Families' Perceptions of Immunodeficiency Virus (HIV)/AIDS Phenomenon and Its Impact on Family Functioning of Puerto Rican Families With Children: A Grounded Approach

by

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Families' Perceptions of Immunodeficiency Virus (HIV)/AIDS Phenomenon and Its Impact on Family Functioning of Puerto Rican Families With Children: A Grounded Approach
ABSTRACT

The purpose of this study was to generate a detailed description of Puerto Rican families' perceptions of their experiences and processes of functioning when the HIV/AIDS phenomenon is present in the family unit. The sample consisted of six family units composed of 29 members who were followed for seven months. A grounded theory approach framed within the symbolic interactionism perspective was followed to answer the research questions and to generate a substantive theory of family functioning. Data were collected, coded, and analyzed concurrently using the method of comparative analysis.

The findings of the study revealed a substantive theory of family functioning which consisted of a dominant core process of protecting the family and the movement of families through five related phases: facing the diagnosis, reacting to the diagnosis, revealing the illness, living with concerns, and seeking balance.

Identification of this substantive theory of family functioning has clinical implications for nursing. The implications include (a) identification of a model that offers a new and broader perspective from which to view how Puerto Rican families with children are dealing with the HIV/AIDS phenomenon, (b) support of the development of approaches to assisting families in the management of feelings, concerns, and decision making, and (c) suggestion of the need to conduct further research regarding the functioning of families dealing with the HIV/AIDS phenomenon.
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INTRODUCTION

The family has been described as one of the most basic units of society. It is within this unit that the individual develops, is nurtured, becomes socialized, and where personal growth and autonomy are fostered (Johnson, 1984). When a member of a family experiences health problems, individual family members as well as the family unit as a whole are affected.

When the diagnosis of chronic and life-threatening illness such as infection with the Human Immunodeficiency Virus (HIV) is given to an individual in the family, the impact is felt by the entire family unit. The HIV, the causative agent of a syndrome that causes irreversible and disabling deterioration of the human immune system, was first identified by the Centers for Disease Control (CDC) in 1981 (Bowen, Lane, & Fauci, 1985). Since then, the number of families of children with HIV infection have increased substantially (Boland & Conviser, 1991; Needle, 1990).

The structure and functioning of families with children affected by the phenomenon of HIV and Acquired Immunodeficiency Syndrome (AIDS) are constantly changing. Unlike families affected with other chronic illnesses, families confronting the phenomenon of HIV/AIDS struggle with unique social stresses associated with this illness, including difficulty in sharing the child's diagnosis with other family members, relatives, and

Because of the stigmatized meanings that HIV/AIDS carries in the community, family members are faced in their everyday lives with the public's fear, a reaction that promotes social isolation, rejection, and ostracism (Boland, 1987; Cohen, 1990). To complicate their problems, many of these families live in inadequate housing and have overwhelming material needs. Their social networks are usually inadequate and their extended relationships precarious (Spiegel & Mayers, 1991).

Since the phenomenon of HIV is relatively new and the number of families with children affected by this phenomenon is increasing, family nursing research is needed to understand more fully the everyday reality of these families (Copeland & White, 1991; Needle, 1990). This understanding will help nurses and other care providers to better serve these families with their complex psychosocial issues and needs.

**Problem Statement**

Families in Puerto Rico have been seriously affected by the phenomenon of HIV/AIDS. The HIV infection has a variety of manifestations, with AIDS currently being considered the most extreme clinical manifestation on the spectrum of HIV-associated illnesses (Cohen, 1991). Children (less than 13 years old) are at present the fastest growing group with HIV/AIDS infection. A total of 12,104 cases of AIDS have been reported in Puerto Rico. From the above total, 300 children with AIDS have been reported (Surveillance Report, 1992).
One of the biggest social problems fueling the HIV infection phenomenon in Puerto Rico is intravenous drug use. In fact, intravenous drug use is considered the most important risk factor affecting the spread of HIV in Puerto Rico. It is estimated that there are 100,000 injecting drug users in Puerto Rico (Cunningham, Ramos-Bellido, & Ortiz-Colon, 1991). Almost 60% of the injecting drug users in Puerto Rico are less than 35 years old, comprising the major risk group for heterosexual transmission, and a main source of perinatal transmission of the illness (Robles, Colon, Matos, Marrero, & Lopez, 1990).

Families are groups of dynamically, interrelated and independent members, who construct individual and shared meanings about relevant phenomena and people (Daly, 1992). In the face of new experiences such as the phenomenon of HIV/AIDS infection, families find it necessary to construct meanings about the illness and about the behaviors that caused it (Walker, 1991). Because each family member, and each family unit, is part of a larger interactive social system, families also must deal with the societal negative meanings given to the HIV/AIDS phenomenon. The family's perceptions of their experience with HIV/AIDS shape the illness experiences and the family's ability to function effectively on a day-to-day basis in relation to the sick member as well as with relatives, significant others and individuals in the health care system and community (Walker, 1991). In order to intervene effectively for the entire family, nurses first need to understand the meaning of the illness to the family members.
Although experts recognize the impact of HIV/AIDS infection on the family units, limited research has been conducted on the families experiencing it and its impact on family functioning (Curtis, 1989; Macklin, 1989; Needle, 1990). This study was conducted to provide a better understanding about the families' perceptions of the HIV/AIDS phenomenon, and how the families' perceptions of their experience impact their day-to-day functioning.

**Purpose of the Study**

The purpose of this study was to explore and generate an accurate and detailed description of Puerto Rican families' perceptions of their experiences and processes of functioning when the HIV phenomenon is present in the family unit. Families' perceptions of their experiences and processes of functioning were studied using a qualitative grounded methodology developed from the symbolic interactionism perspective to generate a theory of family functioning. The product of this endeavor could serve as a theoretical basis to guide effective nursing interventions in these families.

**Research Questions**

The following research questions were addressed in this study:

1. What are families' perceptions of their experiences with a child having HIV/AIDS infection?
2. How does the phenomenon of HIV/AIDS impact the
daily family activities and interactions?

3. What resources, strategies, and interactions are used by these families on a daily basis to deal with the phenomenon of HIV/AIDS?

4. What are the fundamental concepts of family functioning for families that have a child with HIV/AIDS infection?

Definitions of Terms

The major concepts in this study are defined as follows:

Human Immunodeficiency Virus is the causative agent of a syndrome characterized by a progressive, gradual, irreversible, and disabling deterioration of the human immune system (Bowen et al., 1985). HIV infection ranges from asymptomatic infection to the full-blown clinical disease, AIDS.

Pediatric HIV Infection includes children under 13 years of age who are infected with HIV (CDC, 1987). The scheme developed by the CDC essentially divides pediatric infection into three mutually exclusive categories: (a) children who are HIV positive but with indeterminate infection (Class P-0); (b) asymptomatic infected children (Class P-1); and (c) symptomatic infected children (Class P-2).

This study included asymptomatic children included in Class P-1, Subclass A, B, and C and symptomatic children included in Class P-2, Subclass A, B, C, D, E, and F.

Asymptomatic Children (Class P-1) are seropositive infants proven infected by HIV antigen (P-24); viral culture, and
Polymerase Chain Reaction (PCR). Assays of circulating P-24 and viral culture are methods used to detect the actual presence of HIV in blood or tissues. The PCR test detects HIV itself rather than antibodies (Flaskerud & Ungvarski, 1991; Henggler, Melton & Rodriguez, 1992). In this category are included children older than 15 months with HIV infection confirmed by Elisa and Wester Blot antibody test but exhibiting no symptoms of HIV infection. These infants and children who exhibit no symptoms of HIV infection can be sub-categorized according to the level of function of their immune systems as one of the following:

2. Subclass B - Abnormal Immune Function.

To be placed into Subclass B, a child must have one or more of the following immune abnormalities: (a) Hypo- or Hypergammaglobulinaemia, (b) reduction in number of CD4 lymphocytes, (c) decrease in the T4 lymphocyte to T8 lymphocyte ratio, and/or (d) an absolute lymphopenia (Arpadi & Caspe, 1990).

