction with their children

was very high. The finding of no difference between caregiver groups signals that, regardless of their own HIV status, these caretakers are parents first (Wiener et al., 1994).

Both groups had low levels of connection to their community, which is consistent with the social isolation theme permeating the literature (Hansell et al., 1999; Hughes & Caliandro, 1996; Mayers & Spiegel, 1992; M. Rose & Clark-Alexander, 1998; Wiener, 1998). Caliandro and Hughes (1998) found that grandmothers did not wish to participate in support groups with similar families because they did not want to talk openly with people they did not know. Yet, support groups have demonstrated their effectiveness at helping families cope with the challenges of raising a child infected and/or affected by HIV/AIDS (Mayers & Spiegel; Wiener). However, unlike many of the other sources of support, caregivers must openly admit and face the impact of HIV/AIDS on their family when making connections with similar families in their community. Thus, although beneficial, as shown by Mayers and Spiegel and Wiener, the families in this study may not be ready for this type of support.

Birth mothers found less support from church/spirituality than did the other caregivers. This source has been a strength for many people, although no study has explored this relationship between groups of caregivers of children infected and/or affected by HIV/AIDS. Nevertheless, C. Hall (1986) reported that families who espoused spiritual values were found to live more productively and experience more life satisfaction than families without such values. However, birth mothers may fear condemnation or alienation upon disclosure. For example, African-Americans who may be connected with fundamentalist religions may face real or perceived sanctions for their lifestyles or relationships (Mays, 1989). This very real fear of condemnation was

pervasive in the early years of the pandemic, and still exists to a lesser degree today.

However, this is not to say that birth mothers found no solace from church/spirituality. In fact, birth mothers scored just over halfway along the scale's continuum. It may be that self-protective caution has insulated them from pursuing this support further. Additional exploration of this support source is warranted to determine the potential benefits of its use.

There was no difference between either caregiver group on level of support from formal sources, with both scoring in the mid-level range. The majority of caregivers did not utilize either respite care or mental health services. However, over 70% of the total sample felt that the FaCT caseworkers were very helpful. An additional 25% felt they were adequate, with only 5% feeling their support was not helpful. It is important to note that the FaCT caseworkers received special training, which may have bolstered their effectiveness in working with the families. Thus, their scores are not easily comparable to the general population of caseworkers. In addition, the instrument itself was provided and collected by the FaCT caseworker, and must therefore be considered with some caution. As such, caregivers may have provided the answers desired in order not to jeopardize their relationship with someone of power (i.e., the ability to secure needed resources, provide reports to child welfare, etc.). This is not to imply any intentional misuse of influence by the caseworkers, but rather as a potentially biasing artifact of the data collection strategy. Despite this limitation, it appears that the overall support provided by the FaCT caseworkers was positive, and future practitioners should avail themselves of similar training.

The majority of birth mothers had at least some (+) stress, with other caregivers reporting significantly lower amounts. Surprisingly, neither group scored in the high (++) stress range. However, this is consistent with the findings of Hughes and Caliandro (1996), who reported that "caregivers did not experience caregiving as having a particularly negative impact on their lifestyle and were more in the middle of the lower range on their reports of burden" (p. 353). Additionally, birth mothers, as hypothesized, reported significantly lower arousal scores than did other caregivers; although both groups scored in the positive (+) range. These higher stress and lower arousal scores may be due to the birth mother's fear that her own health will deteriorate before that of her child (Wiener et al., 1994). As such, the birth mother's own HIV infection diminishes her ability to maintain a cohesive family structure and cope with the child's needs; thus interfering with her ability to adapt to the caregiving demands.

When examining the independent variables impact upon each of the dependent variable, the surprising significance of the caregiver's health limits upon their level of stress and arousal, which has been largely overlooked in this literature base, is striking. However, one other study examined the health of birth and alternate caregivers and found no difference in physical quality of life between the groups, with both groups having some health difficulties (M. Rose & Clark-Alexander, 1998). In contrast, Hughes and Caliandro (1996) reported that a dichotomous caregiver illness status variable (i.e., HIV positive vs. HIV negative) did not significantly predict caregiving stress.

Indeed, 44.5% of the caregivers in this study experienced health problems which impinged upon their daily living, with almost 1/5 of them almost always affected. Hackl et al. (1997) reported one mother in their sample stating that "[my son] will be here all

alone, and I feel like I've failed him. I don't have anyone in my family responsible enough to take care of my 12-year-old. My biggest challenge is finding some place for my children" (p. 57). In fact, they found that many of the mothers concealed their illness from their younger children. Thus, fatigue and other illness-related problems that affected their ability to continue managing the home resulted in increased guilt. F. Cohen et al. (1995) reported similar findings, with mothers feeling that as their own illness progressed and their health deteriorated they would be much less able to care for their children. Many desperately wanted to give their children as normal a life as possible, and felt that this was not possible if they were ill. Mothers also wanted to be there for their children, and felt that they were abandoning them when their own illness made them incapable of providing daily care.