3. Subclass C - Immune Function not tested.

Symptomatic Children (Class P-2) are those children who manifest symptoms related to HIV. These children may be placed into several subclasses depending on the constellation of illnesses and disorders they manifest (Arpadi & Caspe, 1990).

1. Subclass-A nonspecific findings includes infants and children with two or more of the following signs and symptoms persisting for more than two months: (a) fever, (b) failure to thrive, (c) weight loss (10% or more of baseline weight), (d)
spleenomegaly, (e) lymphadenopathy, (f) diarrhea, and/or (g)

2. Subclass-B progressive neurologic disease includes
infants and children with (a) loss of developmental milestones or
intellectual function, (b) impaired brain growth, and (c)
progressive symmetrical motor deficits.


4. Subclass-D secondary infections includes children with
opportunistic infections and secondary bacterial infections.

5. Subclass-E secondary cancers.

6. Subclass-F other diseases possibly attributable to HIV
infections.

Acquired Immunodeficiency Syndrome (AIDS) includes children
seropositive for HIV with any of the following: (a)
opportunistic infection, (b) lymphoid interstitial pneumonitis
(LIP), (c) progressive encephalopathy, (d) wasting syndrome, and
(e) malignancy (Boland & Conviser, 1991).

Family includes two or more individuals who define
themselves as a family, and who over time assume those
obligations to one another that are generally considered as
essential components of the family system (Hartmann, 1981). For
the purpose of this study, a family is defined as two or more
Puerto Rican family members living in the same household, with at
least one biological caregiver (mother or father) with a child
under 13 years of age who has been diagnosed with HIV/AIDS
infection.
**Perceptions** are the families' interpretations of their experience with the phenomenon of HIV/AIDS. Their interpretations give meaning to the illness experience and the family's daily functioning.

**Family Functioning** is the way in which the family interacts on a day-to-day basis as described by the family and observed by this researcher.

**Assumptions**

For this research study the following assumptions are made:

1. HIV/AIDS infection has been described as a highly stigmatized illness. People who are affected with HIV/AIDS experience the effects of stigma from relatives, friends, and society in general.

2. The family's perceptions of their experience with HIV/AIDS infection will influence the illness experience and the family members' ability to function on a day-to-day basis (Walker, 1991).

3. Families participating in this study will have an accurate interpretation of their experience and functioning with the phenomenon of HIV/AIDS.

4. Concepts related to the family's perception of their experience and family functioning can be identified and validated from the families' perspective.

**Limitations**

The following limitations must be recognized:

1. The sample included only six family units who were
studied over time by one independent researcher. More families could have been included and studied if other resources had been available for the data collection and analysis. Nonetheless, in order to add credibility to this study and to address validity and reliability issues, the researcher reinterviewed the majority of family members from these family units.

2. The sample of families was limited to one clinical setting. Therefore, this substantive theory is valid for the studied sample only. However, the identified basic social process and concepts could be relevant and applicable to other nurses providing care to families of children with HIV/AIDS infection in other settings in Puerto Rico.

**Significance of the Study**

The family as a unit has always been served by nursing. During the last 15 years, major trends have been occurring in the nursing care of families in the area of clinical practice, research, and education (Wright & Leahey, 1990). According to Murphy (1986), a special interest in family nursing research has now emerged out of the need for greater understanding of family phenomena in health and illness. Family nursing research is directed toward developing middle range theories that will describe, explain, and predict human responses to actual and potential health problems (Feetham, 1990).

Pediatric HIV/AIDS infection is categorized as a chronic illness with periods of progression and stability, multisystem involvement, and a wide range of psychosocial effects on the
infected children and family members. Considering that increasing number of Puerto Rican families with children having HIV/AIDS, and the fact that the spectrum of the HIV/AIDS phenomenon is relatively new, family nursing studies in this area are needed.

Nurses play a major role in responding to the health care needs of these families because nurses are usually the primary care providers for these families. Since the field of family nursing research is a relatively recent development, nursing has few middle range substantive nursing theories that explain the everyday world of patients and families (Hutchinson, 1986). Nursing research is needed that explores and describes families' perceptions of their experiences and processes of functioning when the HIV/AIDS phenomenon is present in the family unit. The families' perception of any illness is important, but it becomes more significant in severe and life-threatening illnesses of the type that involves uncertainty, fear, and stigma, such as HIV/AIDS infection.

Larson and Ropka (1991) point out that in order for the nursing profession to influence the health of individuals infected with HIV/AIDS, nursing research must increase its emphasis on studying these individuals, as well as related physical and psychosocial problems.

Utilizing a qualitative approach, nurses can get closer to the reality of these families and gain a comprehensive understanding of the shared meanings, responses, problems, and
strategies used by these families as they manage HIV/AIDS. With such understanding of the unique aspects of the experience, nurses will be able to more accurately assess and plan appropriate interventions for the entire family.

Research such as this will also add to the growing knowledge base in the discipline of family nursing science. Such increasing knowledge development of family experiences and functioning may influence family nursing practice or research concerning families with children affected with HIV/AIDS infection.
CHAPTER II
REVIEW OF LITERATURE

The review of literature for this study is presented in three sections. First, the magnitude of HIV/AIDS in women is reviewed for its relevance to pediatric HIV infection. Next, a section is devoted to the unique characteristics of children affected by HIV/AIDS illness. In section three, research addressing HIV/AIDS phenomenon and its impact on families is examined.

Magnitude of the Problem

In the early years of the epidemic, the diagnosis of HIV/AIDS was initially reported among homosexual men. Because of this tendency, it was believed that AIDS was limited to the male adult population. As the epidemic has advanced, the demographic characteristics that had been relatively consistent for homosexual men began to change. Currently HIV/AIDS infection is recognized as a major public health problem affecting heterosexual men, women, and children worldwide. According to the World Health Organization (WHO), approximately 13 million adults worldwide have HIV infection. In the United States alone, more than 100,000 women are currently infected with HIV (Pizzi, 1992). HIV/AIDS has become the leading cause of death for women between the age of 20-40 years (Hankins & Handley, 1992).

In Puerto Rico, it is estimated that approximately 55,000 to 60,000 people are infected with HIV (Rullan, 1990). HIV/AIDS
infection is affecting young men and women between 25-44 years of age. Women, especially those who are in childbearing age, constitute a growing proportion of people with AIDS in Puerto Rico. Women account for 18 percent of the total number of AIDS cases reported in Puerto Rico (Comision Nacional Del SIDA, 1992). Currently, pediatric HIV infection and women with HIV/AIDS infection are closely linked. Research suggests that since the rate among women with HIV/AIDS is increasing, a great number of children also will be affected by this illness. Injecting drug use and heterosexual contact are the first two transmission modes for HIV/AIDS infection in women. In Guinan & Hardy's (1987) study of AIDS in women in the United States from 1982 through 1986, the findings showed that from 1,819 cases of women with AIDS, the majority of the women contracted the illness through injecting drug use. The second largest category was woman who contracted AIDS through a heterosexual contact with an infected partner. This particular group of women increased significantly from 12 percent to 26 percent in the mentioned period of time. The majority of women with AIDS were of reproductive age, between 13 and 39 years old. As a result of their work, Guinan & Hardy estimated that if the prevalence of women with HIV infection continues to rise, a great number of children infected with HIV will be born. Scott et al. (1989) validated Guinan & Hardy's findings that the proportion of heterosexually infected women with HIV has systematically increased every year. Scott et al. also found that 69 percent of women were infected through
heterosexual contact. The incidence of HIV infection among heterosexuals has also been increasing in Puerto Rico. A 1992 report from the Health Department in Puerto Rico showed that 43 percent of women with AIDS were infected through heterosexual contact with a sexual partner who was an injecting drug user (Comision Nacional Del SIDA, 1992). The transmission of HIV by sexual contact appears to be higher for women than for men for several reasons: (a) since more men have HIV infection, it is more likely that women would have an infected partner rather than vice versa (Cohen, 1993); (b) the high rate of women with AIDS may be also related to the fact that many women perceive themselves as relatively powerless in their sexual relationships; and (c) many other women do not realize that they are at risk for HIV infection or that for anatomical reasons, retention of secretions is common in women (Cohen, 1993; Guinan & Hardy, 1987).