Caregivers, both birth mothers and others, may be expressing feelings similar to those described by S. Andrews et al. (1993) where HIV positive mothers felt increased anxiety in relation to their children, whether or not the child was HIV positive, due to concerns about the eventual placement of surviving children. This fear is universal and not unique to HIV positive or health compromised caregivers. However, the impending nature of the illness makes the issue forefront in the minds of caregivers.

Although birth mothers reported significantly more health related difficulties, many of the other caregivers also reported health problems. Caliandro and Hughes (1998) reported that grandmothers, which constitute many of the alternative caregivers, tend to minimize their own personal illness such as high blood pressure, ulcers, gastrointestinal bleeding, chest pain and asthma. The grandmothers feared acknowledging the illness and its potential to negatively impact their ability to care for

the HIV positive child. Hansell and her colleagues (1998) reported that for an HIV positive birth mother with an HIV positive child, the caregiving situation is both a personal health crisis and a caregiver crisis. It would appear that this is not limited to birth mothers, but that health concerns must be considered among all individuals assuming this taxing role.

Having another child ill was a significant predictor of caregiver arousal level, but not stress level. Of the two stressors variables, only illness management was significant within 3 of the 6 arousal regression equations (Child Support, Community Connections, and Formal Service Support). Thus, it appears that under specific circumstances the amount of burden placed upon the caregiver, as indicated by the having more than one child ill (although it was not specified if the second child's illness was HIV-related), may significantly influence the level of arousal experienced by the caregiver.

Thus, the level/stage of the child's illness may have an impact on the caregiver under certain scenarios. The children in this study averaged 4.5 years of age ($SD=3.84$). This is similar to Hardy et al. (1994), who reported that the children in their study ranged in age from 4 to 7 years, with a mean of 5.25. Overall, the children in this study appeared to be relatively healthy, with only a slight majority (51.9%) HIV positive. The children were, on average, taken to the hospital less than one time in the previous 6 months, and to the doctors once every 1-3 months. Mellins and Ehrhardt (1994) reported similar findings in that the children in their study, although not severely ill, had been hospitalized at least once, with a small percentage hospitalized more than 10 times. In addition, it was found (falsifying the hypothesis) that there was no difference between caregiver groups on overall illness management tasks conducted on the child's behalf. Birth mothers also

had significantly less HIV positive children in their care than did the other caregivers (44% vs. 68%). However, some of this skewness may be due to sampling bias, as other caregivers may have a higher propensity to be known to programs such as this, and thus have a greater chance of being included in the sample. Lastly, contrary to the hypothesis, other caregivers also had more than twice as many other sick children in the home.

There remains some controversy on the importance of the child's level of illness. Hughes and Caliandro (1996) reported that when considered with other variables it did not significantly predict caregiving burden. However, Wiener et al. (1994) found that scores did not vary according to degree of debilitation until the child was extremely ill. They hypothesize that due to the nature of the disease "parents have encountered the pattern of debilitation and partial recovery so frequently that they deny depression and anxiety in order to participate in the care of the child and avoid experiencing what one parent called the 'emotional roller coaster'" (p. 491). However, when the child finally becomes extremely debilitated, the parent can no longer deny these feelings (Wiener et al.). Findings from these studies help illuminate the mixed findings within this study regarding this variable.

The current study also found mixed results between the various social support sources and either stress or arousal. Support from friends was found to have a significant main effect within the arousal scenario. Thus, support from friends directly impacts the level of caregiver arousal, irrespective of the level of either stressor. As such, a buffering effect was not indicated. However, there was one significant interaction between illness management and child support (although one more, formal*illness management, was

approaching significance²). Support from the index child significantly buffered the negative effects of illness management upon the caregiver's level of arousal. As such, a lower level of arousal is associated with caregivers having a high amount of illness management tasks, yet little to no support from the index child. This may indicate that caregivers with positive relationships with the infected and/or affected child have sufficient levels of arousal despite increasing amounts of illness management tasks. Yet, those caregivers with negative relationships with the index child have decreasing levels of arousal as illness management-related tasks increase in frequency.

As discussed, the personal factors, especially caregiver health limits, explained the greatest proportion of the variance in each of the regression equations. Illness management was also found to be significant in several of the scenarios. In addition, the impact of social support was mixed, with one exhibiting a main effect and another demonstrating an interaction effect. Theory development, as well as implications for practice, policy and future research, as guided by these findings, will be discussed in the subsequent sections.

Theoretical Implications

The model put forth in Chapter 2 illustrated the moderating relationships hypothesized between the stressors and conditioning variables upon stress and arousal levels, with no direct main effects present. However, several strong effects from the personal factors were demonstrated, with only intermittent significance from the illness

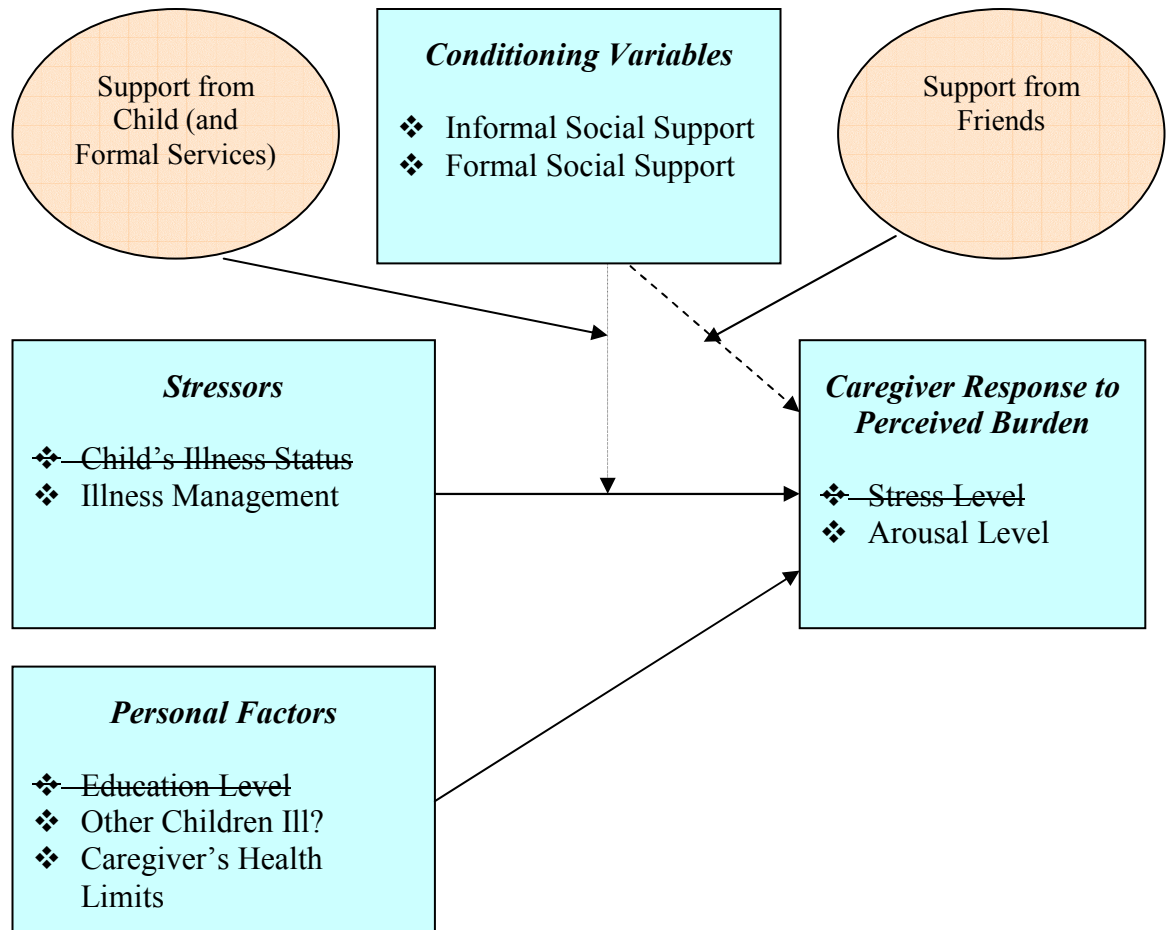
² While child support was significant at $p < .01$, formal service support was approaching significance with a p-value of .06.

management stressor. Additionally, only one significant social support main effect and one significant interaction variable were found. Thus, modifications to the model, as presented in Figure 7 below, are warranted.

In general, there are two models which hypothesize the effect of social support upon stress. The first model purports that social resources, such as support, have a beneficial effect on the individual irrespective of whether the person is experiencing stress or not (AKA the main effect) (Cohen, S. & Wills, 1985). As such, there is no interaction between the stressor and social support. Social support acts as a main effect upon the dependent variable (i.e., stress and/or arousal) irrespective of the existence or level of stressor. S. Cohen and Wills posit that "there may be a minimum threshold of social contact required for an effect on mortality to be observed, with little improvement in health outcomes for levels of support above the threshold" (p. 312). For example, an individual with a great deal of support from friends may receive positive regular experiences which may be related to one's overall well-being.

Figure 7: Modified Conceptual Model

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



The second model, as proposed in Chapter 2, states that support is related to well-being under varying conditions of stress (AKA the buffering, moderating or conditioning effects). As such, social support protects the individual from the harmful effects of the stressor (S. Cohen & Wills, 1985). S. Cohen and Wills argue that within the buffering model "support may intervene between the stressful event...and a stress reaction by attenuating or preventing a stress appraisal response. That is, the perception that others

can and will provide necessary resources may redefine the potential for harm posed by a situation" (p. 312). They contend that there must be a reasonable match between the coping requirements and the available support in order for buffering to occur (S. Cohen & Wills).