Current information suggests that 96 percent of all children with HIV acquired the illness by vertical transmission, that is from an infected mother to infant (Arpadi & Caspe, 1990). The rate of vertical transmission has been investigated among different groups of mothers in different countries. In one European collaborative study, Newell (1993) presented findings indicating that the vertical transmission average rate was approximately 15 percent Europe (20 percent Switzerland and 18 percent in France), 20-30 percent in the United States, and 30-35 percent for developing countries. Firm evidence of how many
mothers with HIV will transmit the illness to their children and why some children get it and others does not exist (Husson, Comeau & Hoff, 1990; Rubinstein, 1988). Andiman and Modlin (1991) have stated that it is likely that the risk of vertical transmission varies among different populations based on the clinical status of maternal HIV infection during pregnancy. Mothers with AIDS appear to be more at risk of transmitting the HIV to their infant than those mothers with less advanced HIV infection (Kurth, 1993; Newell, 1993).

By 1994, it is estimated that 7,500 children in the United States will have developed AIDS from being infected in utero, delivery, or through breast feeding after birth. Michaels and Levine (1992) estimated that by the end of 1995, maternal deaths caused by the HIV/AIDS epidemic will have orphaned approximately 24,600 children and 4,000 adolescents in the United States. Puerto Rico currently has the second highest per capita incidence of AIDS in the United States, after Washington, D.C. Puerto Rico also has one of the highest rates of pediatric HIV infection. Children in Puerto Rico account for 6 percent of diagnosed AIDS cases in the United States. Because of the HIV/AIDS epidemic, it is estimated that by the year 1996, this illness will have left motherless 2,000 children in San Juan, Puerto Rico (Comision Nacional del SIDA, 1992).

Kazak (1989) commented that children infected with HIV and their families are likely to pose a major challenge to all aspects of the health care system. These families require
extensive and specialized tertiary health care, including intense emotional and psychosocial services.

Children with HIV pose a unique threat to the integrity of their families (Lewert, 1990). This is because the diagnosis of HIV/AIDS infection in a child may be the first indication that parents and other family members of the household are also infected (Volberding, 1991). Although HIV infection is everyone's crisis, people tend to set this illness apart from other chronic illnesses, provoking social and moral judgements regarding transmission behaviors (MacDonell, Abell, & Miller, 1991).

Characteristics of Children with HIV/AIDS Infection

Studies conducted since the first case of AIDS in children was reported in 1983 confirmed that the natural history of the illness and the clinical spectrum in this population are different and less understood than in adults. Several authors (Andiman & Modlin, 1991; Burr, 1993; Peckham, 1993) have stated that precise diagnosis for vertically acquired HIV is more complicated for children than for adults because it cannot be confirmed immediately after the infant's birth. Since all children born to a woman who is HIV positive will carry her antibodies for almost 15-18 months of age, a positive HIV antibody test only indicates exposure and possible infection and not the illness itself. Because children's immune systems are immature, the manifestations of HIV appear earlier than in adults. Primary signs and symptoms reflecting immune dysfunction
more commonly described in children than in adults include failure to thrive, poor growth, recurrent fever and bacterial infections, weight loss, generalized lymphadenopathy, and persistent and severe fungal infection (Burr, 1993; Cruz, 1988; Gupta, 1987; Hutchings, 1988). The incubation period for children infected perinatally is also substantially shorter than in adults who contract AIDS or children infected by other modes (Prober & Gerson, 1991). Burr (1993) suggested that two clinical courses are commonly observed in children perinatally infected with HIV. First, when the onset of illness symptoms appear before 1 year of age, the mortality tends to be high. In the second clinical course, children may remain asymptomatic for years, gradually showing signs and symptoms.

The survival rate has been investigated among different groups of children with HIV infection. A 1988 report from Italian Multicentre showed that the signs and symptoms of children infected perinatally (N=486) were more severe and the outcomes very poor when compared with children (N=57) infected by contaminated blood products. This finding was also validated in Krasinski, Borkowsky & Holzman's (1989) study. After reviewing 111 records, they found that survival of children infected through blood products was significantly longer than survival of children with perinatal infection. In 1989, Ryder et al. conducted a study with infants (N=475) of HIV seropositive mothers and compared them with infants (N=616) of mothers negative for HIV infection. Findings indicated that children
born of HIV positive mothers were more frequently premature, had lower birth weights, and had a higher death rate in the first 28 days of life compared with infants of mothers negative for HIV. They also reported that after one year of follow-up, 21 percent of the infants of seropositive mothers had died as compared with 3.8 percent of the infants of HIV negative mothers.

It has also been found that HIV infection affects the nervous system of the developing child. Children who have been infected with HIV exhibit some degree of mental retardation and brain damage (Fallon, Eddy, Wiener & Pizzo, 1989; Rubinstein, 1988). Diamond (1989) reported that the incidence of neurodevelopmental dysfunction in children with symptomatic HIV usually ranges from 78-90 percent, compared with figures of 39-60 percent in adults. Some of the signs and symptoms exhibited by children include growth deficit, slow acquisition of developmental milestones, or loss of acquired skills including cognitive function. Because of the nature of these effects, children require frequent assessment of developmental and neurological status. Septimus (1991) stated that although it has become common to compare children with HIV infection with other chronic illnesses, the problems posed by these children and families require a different focus and different psychosocial interventions. Although knowledge of the epidemiology, pathophysiology and symptomatology of HIV/AIDS in children has increased, the experience, psychosocial issues, and functioning of their families has not been sufficiently investigated.
HIV/AIDS Infection and Its Impact on Families

Research regarding the impact of HIV/AIDS on family units is limited. In a critical review of literature of nursing research studies related to HIV/AIDS infection, Benedict (1990) and Larson and Ropka (1991) found that the focus of the majority of studies has been on the etiology, pathophysiology, epidemiology and the course of the infection, and on diagnostic and treatment modalities. The experience of young homosexual men with AIDS or the families of either homosexual or drug injecting users with AIDS have been the primary focus of psychosocial research. This may be partially due to the fact that until recently HIV infection seemed to occur almost exclusively among young homosexual or bisexual men and injecting drug users rather than in heterosexual men and women.