There is at least some evidence that not all sources or types of social support are equally effective in reducing distress (Thoits, 1982). Many of the studies exploring the buffering relationship of social support upon stressors have not examined specific supports, and instead utilize a global 'social support' variable encompassing all forms of support (Bass et al., 1996; Blaney et al., 1991; Pearlin et al., 1981). However, it is clear that social support can be provided to individuals by a variety of people, such as a spouse, child, parent, friend, therapist, minister, co-worker, etc. Yet, to obtain a thorough understanding of how much support individuals receive would require an assessment of how much affect, affirmation, and aid they obtained from every person whom they perceive as supportive. To that end, Abbey, Abramis and Caplan (1985) tested the buffering effect of social support from two sources of social support - 'social support from *people*' and 'social support from *some one person*'. The buffering hypothesis was supported for the latter, but not the former. Their study, as well as this, support the need to focus on individual sources of support when studying this phenomenon.

It appears that a mix of the aforementioned influences are at play. For example, as shown in Figure 7, support from friends has a main effect on caregiver arousal level with no interaction effects present. Conversely, child support's interaction with illness management had a significant impact upon caregiver arousal levels, with no main effect present (similar findings are present for formal service support, which is approaching

significance). However, it is hypothesized that this may be due to the result of both child support and formal service support being unique to this caregiving scenario. Individuals may have previously existing relationships with family, friends, and their church.

However, the special relationship between caregiver and child noted in the literature and support by this study is uniquely different to the typical parent-child relationship due the social isolation and intensity of the illness situation. In addition, families would not be exposed to formal services outside of this scenario. Although it was clear that neither caregiver group was connected with the great HIV community, it is further hypothesized that a buffering effect may be present for those families engaging in these activities.

Thus, it may be that some sources of social support exert a buffering effect while others demonstrate a main effect, depending upon the specific crisis at hand. This possibility demands further examination, and could greatly influence future practice and policy development.

Practice Implications

Although this study was exploratory in nature and needs further investigation to confirm the findings, certain implications for practice can be suggested. Given the minority representation among families living with HIV/AIDS, the first suggestion to engage and empower caregivers is that any intervention must be culturally and gender sensitive. To be effective, interventions must include a culturally sensitive approach to assessment and intervention, use key indigenous people, and utilize interdisciplinary collaboration including physicians, nurses, social workers, etc. (Goicoechea-Balbona, 1998). In a qualitative study examining the efficacy of a culturally sensitive intervention with migrant minority families, Goicoechea-Balbona found the Culturally Specific Health

Care Model (CSHCM) to be effective in engaging and empowering families impacted by HIV/AIDS. To engage families and facilitate support, practitioners must consider the person-in-environment, which includes factors such as the client's gender, race/ethnicity, SES, formal education level, and living arrangements, to name a few. It is clear that practitioners working with members of this caregiver group must be considerate of these issues when attempting to build connections.

Practitioners working with families living with HIV/AIDS have suspected the importance of social support upon caregiver levels of stress, arousal, depression, guilt, and other factors for some time. This research lends empirical support to this argument. Thus, it is also recommended that practitioners assist caregivers of both groups in connecting to various supportive sources. Interventions should first be aimed at maintaining and strengthening the integrity of the current social support network. Support from friends and other more traditional sources may assist the caregiver maintain her current living situation, irrespective of the stressor effects. However, it may be that as support network members are made aware of the HIV status of the caregiver and/or child a buffering effect may take place as specific source support is focused on addressing stress resulting from caring for a child infected and/or affected by HIV/AIDS. Of course, given the possible negative consequences, any disclosure by the caregiver to any network member should occur after careful discussion. Practitioners can assist caregivers in talking with support sources through role-plays and other exercises. For example, practitioners can help clients assess the degree of receptivity from support sources to the caregiver and/or child's HIV diagnosis, as well as model caregiver responses to resistance that may be received. These activities may enable caregivers to

address concerns, fears and other issues expressed by potential support sources. This process may help to educate support sources on the needs of the child and/or caregiver and assist supports in providing specific helpful relief, whether emotional, informational or tangible.

Practitioners must also recognize the importance of the caregiver-child relationship for families living with HIV/AIDS. The caregiver's satisfaction with this relationship significantly buffers the negative effects resulting from multiple illness management tasks. Thus, practitioners should work with this dyad to support and strengthen this bond through a variety of sources such as the provision of outside activities to allow them to spend time together, teaching the caregiver about methods to engage the child, and the provision of therapeutic services. To assist in preserving the family structure as long as possible, the provision of services by formal sources, such as therapy or respite care, may strengthen the caregiver-child relationship and other aspects of the caregiving role. Similarly, fostering connections with similar families in their community, although not significant in this study, may provide a beneficial support for families (Mayers & Spiegel, 1992; Wiener, 1998). Although it is important to work with families to address potential intrapersonal and environmental barriers to utilizing support-type groups, the families in this study may not have been ready for this type of support. However, supports such as those listed may help caregivers better manage illness-related tasks for the index child, as well as any other ill children in their care. Practitioners should be aware of the potential benefits of this support sources, and assist client in determining their appropriateness for participation.

Lastly, social workers should recognize the important role the caregiver's own health plays upon her ability to care for a child impacted by this disease. Parenting while ill can be particularly challenging, with children experiencing heightened anxiety and behavior problems (Christ et al., 1993; Siegel et al., 1992). These compounding factors can work to increase stress and decrease arousal, leaving caregivers vulnerable. Assisting caregivers in arranging for permanent child care choices is a significant matter when children will be left without a caregiver. Custody arrangements should be established to provide for the children's long-term care. For example, standby guardians (described further under 'Policy Implications') allows an HIV positive caregiver to designate an individual to become the child's guardian upon the caregiver's incapacitation, yet is revocable when/if the caregiver recuperates. Assurance for these matters may provide some relief to the caregivers. Therefore, it is incumbent upon practitioners to be fluent in the legislative and policy matters such as this that may facilitate or impinge on the caregiver's ability to plan for the child in her care.

Policy Implications

Current policy does not recognize the important role of social support, especially from informal sources. Other social welfare programs, such as Ohio's Family Stability Incentive Fund that provides 'flexible' dollars to allow communities to creatively prevent out-of-home placements, have utilized vouchers to allow clients to 'purchase' support from willing friends, family members, etc (Tracy, Biegel & Johnsen, 1999).

Unfortunately, the Ryan White Act, which is the "payor of last resort" (Health Resources and Services Administration, 2000, p. V.3), clearly states that funds cannot be used to pay informal support sources such as a family member or friend. Instead, individuals

providing informal support would need to become a home health provider or employed by a contracting agency in order to receive any compensation. Thus attempting to institutionalize informal support by transforming them into formal service agents. Yet this fundamental change may adversely alter the dynamics within the informal support relationship.

Under Ryan White eligible participants may, under very specific circumstances, utilize a voucher system to purchase services from informal providers (Health Resources and Services Administration, 2000). Yet, in such instances, states are also cautioned that such funds should be limited and carefully monitored to assure compliance with all regulations. In addition, such arrangements may also raise liability issues for the funding source, who are once again cautioned that this should be carefully weighed in the decision-making process (Health Resources and Services Administration, 2000). Consequently, if even offered, states impose many qualification requirements which serve as deterrents to interested families (Sheila McCarthy, Health Resources and Services Administration Representative, personal communication, September 18, 2000). On the contrary, Leon (1999) reports that access to sufficient and appropriate resources and services without the imposition of unnecessary 'red-tape' is integral to successful service delivery and the empowerment of the families. Thus, these hurdles effectively exclude informal caregivers from accessing funds that may have allowed them to offer additional support.

In a survey of AIDS service organizations that asks directors to list any health and care-related services not covered by Medicaid and Ryan White Titles I and II, Buchanan and Chakravorty (1999) found that respondents reported that these programs did not

cover emotional and practical support. In addition, a director responded that the programs did not cover support services for family and friends, stating that "often we encounter family that feels 'left out' because services embrace the HIV infected individual but not the [other] affected person[s]" (Buchanan & Chakravorty, p. 28). This has dire implications for caregivers and other family members (such as siblings) who live in the home with one or more HIV infected individuals.

In addition, family stability services such as permanency planning may also be allowable under Ryan White (Health Resources and Services Administration, 2000). Eighteen states, including Maryland, have enacted legislation that allow parents to appoint standby guardians for their children (Wassermann, 1999). These laws were passed in the latter half of the 1990s to enhance parents' ability to plan for their children. Under the laws, guardians can take authority over the children while the parent is unable to care for them. However, when the parent is able to resume caring for the child they are able to do so (Wassermann). Federal legislation passed in 1997 that encouraged all states to enact such legislation, yet it has yet to be implemented in the other 32 states. This study supports the need for such legislation, as it is clear that mothers are deeply concerned with the permanent plan for their children, and that being in control of this plan would help alleviate stress and bolster arousal levels.

Support for this legislation, curiously, is not unanimous. As Forehand et al. (1999), in a study of 20 children, reported that "even without legal arrangements prior to the mother's death, most children were living with the mother's preference for a caregiver. Thus, policies facilitating legal arrangements prior to the mother's death may not be necessary" (p. 721). Indeed, it may be true that the 20 mother's in their study did not

need this service. However, such sweeping statements based upon such a small sample of the hundreds of thousands of HIV positive parents over generalizes the study's results. Given the stigma and discrimination faced by the numerous mothers described in previous articles, it is felt that recommending against enacting policies which may help protect a caregiver's permanency choice for her children is irresponsible and potentially harmful to mothers.