The psychosocial impact generated by the HIV/AIDS illness on individuals has been documented, but not on families. Cohen (1990) noted that with the HIV/AIDS phenomenon, the individual's psychosocial responses are more intense and more negative because of fear of contagion and the nature of the risk behaviors associated with HIV/AIDS. Persons with HIV/AIDS infection have been described as living with a lack of a support network and fewer resources with which to cope. These persons also are vulnerable to stigmatization, social isolation, and rejection from relatives, friends, neighbors, and employers. Most people with HIV/AIDS infection experience a great deal of loss in health, jobs, intimacy, body image, control, energy, and life.
(McDonell, Abell & Miller, 1991; Raveis & Siegel, 1991; William & Stafford, 1991). Frierson, Lippman, and Johnson (1987) reported about psychosocial responses in a study conducted with 50 relatives of homosexual, bisexual, and injecting drug users. They found that (a) fear of contagion, (b) difficulty to accept a homosexual lifestyle and fatal illness, (c) fear of being stigmatized, (d) helplessness, and (e) a grieving process characterized by unrealistic guilt, anger, depression, and denial were common. They indicated that the grieving process was especially intense among families having young children, since many of them never expected to outlive their children. In Levy, Tendler, Van Devanter and Cleary's (1990) study with homosexuals, the most psychosocial dilemma for the patients was that unlike most others with chronic or life-threatening illnesses, they were reluctant to share information about their infection with families and friends. Gaskins and Brown's (1992) study of 10 homosexuals and bisexuals reported similar results, suggesting that individuals dealing with HIV/AIDS experience unique psychosocial responses not seen in other illnesses. Unlike other illnesses, these persons were faced with (a) uncertainty, (b) handling multiple losses, (c) living with a terminal illness, (d) accepting homosexuality, and (e) ambivalence on feelings. Gordon and Shontz (1990) identified similar themes in their description of psychosocial responses experienced by a homosexual man with HIV/AIDS infection (a) feeling infected and infectious, (b) facing death and dying, (c) experiencing ambivalence, and
Researchers have found that when HIV/AIDS diagnosis is made, more than one person in the family unit is always affected. Lockhart and Wodarski (1989) have stated that the family struggles to accept the changes and the catastrophic nature of the illness and then to acknowledge long-held secrets about drug use, homosexuality, bisexuality or prostitution and integrate the knowledge that significant others and especially youngsters have been placed at risk. Few studies addressing the family's experience have been conducted on caregiving and families of adults with AIDS. These studies supported the assumption that AIDS has a significant psychosocial impact on the daily lives of family members responsible for care of persons with AIDS. Brown and Powell-Cope (1991) conducted a grounded study to describe the experience of families and significant others of a person with HIV/AIDS infection at home. After interviewing 53 persons, uncertainty was a dominant theme in the lives of families and significant others acting as caregivers for the ill person. Feelings of uncertainty in AIDS family caregiving were closely woven into the other themes of (a) managing and being managed by the illness, (b) living with loss and dying, (c) renegotiating the relationship, (d) going public, and (e) containing the spread of HIV.

Matocha (1992) reported a longitudinal multiple case study approach with 8 family caregivers who provided care for persons with AIDS. The author found that giving support and assistance
to a person with AIDS on a daily basis was particularly stressful for caregivers. Since the HIV/AIDS illness is long and extended, caregivers experienced enormous demands in their physical, psychological, economic, social, and spiritual areas. The research regarding the personal experiences, psychosocial responses, and functioning of families with children with HIV/AIDS is extremely limited. To date, only two studies have been reported that related to the experience and changes in families' functioning and structure of families of children with HIV/AIDS infection. Dolan and Nokes (1992) were concerned about the experience of Puerto Rican families living in New York and who were dealing with the phenomenon of HIV/AIDS. Members of three family units with a member diagnosed with AIDS were interviewed. Using a phenomenological approach, the investigators found three common themes (a) loss, (b) reaching out, and (c) hopes for the children. Loss was experienced in all of the families. Families also were in constant need of social assistance to meet their psychosocial issues. Lastly, a great deal of concern was expressed for the children.

Principi, Fontana, Marchisio, Picco, Massironi and Tornaghi (1992) attempted to find out what the changes were in family structure during the first 5 years of life of children born to mothers with HIV/AIDS infection. Data were collected from records of 132 children. Findings indicated that the proportion of children having both parents alive and living together decreased significantly from 76 percent when the child was 6
months of age to 35 percent at the age of 5 years. Principi et al. (1992) indicated that since the parents' presence rapidly decline during the first years of life of the child, an attempt must be made to understand and meet the complex needs of these children and their families.

Summary

The studies that have been conducted on the HIV/AIDS epidemic support the fact that this phenomenon has increased significantly in the last years among men and women in the United States and Puerto Rico (Guinan & Hardy, 1987; Pizzi, 1992). Women with HIV infection, of especially those who are in childbearing age, constitute a growing proportion in Puerto Rico (Comision Nacional Del SIDA, 1992). Research regarding mother-child transmission suggests that 96 percent of all children acquired HIV from an infected mother (Arpadi & Caspe, 1990). A recent study showed that the vertical transmission average rate may range from 15-35 percent (Newell, 1993).

Many studies have been conducted to understand the epidemiology, pathophysiology, symptomatology, and survival rate of children with HIV/AIDS (Andiman & Modlin, 1991; Burr, 1993; Gupta, 1987; Hutchings, 1988). Findings of these studies showed that pediatric HIV infection has unique characteristics when compared to adults with HIV/AIDS infection. Due to the fact that originally HIV/AIDS infection seemed to occur mainly among homosexuals, bisexuals, and injecting drug users, researchers
have focused their attention to understand the experience of this group of people. Little effort has been put into studying the experience and functioning of families of children with HIV/AIDS infection. A need for further research which describes the experience and functioning of families with children who are infected with the HIV phenomenon exists. This study investigated families with children and their experience and functioning dealing with the HIV/AIDS phenomenon.
CHAPTER III

METHOD

This chapter includes a description of the design and method employed in conducting this study. Included is a discussion of the qualitative research method used to explore and describe Puerto Rican families' perceptions of their experiences with the HIV/AIDS phenomenon and how this phenomenon impacted the families' daily functioning. The sample for the study, setting, protection of human rights, instrumentation, data collection procedures, data analysis, and validity and reliability are also described.

Grounded Approach

The grounded approach as a qualitative research method was selected for studying the Puerto Rican families' perception of their experiences with the HIV/AIDS phenomenon and how this phenomenon impacted the families' daily functioning. The grounded method is a systematic research method that has evolved within the social sciences, particularly within the sociological tradition of symbolic interactionism to explore social processes present in human interaction. As interpreted by Blumer (1969), symbolic interactionism is a socio-psychological theory of social action designed to yield verifiable knowledge of human group life and human behavior. It can be used to describe basic and psychological problems and processes of which little is yet known, or this approach can also be used to gain a fresh
perspective on problems and processes in a familiar situation (Stern, 1980; Strauss & Corbin, 1990).

Since the human being is the focus of concern in nursing, the grounded approach is very useful for describing and gaining knowledge about human behavior in normal life events and critical life situations. The grounded methodology provides for the study of basic social processes of individual and family behavior as they take place in natural settings. As related to family, symbolic interactionism can be utilized to interpret processes of interaction within the family group. The family is conceived as a living, changing, and growing unit, not a static entity (Schvanevelt, 1966). By interacting with family members and distinctive groups in the society, the individual learns to share meanings and values about relevant phenomena and people. An important premise in symbolic interactionism is that as human beings, we act toward things on the basis of the meaning that the things have for us. The assumption incorporated in this premise is that human beings live in a symbolic and physical world of objects and their activities are formed around objects. It may be a physical object, social object, or abstract concept. Included in these categories are people, events, issues, rules, and behaviors, or a combination of these. However, human beings do not automatically respond directly to objects that they encounter in the environment, but assign meaning and value. It is through the meaning and value which these objects have for us that we try to interpret our world and the people who interact
with us. The meaning and values individuals assign to objects is important in understanding their behavior.

To Blumer (1969), the meaning of objects for a person arises fundamentally from the shared interaction of individuals in human society. As Blumer pointed out, the meaning of anything and everything has to be formed, learned, and transmitted in the context of social interaction. It is in the context of the family and through interaction with members of the family that one initially learns the meaning and value of objects. Similarly, it is within the family unit where the individual also learns the characteristics and attributes that are expected in society and the attitudes toward people who do not meet the characteristics.

The meanings and values thus learned set the way in which the individual perceives the objects, the way in which she or he is prepared to act toward objects, and the way in which she or he is ready to talk about them (Blumer, 1969). Symbolic interactionism holds the assumption that human beings are capable of selecting and interpreting the symbolic and physical environment to which they respond. As Blumer (1969) said, the individual confronts a world that she or he must interpret in order to act. As an active participant, the human being selects, checks, suspends, regroups, and transforms meaning in the light of the situation in which he or she is placed and the direction of his or her action. Meanings and values are used and revised as instruments for the guidance and formation of action.
As related to the family, symbolic interactionism also recognizes families as being unique and sensitive to the realities of their situation. From this perspective, family members respond symbolically, that is, in terms of definition of the situation present in the family environment (Schvanevelt, 1966). In the face of new situations or new experiences, families find it is necessary to make new interpretations and reformulate new meanings.

Family structure and functioning are influenced by many forces inside and outside the family unit. The HIV/AIDS illness, a relatively new phenomenon, has placed new demands on family structure and functioning, and this particular illness also carries an extraordinary burden of social stigma. Although HIV/AIDS is an illness of individuals, it has an intense stigmatized social meaning. A stigma is a mark or attribute which discredits and lowers the status of a person once it is known that the person have this attribute. Goffman (1963) reported that the term stigma was first used by the Greeks to refer to bodily signs designed to expose something unusual and bad about the moral status of the person. Goffman further expanded the concept to include three different types of undesired attributes, which are likely to generate negative reactions or stigmatization of individuals in the society: (1) physical marks, (2) observed or reported character aberration, resulting from socially deviant behaviors, and (3) inheritable features like race, religion, and nationality. Goffman stresses
that social context is crucial in determining stigma. The stigma is socially constructed and socially transmitted. It is through the socialization process that members of a social group learn to categorize or mark individuals and incorporates the standpoint of the normal, acquiring thereby the same beliefs of the wider society of what it would be like to possess a particular stigma (Goffman, 1963). Categorization creates expectancies that shape the course of interactions within both casual and long-term relationship. Stigmatization as a complex process of social interactions lead to rejection of persons with certain undesirable attributes that make them appear different and separate from others. Persons who possess one or more undesirable attributes are viewed as deviant, and therefore stigmatized because of it. As Jones et al. (1984) stated, these undesirable attributes define the identity of the individual and they become the filter through which individuals characteristics are seen.

The HIV/AIDS illness is perceived as affecting in greater proportions the already stigmatized groups in society. Since the beginning of the epidemic, the image of HIV/AIDS in society is intimately connected to certain groups, such as homosexuals, bisexuals, prostitutes, and injecting drug users. In addition, since the dominant factor of transmission of HIV/AIDS is through sexual activity, the connection of the illness to some immoral behaviors such as promiscuity has been made repeatedly. Sontag (1990) pointed out, that the sexual transmission of the HIV/AIDS
illness, considered by most people as a calamity one brings on oneself, is judged more harshly than other means, especially since HIV/AIDS is viewed as a punishment for deviant sexual excess and perversity. Many of the stigmas generated by society related to the HIV/AIDS illness has greater consequences for the person who has the illness, family members, and significant others. This is because stigmatization is also spread to everyone who has a close relationship with the sick. As Goffman (1963) said, families and significant others are all obliged through courtesy stigma to experience some of the discredit of the stigmatized person to whom they are related. The courtesy stigma is considered as a situational induced social construct rather than a constant attribute of the person (Birenbaum, 1970).

The presence of HIV/AIDS illness may lead to alienation and discrimination, since families, relatives, and friends may be frightened about the possibility of contagion. The effect of the illness and the stigma attached to it, also may lead to the family's withdrawal socially and physically from other people because feelings of shame and guilt. Family members may tend to see themselves as unwanted, failing, accepting the discredit conveyed by society and discrediting themselves. Since the HIV/AIDS is stigmatizing, it must be concealed. Anticipating how others might respond and knowing the consequences of possessing the stigma, families find necessary to be carefully secret about the illness in order to avoid the moral judgment and hostile, discriminatory attitudes from people.
Nursing professionals need a better understanding of families, experiences and interactions when the HIV/AIDS phenomenon is present in their units. Unfortunately, sufficient research of the families' perceptions of their experiences and interactions dealing with the HIV/AIDS phenomenon is lacking. The grounded approach framed within the basic concepts and assumptions of symbolic interactionism provide a way to become immersed in the experiences of these families as it exists and obtained first hand data on their experience and processes by which families create, sustain, and discuss their own family realities dealing with the HIV/AIDS phenomenon.

**Sample**

Grounded approach procedures require a simultaneous and ongoing collection, categorization and interpretation of data. This systematic set of steps leads to the development of a well-integrated set of concepts that provide a logical theoretical explanation of the social phenomenon under study. These steps are also designed to give the analytical process precision and rigor (Strauss & Corbin, 1990).

Theoretical sampling, the process of data collection for generating theory, was used to select participants for this study. In order to participate in the study, the family unit had to be composed of two or more family members living in the same household, with at least one biological caregiver (mother or father) with a child under 13 years of age who had been diagnosed with HIV/AIDS infection. The child had to be asymptomatic and
included in Class P-1, Subclass A, B, and C or symptomatic and included in Class P-2, Subclass A, B, C, D, E, and F.

Six family units composed of 29 members were included in this study. Included were a total of thirteen adults and sixteen children. The participants were predominantly white and Puerto Rican.

**Setting**

Qualitative research demands that the researcher engage, collect, and analyze data from natural contexts in which the phenomenon occurs. Naturalistic settings capture the social world of the individuals engaging in the phenomenon under study (Chenitz & Swanson, 1986).

Families for this study were selected from one ambulatory clinic located in one large public teaching hospital located in San Juan, Puerto Rico. Although permission to conduct the research study was requested in two larger hospitals located in the San Juan metropolitan area, only one authorized the researcher to use the clinical facility. The researcher's initial intention was to select families from both hospitals to provide for regional variation in families' experience and functions. However, since the hospital that granted permission provides services to families from many cities outside the San Juan metropolitan region, the regional variation was always in this study. The selected ambulatory clinic has been providing services to approximately 228 children with HIV infection fifteen years of age or younger. Almost 96% of these children were
infected perinatally. Mothers were infected through sexual contact with an infected partner.

The homes of families comprised an additional setting for this study. The researcher visited the families' homes during selected scheduled periods of time. The researcher also spent many hours with participants in multiple settings. These additional settings included outpatient clinics, emergency rooms, laboratories, government agencies, and cafeterias. By taking part actively in participants' lives, the researcher not only had the opportunity to establish meaningful relationships with them, but also facilitated firsthand observation of participants' behaviors and interactional processes with others in natural contexts and under a variety of conditions.

Protection of Human Rights

The study was initiated after receiving approval from the Louisiana State University Medical Center and the University of Puerto Rico, Medical Campus Institutional Review Boards (Appendix A). To protect confidentiality and privacy of participants, the following ethical considerations were taken in this study:

1. The content of the consent forms, purpose of the study, procedure, and participation in the study were explained before the participant signed the consent forms.

2. The consent forms signed by the participants were kept in a safe, inaccessible place in the investigator's home and separate from the audiotapes, interview transcriptions, field notes, and memos.
3. All interviews were always conducted in a private setting.

4. Field notes were coded in order to identify participants by letter only.

5. Names and identifying information were changed to protect the confidentiality of participants.

6. All tapes were erased after the data was transcribed.

7. The investigator used a number to identify each audiotape, interview transcriptions, and written notes.

8. Confidentiality was maintained between and among family and staff members.

**Instrumentation**

In this study the researcher utilized a combination of methods for data collection including unstructured interviews, participant observation, literature review, and a diary to answer the research questions and understand the phenomenon under study. The data collecting instrument used in this study also included a demographic data form (Appendix B). An interview guide (Appendix C) was used to get an initial picture of the families' activities in the setting where they were receiving health services. An additional interview guide was used to identify personal thoughts, feelings, and concerns in the context of the parents' perspective (Appendix D). As data collection progressed, semistructured interviews were also conducted with family members, including children and siblings who knew about the HIV diagnosis and who were able to describe their viewpoints about
the illness (Appendix E). Each participant was asked the same initial questions so that comparable data would be available across participants. These interviews were always conducted in a private setting such as a room in the ambulatory clinic hospital or in the participant's home. The researcher always scheduled interview times so the participant's daily activities would not be interrupted.