Public programs, such as Medicaid and Ryan White, are the primary payers for the health and *care-related* services provided to HIV positive individuals. Expanded use of these waiver programs is recommended. Although these programs are intended to provide a safety net to HIV positive individuals, clients are being caught in the confusing web of this net. It is imperative for professionals to familiarize themselves with the available programs, locally and nationally, to better support families' access to available services. In addition, social work professionals should advocate for more flexibility in the program guidelines to have funds dispersed to other members of the HIV positive individual's support network who may otherwise not be able to assist in care-related tasks due to financial concerns and unnecessary red tape.

Study Limitations

This study addresses several of the common concerns listed when examining this population such as adequate sample size and multivariate analytic techniques. However, as with all research, this study also possessed several limitations which should be noted. This section will review those major limitations identified within the conceptual, sampling, data analysis and instrumentation domains.

Conceptual

Most studies, including this one, restrict the ‘primary caregiver’ to those thought to have total care responsibility. However, this focus on a single individual caregiver allows little or no consideration of potentially multiple caregivers within the caregiving situation (Barer & Johnson, 1990). Although a primary caregiver may be indicated, caregiving within families impacted by HIV/AIDS may be shared between many members. In families where both parent and child may be infected, caregiving responsibilities may actually fall upon a grandparent. As such, the grandparent may be reluctant to be identified as the primary caregiver, which may deal a psychological blow to the parent. Thus, this complex constellation of care in which roles may shift according to health status is not adequately addressed within the current research design. The cross-section design does not allow for the shift role patterns which may take place throughout the illness trajectory, nor does the current model allow for multiple caregivers existing at the same time.

Another limitation is the shifting of caregiving over time. The illness progresses through various stages of remission/dormancy and activity along the trajectory, ultimately ending in the caregiver and/or child’s death. This study does not capture where along the illness continuum (i.e., remission or activity) the data were collected, nor does it follow the illness through a longitudinal model. As such, the cross-sectional data obtained from families experiencing illness remission may provide different responses than those families struggling with a severely ill family member. Combining these two populations may serve to confound the findings.

A third limitation is the time since the confirmation of the illness. Families who have known of the illness for several years may have had sufficient time to integrate the information, whereas families that have just learned of the diagnosis may be in a different stage of the anticipatory grief process. This study did not capture this data.

Caring for a child infected and/or affected by HIV/AIDS has special challenges. However, many of the tasks are encompassed by the traditional parenting role. Thus, this and many studies do not adequately discern those tasks which are deemed above and beyond the normal call of duty from the daily hassles of parenting. Crnic and Greenberg (1990) 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. 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 et al., 1982; Crnic & Greenberg; Garner & Thompson, 1978; Kovacs & Feinberg, 1982; Pless & Satterwhite, 1975). For example, taking children to the doctors only once every 1-3 months, as the caregivers in this study reported, may be considered to be within the bounds of normal parenting. This study did not control for the stressors threshold that may be attributed to the normal parenting context as opposed to the illness context.

Stress and coping in caregivers of children with HIV/AIDS presents in a highly complex pattern. In addition, caregivers themselves present with multiple problems in living including transportation, finances, housing, food, schools, employment, clothing, as well as treatment for the child, self and family (Black et al., 1994; Hansell et al.,

1998). Mellins and Ehrhardt (1994) further discuss other stressors that can impinge upon families living with HIV/AIDS such as poverty, violence, drug abuse and housing. F. Cohen et al. (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). The numerous stressors noted which may impact the caregiver’s ability to cope with the situation were not adequately captured in the current research design.

Just as there are numerous stressors that may impinge upon caregivers, there are a multitude of support sources. R. Hays, Chauncey and Tobey (1990) found that about 1/3 of the HIV positive gay men turned to family for social support. However, within that context, siblings were preferred to parents. This study does not identify individual sources, and only utilizes the more global term 'relative'. In addition, several structural questions (i.e., partnered/non-partnered), as opposed to more functional inquiries of support are asked. Thus the existence of a source is confirmed, but not the quality of the partnership. As such, additional specificity on the relationships and sources of support may be warranted.

In addition, this study did not differentiate between helpful and unhelpful acts from support sources. Barbee et al. (1998) found that of the acts of support provided by friends, 62% were classified as helpful and 38% as unhelpful. Unhelpful acts, while well-meaning, may include statements such as offering advice to get tested again, or to "put yourself into a home because you never know when you might fall sick" (Barbee et al., p. 95). In addition, Ingram et al. (1999) identified four types of unsupportive

responses/acts that HIV positive individuals often receive - insensitivity, disconnecting, forced optimism and blaming. Utilizing a hierarchical regression model, they found that unsupportive social support predicted a significant amount of the variance in depression. This study examined the provision (or absence) of positive support, yet did not explore the potential impact of negative influences on caregiver stress and arousal.

Lastly, this study did not fully capture the internal coping strengths of the caregiver. The focus of this study was on social support as one mechanism of coping. However, Stress-Coping models may also include the individual caregiver's personal coping resources. Thus, in keeping with the tenets of social work practice, caregivers strengths must be recognized (Saleebey, 1992). It is clear that caregivers of children infected and/or affected by HIV/AIDS possess enormous strengths, yet this is often lacking in the literature. Future research must include this if it is to portray an accurate picture of the caregiving situation.