Participant observation was especially appropriate for this qualitative study because it required the researcher to become directly involved as a participant in the families' daily lives. Continuous and intensive involvement provided the opportunity for a more accurate and objective description of the families' daily activities, behaviors, and interactions. Immersion in the families' lives for extended periods of time through participant observation also enabled the researcher to empathize with their needs and problems.

The researcher followed some participants more closely than others, as it was found that some families were having more problems and needs than other families. Many times the researcher stayed in the clinical unit with the children while the mother or father attended an appointment for themselves or another child in the medical center. Sometimes the researcher picked up prescriptions in the pharmacy for the parents to let them stay in the unit with their children or to let them go early to their homes. The prescriptions were later given to them in a home visit. When needed, the researcher provided transportation
to participants.

There was one instance where one of the participants became very ill. The researcher accompanied the participant and his wife for several hours in the emergency room. Since the participant was hospitalized for several days, the researcher also conducted frequent visits to the hospital.

Many times the researcher visited the family's home and spent from one to six hours observing and interacting with family members in the course of the day's activities. A variety of interactions and activities occurred during the time the researcher was visiting the family's home. The researcher had the opportunity to share breakfast with some of the families and the lunch or dinner with others. The researcher observed family members playing games together, cleaning the house, watching television, arguing about things that happened during the day or about things not done by the children while at home, talking to a neighbor, conversing on the telephone, and discussing things that happened at school and in the community. Family members seemed to behave as usual in spite of the researcher's presence.

As the study progressed, it was necessary to collect additional sources of data outside the family unit. These data helped the researcher to interpret, clarify, and validate the primary data obtained from participants. Additional data were collected from key personnel involved in providing direct and indirect health care services to the children and families in the ambulatory clinic. Three unstructured interviews were conducted
with two nurses and one social worker.

Data was also collected from observations and written information found in the literature. Written information was obtained from newspapers, conferences, magazines, and books. Two books on HIV/AIDS written by parents who were confronted with this phenomenon in their family unit were coded in the same way as the interviews and field notes (Ashe & Rampersad, 1993; Oyler, 1988).

The researcher also had a personal diary where she recorded her thoughts, feelings, and reflections while conducting this study. The researcher also recorded her behaviors and interactions with participants. Having a personal diary and talking to staff members, trusted colleagues, and friends helped this researcher to receive informal support and to reorganize some of her feelings and put them in perspective several times.

Data Collection Procedures

Access to the institution and the selected clinical unit was provided first by the Nurse Director and secondly the Nurse Coordinator (Appendix F). Authorization was granted to start data collection with a recommendation to work closely with the team to assure confidentiality and privacy of the families. During the first day in the selected ambulatory clinic, the nurse coordinator introduced the researcher to each staff member and explained the purpose of this study. Two to six hours per day were spent in the clinical setting four days a week during the two-week period to learn about people and activities in the
Since the researcher was the only one conducting this kind of research in the unit, an information sheet outlining her background and the research project was designed and circulated among staff members.

Participants who met the study's criteria and who agreed to participate were asked to sign a consent form (Appendix G). Parents signed consent forms for the children. However, the children were also asked to sign the consent forms. Only one parent refused to allow their children to be interviewed. The selection of six family units incorporated families from different cities in Puerto Rico (Caguas, Loiza, Cidra, Carolina, Vega Baja and Guaynabo). Families were followed for seven months.

The first family unit was referred by the social worker of the unit. Before the initial contact, the social worker shared basic data about the family such as (a) the number of family members, (b) where they lived, and (c) social services received. The social worker also provided this researcher with suggestions regarding strategies to protect confidentiality and privacy of families in the community and in the families' homes.

Additional participants were selected mainly through personal contact and according to the theoretical needs of the study. For example, each successive participant was selected to extend information already obtained, to obtain additional information to compare for similarities and differences, or to fill in gaps in the information obtained from previous
participants. Each selected participant provided relevant information for the evolving categories.

A total of 30 interviews were conducted in this study between May and December, 1993. Individual interviews lasted approximately 1 hour. Each interview was audio-taped, transcribed, and coded within 24-48 hours of data collection. A total of fifteen family members were interviewed about their perceptions of their experiences and processes of functioning dealing with the HIV phenomenon. Four children were allowed by their parents to be interviewed. Familiarity and rapport with children were achieved after the children saw the researcher interacting for almost 3 months with their parents. Eleven participants were formally interviewed twice to validate some of the information, clarify concepts and expand categories.

Probes were used to elaborate on data already collected from participants. The following are examples of such probes: What do you think about what is happening in your family?; Tell me more about...reactions; What do you see are the most significant concerns faced by ...? Additional unstructured interviews were also conducted with the participants by telephone, in the clinical unit, in their homes, and when the researcher accompanied participants through their appointments in other clinical settings and agencies. Data collected through participant observation were recorded in field notes.

**Data Analysis**

The method of constant comparative analysis was used
throughout this study to generate a substantive nursing theory of family functioning for Puerto Rican families with children having HIV/AIDS infection. The constant comparative method provides standard analytic procedures with specific directives for using the data systematically (Glaser & Strauss, 1967). Using the constant comparative procedure, data collection, coding, and analysis were made continuously in order to develop and refine reductions of the data and to identify problems and processes occurring within the family units. From the beginning of the study until near its end, the collection, coding, and analysis were conducted step by step, each one building upon the other.

What follows is a description of the grounded approach procedures and strategies used in this study.

**Theoretical Coding**

The initial step in analysis was coding the data. Data coding means labeling it to note what is going on (Stern, 1985). Data collection started from the researcher's first contact with the setting and people. The researcher started writing field notes in a format she designed. As a strategy, the field notes were dictated into a tape recorder as soon as each contact was finished. Things such as (a) the time the researcher arrived and left, (b) observations about events that happened in the setting, (c) nonverbal behaviors, (d) what families and staff did in the setting, and (e) the researcher's reflections were all recorded, transcribed, and then typed for analysis. The codification process started immediately after the field notes
and interviews were transcribed and typed on the left half of the margin page. Data were analyzed line by line and paragraph by paragraph, highlighting important passages.

As recommended by Hutchinson (1986), the researcher asked the following questions during the coding process:

1. What did I see in the data?
2. What is the problem that these people are dealing with?
3. What processes help them cope with the problem?

These questions were carefully followed in the initial stage of the encounters with the study participants to ensure full accounting of the data. As data collection progressed, the theoretical sampling, coding, and analysis was more selective and focused to answer the research questions developed for this study. The statements, observations, events, and incidents were rewritten as concepts in the right half margin of the page next to the appropriate line.

The concepts are relevant theoretical abstractions about what is going on in the area studied (Glaser & Strauss, 1967). Several concepts were selected from participants' own words or phrases. Others were named by the researcher. The identified concepts were then compared for similarities and differences. These comparisons were recorded in memos. Those concepts that seemed to pertain to the same phenomenon were grouped together under a higher order of classification called category (Strauss & Corbin, 1990).

To determine how well categories were developed, the
following questions suggested by Corbin (1986) were asked:

1. What is the name of this category?
2. What are its properties?
3. Under what conditions does it occur and under what conditions does it not occur?
4. How does it happen or does it not happen?
5. Who is involved, and with what consequences?

The emerging categories were compared with each other to ensure that they were mutually exclusive and cover the behavioral variations (Hutchinson, 1986). The literature and pertinent documents were used as an ongoing process for clarification and expansion of the emerging categories and theory. It was necessary to move back and forth in the field for further data collection that allowed for clarification, validation, and elaboration of categories.