Sampling

The respondents were comprised of a self-selected convenience sample of caregivers and are thus inherently biased (Barer & Johnson, 1990). Nonprobability sampling such as utilized herein increases the risk of producing biased and inefficient estimates of regression coefficients and exaggerated R^2 's (Guo & Hussey, 2000). The study would have been strengthened by the utilization of a randomly selected group of caregivers of children infected and/or affected by HIV/AIDS that were subsequently randomly assigned to a treatment (social support exposure) and control group (no social support) (Cook & Campbell, 1979). Other comparison groups could include caregivers of healthy children, as well as caregivers of children stricken with other illnesses. This

would have improved the study's external validity and ability to generalize to the population of caregivers of HIV/AIDS impacted children. Cook and Campbell write that "accidental samples of convenience do not make it easy to infer the target population, nor is it clear what population is actually achieved" (p. 71). Instead, this study utilized a variant of what Cook and Campbell describe as a 'model of deliberate sampling for heterogeneity'. This model does not require random sampling (thus, no generalizability). However, one can conclude that an effect has or has not been obtained across the particular sample criteria, such as African-American female caregivers.

In addition, the low levels of stress and high levels of reported child support may indicate a strong bias within the obtained sample. Researchers must overcome the dilemma that those caregivers most willing to consent to a study may also be those functioning most successfully in their roles. Presumably, those facing the most overwhelming challenges simply denied consent to participate in the first place. Community outreach must be done in order to ensure a full range of representation within the sample.

Instrumentation

The instruments utilized in this study were created as part of a larger program evaluation, and, as such, were not specifically crafted for research purposes. Thus, one cannot be sure if the scales utilized herein were valid measures of the constructs under consideration. The independent variable measures utilized had low alphas, ranging from a low of .10 for formal service support to a moderate .69 for church/spiritual support. Those in the low range (i.e., .10 - .35) include family support, child support and formal service support. The remainder fell within a moderate range of reliability, with alpha's

ranging from .44 to .69. These included community connection, friend support, illness management, and church/spiritual support (listed from lowest to highest). As described by Cook & Campbell (1979), “measures with low reliability cannot be depended upon to register true changes” (p. 43). A suggested correction for this limitation is to create longer tests with items that have been selected a priori for their representativeness of the construct and their high intercorrelations (Cook & Campbell). Thus, one must question if the scales truly capture the constructs under investigation. One of the difficulties in exploring this type of relationship is that there are no standard, well-validated ‘off-the-shelf’ scales. Typically, each researcher devises his/her own instrument for the specific study depending on the focus (Green, 1993). This difficulty is compounded by SES, culture, race, gender, sexual orientation and other variations.

In addition, 19 of the adjectives on the SACL did not meet the various criteria needed for inclusion and were eliminated. The remaining adjectives comprised the two scales: stress – bothered, uneasy, dejected, nervous, distressed, uptight; and arousal – cheerful, contented, pleasant, comfortable, calm. It appears from the adjectives loading on the arousal factor that a modified form may be at play. M. Rose and Clark-Alexander (1998) discussed a 'confrontative coping' style which focuses on constructively handling the stressful situation and directly confronting the problem, and a 'passive coping' style which depicts the modulation of tension by reframing the situation without directly confronting it (M. Rose & Clark-Alexander). It was hypothesized that the more active form may be present. However, it appears by the adjectives retained that the more passive form of coping may be present in the sample. Due to the study's sample size, which was inadequate to meet the suggested standards for factor analysis (i.e. 10 subjects

per item), it is unclear the exact nature of coping that may actually be utilized by these caregivers (Nunnally & Bernstein, 1994). Consequently, results discussed herein must be viewed as preliminary, and interpreted with caution.

Data Analysis

More robust statistical methods are needed to capture the more complex interactions described above. Structural Equation Modeling (SEM) is a powerful multivariate analysis technique that utilizes cross-sectional data to determine the validity of complex hypothesized models. As such, SEM allows multiple measures to be associated with a single latent construct, taking into account the modeling of interactions and mediating variables, as well as nonlinearities. In addition, the assumptions of the model are more flexible than the traditional OLS regression, and it is able to test the overall model simultaneously rather than individually, as in this study. It also has the ability to test models with multiple dependent variables, as well as controlling for the multiple interactions between the various sources of support. Revenson et al. (1983) found that support may contain elements of both 'true' support and threats to self-worth. They write that social 'support' may be nonsupportive and even insupportable; in fact, it may at the same time constitute a source of stress and a source of support. Through the utilization of SEM and the other recommendations contained above, it will be possible to discern the significant relationships and identify the combination most helpful to various constellations of families.