**Theoretical Memos**

Theoretical memos are written records of analysis of ideas about data, emerging concepts, and their theoretical relationships. According to Glaser (1978), the development of memos allows the researcher to:

1. Raise the data to a conceptualization level.
2. Develop the properties of each category as they are reflected in the data the category represents.
3. Present hypotheses about relating categories and/or their properties.
4. Being able to integrate these relationships with
clusters of other categories to generate theory.

In this study, memos were written to document the researcher's ideas and analytical process about the data and the coded categories, to keep a record, and to organize the results of the analysis. Memos were written throughout the research process, starting with the first interviews and observations conducted by this researcher. As the researcher wrote memos, the following strategies were followed: (1) Each memo contained a heading denoting the concept or categories to which it pertain; (2) Each memo was numbered following the order of writing during the research, titled, and dated. Each memo included reference to the field notes, interviews, or documents from which it was taken; (3) These memos were identified with a number known only to the researcher in order to protect the privacy and confidentiality of the study participants.

When memos became saturated, that is, when the same theme or pattern continued to emerge, they were sorted and ordered. Through the process of sorting memos, the data and ideas were theoretically ordered. By following this step, the researcher was able to identify the core category, which also constituted the central process of family functioning for families of children with HIV/AIDS infection.

Diagramming

Diagramming was done in this study in order to provide a visual framework of the relationship that exists between categories and the core category. The core category is the
central process that occurs continuously in the data and seems to explain the major action in the phenomenon under study. Therefore, all other categories were integrated around this category.

Validity and Reliability

The grounded theory approach as a qualitative approach has specific procedures for data collection and analysis that enhance the credibility of the findings and interpretations of the phenomenon under study. As the study utilized the grounded approach, specific procedures were incorporated from the beginning of the study until the end. The following is a description of the procedures which were employed to establish precision and rigor in this study.

When using a qualitative methodology, one important principle is that the researcher must spend enough time in becoming oriented to the context to be certain that the context is thoroughly appreciated and understood (Lincoln & Guba, 1985). In this study the researcher completed seven months of intensive engagement with staff and families. Data were collected during this period of time in the clinical setting and many other contexts outside the selected unit. The period of prolonged engagement provided for persistent observation, constant and continual validation of data, and analysis about the participants' needs, problems, and strategies as well the families' functioning dealing with the phenomenon of HIV/AIDS. It also helped this researcher to build and keep adequate trust
and rapport with staff members and participants.

In the beginning of the study, the researcher spent adequate time learning the setting and building trust and rapport with staff members and families. Once she gained some trust from and understanding about the people in the context, the interviews with staff and participants were initiated.

In this study, the analytic process began the first day in the field. This is because when the grounded approach is used, validation of data occurs as an ongoing process. All information collected through interviews, observations, and other multiple documents were coded and analyzed using the constant comparative procedure. Data were analyzed and compared several times, thus providing a check on validity (Hutchinson, 1986). The analytic process was stopped when the main theme happened over and over again and nothing new happened as this researcher reviewed the data.

Although this study involved a relatively small sample of participants, thirty interviews were conducted. Some participants were interviewed once, but the majority were interviewed two times. This strategy helped to assess the stability of theoretical relationships. The interviews were tape recorded and transcribed by this researcher within 24-48 hours of data collection. Tape recording and transcription of interviews together with participant observation assured valuable and reliable information for this study. After the interviews, the researcher had the opportunity to follow up with the participants
for clarification of data and further interviews. Through participant observation, the researcher was able to get involved in the social world of these families and hear, see, and experience reality as the families did. Therefore, this researcher was able to check descriptions against facts (Lincoln & Guba, 1985).

Another procedure utilized to assure rigor in this study was a personal diary for self-monitoring of the researcher's comments, impressions, methodological decisions, thoughts, and feelings throughout the study. In qualitative studies the instrument of choice is the researcher. Therefore, by having this personal diary, the researcher was able to become reflective and aware of personal feelings, possible biases, and distortions introduced during data collection. Utilizing the diary as a source of data helped the researcher not only to realize how intense her work with families was, but also to realize her strong identification with participants' needs, fears, anger, frustrations, and hopes. There were few instances where the researcher experienced burnout symptomatology making it necessary to back off from the field for days before starting to work again with the data and participants. However, it was these kinds of intense and personal interactions between the researcher and participants together which generated the rich data for this study.

Additional procedures to safeguard against possible biases and distortions were implemented. The researcher sought
validation of data from participants, staff members, and friends who were working with people with HIV/AIDS infection to also assure credibility in this study.

A member check procedure was used to obtain feedback from participants to ensure the researcher's interpretations of data accurately reflected their perspectives and everyday reality. Member check was implemented in three ways. First, some participants were asked to review the transcription of their interview to evaluate them for accuracy and completeness. Second, on interview transcripts that were very long, the researcher wrote a summary of the interview. Then the participants were asked to provide their verbal feedback of this summary. All comments were noted and also transcribed. Some of the participants' feedback was also tape-recorded and transcribed. For other feedback the researcher only took notes about the participants' comments and corrections. These comments were attached to the original interview transcript. As a result of the feedback, the participants had the opportunity to share additional information. The researcher also had the opportunity to ask new questions of participants and expand information.

Third, near the end of the study the researcher also prepared a detailed case summary for each family unit. The researcher's intention was to describe the participants' perspectives and experiences since the time the HIV phenomenon appeared in their family unit. Consistent with the research questions of this study, the summaries included the following
aspects: (1) a description of the moment when the diagnosis was revealed, (2) the participant's family's and friends' reactions, (3) their definition and vision of the illness, (4) changes that occurred in the family unit, (5) major needs and concerns, and (6) strategies and resources used to deal with the HIV/AIDS phenomenon.

Descriptive statements from the participants were included in these summaries in order to provide them with examples. Each participant was asked to comment and evaluate the researcher's accuracy in portraying the family's perspectives and everyday experiences. The following questions suggested by Stern (1985) were addressed to participants in order to validate this researcher's grasp of their perspectives and the everyday reality of their situation: (a) Is this how it is? and (b) Does this describe your experience? Be it said that only one participant made correction, on two areas of the summary.

During the process of the study, the researcher also consulted with staff members and friends who were also working with people with HIV/AIDS. A preliminary presentation of this study's findings was given to staff members of the selected unit. This process allowed an opportunity for this researcher to share some of the findings and interpretations of the data. It also provided an opportunity to share the researcher's feelings working with them and participants for seven months.

Summary

This research study used the grounded theory approach and
the basic concepts and assumptions of symbolic interactionism to explore and describe Puerto Rican families' perceptions of their experiences and processes of functioning when the HIV/AIDS phenomenon is present in the family unit. Families confronted with the HIV/AIDS phenomenon must deal not only with a biological illness but also with one that is highly stigmatized by individuals in the society. The family is forced to make significant changes in their patterns of interaction on a day-to-day basis. The family finds it necessary to redefine and reformulate meanings based on the definition of the situation and how other individuals perceive and interpret their reality. In order for nurses to become more helpful to families of children infected with HIV/AIDS, a clear understanding of the families' perceptions and everyday interactions needs to be explored and described.

The grounded theory approach procedures were used in the selection of participants for the study and in data collection, analysis and presentation. Six family units were selected through theoretical sampling from one large pediatric teaching hospital. To enhance precision and rigor in this study, the researcher spent seven months of prolonged and intense engagement with participants. Participant observation and unstructured interviews were conducted in a variety of settings. The analytic strategy of constant comparative was used concurrently with data collection. The researcher sought member check procedures including a personal diary to validate data from participants,
staff members, and friends.
CHAPTER IV

RESULTS

The purpose of this study was to explore and generate a detailed description of Puerto Rican families' perceptions of their experience and processes of functioning when the HIV/AIDS phenomenon is present in the family unit. This chapter summarizes the results generated from the analysis of the data resulting from the field work experience with families. The approach employed in this study was qualitative, framed within the symbolic interactionism framework, with the intent of developing a substantive grounded theory of family functioning for families with children with HIV/AIDS infection.