Design

This study was designed to examine a single data collection point. However, as discussed previously, this fails to consider the temporal effects of the illness trajectory. Therefore, when attempting to conduct future longitudinal studies with this population, a Hierarchical Linear Model (HLM) should be employed to analyze the data. HLM offers several advantages over other longitudinal statistical techniques such as repeated measures MANOVA. This flexibility includes handling the attrition of subjects, as well as data with non-equal spacing of time collection intervals, simultaneous controlling for the effects of potentially confounding independent variables, and correcting for intra-class correlation (Guo & Hussey, 1999).

Research Implications

The results of this study support the National Institutes of Health's (2000) HIV-Related Research goal of "[reducing] the negative impact of HIV on individuals with HIV infection, on their families, on the health care system, and on society" (p. 127). Their priority areas include: 1) the testing of interventions to support formal and informal caregivers and family members of HIV-infected persons in order to prevent depression and burnout; 2) developing instruments for measuring social networks; 3) longitudinal analyses; 4) improved sampling techniques; and 5) innovative theoretical and mathematical models. Each of these areas has also been addressed through this study and its subsequent recommendations. This section will put forth some considerations for future research, as well as pose questions for further exploration into caregiver stress and related topics such as the needs of the infected/affected child and his/her sibling.

As caregivers are examined further under this model, it is also possible that moderation and mediation may be found to exist within the same model and variable (i.e., the stressor 'illness management tasks' may also be mediated by child support in addition to its current buffering effect). In addition, non-recursive relations may also be present, such that the support provided by a friend may directly influence the stressor, as well as the level of the stressor influencing the amount of support given by the friend. As outlined earlier, SEM has been suggested as a statistical model that can incorporate each of these factors (see Hoyle, 1995 for an overview).

One of the major difficulties present in this study was the lack of currently validated and reliable measures that could be utilized with this population. Existing general measures are not sensitive to the special circumstances found among individuals with HIV. For example, when conducting research with HIV positive individuals, current standardized measures may be skewed against the HIV positive individual. According to Kalichman (1998), 7 of the 21 items on the Beck Depression Inventory directly parallel common symptoms of HIV infection, such as problems in concentration, sleep disturbance, fatigue and others. Newly crafted instruments or modifications to existing ones must be validated with families living with HIV/AIDS. In addition, to provide comparability among studies, the instrument must be made available to researchers for inclusion in multiple study situations. Lastly, any measures must be sensitive to, and considerate of, gender, culture and other relevant factors. To ensure that future instruments consider these factors, researchers can employ focus groups as suggested by Zastrow (1992) to obtain input from target populations.

Some questions for further research which emerge from this discussion include:

1) How do different families describe HIV and its impact on their functioning?; 2) What are the usual supports and networks used, and how have these changed since the HIV diagnosis?; 3) Are the members of their support network aware of their (or their child's) HIV diagnosis?; 4) Who was chosen to share this knowledge with and why?; 5) What are the various stressors present in families with multiple family members infected?; 6) What type of support is needed (i.e., emotional, informational and tangible) and when?; 7) How do non-infected children cope after the loss of a parent/sibling?; 8) What is the relationship between the social support and caregiver-child relationship?; 9) To what degree will an individual caregiver's level of stress be moderated by his/her health?; 10) How does the special bond existent within the caregiver-child relationship impact the child along the developmental trajectory?; and lastly, 11) Given the historic role of spirituality within the African-American community (Pinkett, 1992), as well as its sometimes controversial role within the HIV/AIDS community (Kalichman, 1998), in what way can the religious community assist in providing support for caregivers and families infected/affected by HIV/AIDS?. It is clear to see the numerous questions that need further exploration. There is a dearth of studies examining families living with HIV/AIDS in the literature. Indeed, there are commonalities between this and other chronic health conditions. However, there are also significant differences such as its intergenerational impact, and direct transmission between mother and child, that may result in intense feelings of guilt, etc. Answers to these questions will help social workers to create more appropriate interventions to ensure the stability of these families.

Conclusion

This research has opened up new avenues for practitioners and researchers to work with and contribute to the functioning of families living with HIV/AIDS. Social support and its hypothesized buffering effect has enjoyed mixed findings in the literature. However, the healing notion of support continues, as explained by the adage ‘we get by with a little help from our friends’. This study lends credence to the efficacy of social support from specific sources with the finding that support from friends does help boost caregiver arousal, and that the support derived from the caregiver-child relationship can help buffer the stressful effects of managing the many illness-related responsibilities.

Indeed, these families are a conundrum of frailty and strength. Due to their HIV diagnosis, infected caregivers and children will eventually become weakened. Yet through the provision of support, especially from friends and children, caregivers can be assisted in maintaining their family structures. It is hoped that the results contained herein can assist families, through improved practice, policy and/or research, to traverse the difficult times a bit easier and enjoy their special children. As Tolbert McCarroll (1988), an adoptive father of several HIV positive children, writes in his book *Morning Glory Babies*, “the fact that you are going to die does not mean you are dying. When death comes, it comes. Up to that moment you are living” (p. 123). We can help these children and families live better.