To understand more fully the everyday reality and processes of functioning of families with children affected by the HIV phenomenon, intensive and prolonged fieldwork was conducted using a combination of unstructured interviews and participant observation. Other sources of data have contributed to the understanding of families' experiences and processes of functioning. These include scientific and lay literature including newspapers, magazines, and books addressing the HIV/AIDS phenomenon.

The study sample consisted of six family units composed of a total of twenty-nine members. Of the six family units, five reported dealing with the illness for three to five years.
Demographic data for adults were collected in the categories of age, education, sex, marital status, employment status, and HIV classification status (see Table 1). Descriptive statistics were used to analyze families' personal data. The adult participants ranged in age from 32 to 58 years with a mean of 40.2 years. The majority of participants had completed the 9th grade. Ten participants were married at the time of the study. Of the 13 adults, only four were employed at a regular full-time job. One family unit has the widowed father working full-time in his own business on a daily basis. This father lived with his parents, who recently retired, and three children. A widowed mother and her brother were both working part time several times a week. Four parents from two family units who previously worked are now unemployed because of the HIV/AIDS illness and taking care of one child and four children, respectively.

In terms of the classification status, six participants were negative for HIV. Five of the participants were HIV positive, while two were already having AIDS symptomatology. The father and the mother from two family units were deceased from complications of AIDS at the time of the study.
Table 1
Demographic Characteristics of Adult Family Members

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Adults (N=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>40.2</td>
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<tr>
<td>Range</td>
<td>32–58</td>
</tr>
<tr>
<td><strong>Education (in years)</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>9.8</td>
</tr>
<tr>
<td>Range</td>
<td>1–16</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>10</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td>Divorced</td>
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(table continues)
### Demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Adults (N=13)</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
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<td></td>
</tr>
<tr>
<td>Employed Full-time</td>
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<td>30.8</td>
</tr>
<tr>
<td>Employed Part-time</td>
<td>3</td>
<td>23.0</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>30.8</td>
</tr>
<tr>
<td>Retired</td>
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<td>15.4</td>
</tr>
<tr>
<td><strong>HIV classification status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV Positive</td>
<td>5</td>
<td>38.4</td>
</tr>
<tr>
<td>With AIDS</td>
<td>2</td>
<td>15.4</td>
</tr>
<tr>
<td>HIV Negative</td>
<td>6</td>
<td>46.2</td>
</tr>
</tbody>
</table>

Demographic data for children were collected in the categories of age, sex, and classification status. Children ranged in age from 5 months to 15 years with a mean of 8.6 years. The majority were male. The HIV classification status of the children was that four children were HIV positive. Two were having AIDS symptomatology. Nine children were HIV negative. One child born from a mother seropositive for HIV was still indeterminate (see Table 2).
Table 2

Demographic Characteristics of Children

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Children (N=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.6 Years</td>
</tr>
<tr>
<td>Range</td>
<td>5 Months-15 years</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>HIV classification status</td>
<td>Percent</td>
</tr>
<tr>
<td>HIV Positive</td>
<td>4 25</td>
</tr>
<tr>
<td>With AIDS</td>
<td>2 12.5</td>
</tr>
<tr>
<td>HIV Negative</td>
<td>9 56.3</td>
</tr>
<tr>
<td>Indeterminate</td>
<td>1 6.2</td>
</tr>
</tbody>
</table>

Impact of HIV/AIDS on Family Functioning

Analysis of collected data from families indicated that once the HIV/AIDS diagnosis is revealed to families, the impact on family functioning is significant. Family functioning is disrupted, changed, and becomes more complex for families. The theory of family functioning for families of children with HIV/AIDS consisted of a dominant core process and the movement of families through five related phases. For families of children with HIV/AIDS, the basic social problem they must deal with is the presence of a constant sense of vulnerability of being rejected and isolated. This sense of vulnerability includes
families' concerns about how relatives and friends will respond if the illness is revealed to them. Protecting the family emerged as the dominant core process of functioning for families of children with HIV/AIDS infection to handle this sense of vulnerability and to help them feel some control over their lives. This core process of functioning was reflected strongly over and over again in each of the interviews and observations in all of the families. Although, historically, family protection is expected to be a basic function in every family unit, when the HIV/AIDS illness appeared, protecting the family became of paramount importance for families.

Protecting the family is conceptualized as the process of functioning occurring in a family unit through which the members take actions to counteract their sense of vulnerability and strive to protect themselves from being hurt by other people through rejection and isolation. Protecting the family has four properties:

1. It is characterized as an ongoing process of functioning that becomes a way of living as families find out about the HIV/AIDS diagnosis.

2. It includes identification of internal and external protective strategies.

3. It takes place as a continuous process of functioning in each family unit regardless of the number of years dealing with the HIV/AIDS phenomenon.

4. It serves to promote a sense of normality and
functioning within the whole family unit, but family members are in constant need to manage information within the family unit, with other relatives, neighbors, and employers.

Protecting the family was observed occurring within three important contexts. The first was in conversations among families and the hospital staff, but mostly with social workers. The second context was in conversations among families who visited the unit. The third context was among parents and their children at home and between children at school and in their neighborhood. Protecting the family became crucial at school and in the neighborhood since children spend much of their time in both places on a day-to-day basis.

Five phases were identified and related to the dominant core process of protecting the family: (a) facing the diagnosis, (b) reacting to the diagnosis, (c) revealing the illness, (d) living with concerns, and (e) seeking balance. The following is a presentation of these phases as derived from all sources of data.

Facing the Diagnosis

When a positive diagnosis of HIV/AIDS infection is made, it assumes a unique significance for families. General informants sustained the fact that the presence of HIV/AIDS infection changes family life completely since HIV/AIDS implies more than an illness. It implies that normalcy, meaning nothing less than life itself, will be difficult for families to keep. One event, a single test result, now repeatedly threatens and challenges many parts of families' lives. Families find that, after the
diagnosis, their lives are different because they are not only living with the implications of their own diagnosis for their own lives, but also with its immediate and future impact on their children. As parents reflected upon their experiences of facing the diagnosis, they described the experience with notable intensity. Although most families had been dealing with the HIV phenomenon for several years, still clear in their minds was the very first moment of confirmation of the illness.

The element of surprise was central when the illness was revealed to all of these families. Being surprised means that parents were not aware of any risk because of their lifestyles. Of particular relevance to these families is the fact that they were all heterosexual families, so they never conceived of the possibility that HIV infection would enter in their lives. At the time of facing the diagnosis, all families were already involved in the process of seeking explanations for two major critical events taking place in their lives. The two major critical events were (a) the sickness of a child and (b) the sickness of an ex-partner or husband that eventually resulted in the diagnosis of HIV infection.

The process of seeking explanations involves problem-focused actions taken by families intended to obtain more and clearer information to elucidate the problem they had been experiencing in their lives. Some families were dealing with children with many health problems and hospitalizations. Although children were having a clinical picture which was consistent with the
effects of HIV infection, at that point in time health care providers never thought on that possibility. Families sought information to determine what was causing that kind of symptomatology and why they were unable to observe any kind of improvement in the child's health regardless of treatments. After going through multiples tests, many treatments, hospitalizations, and for some families a waiting period of two weeks, parents were faced with a confirmatory test for HIV infection. A mother of a two-year-old girl remembered the day when she faced the child's diagnosis:

Everything began when the child was born. Once she was born she started having health care problems such as hepatosplenomegaly and cardiac problems. She became very ill and was hospitalized with pneumonia. They didn't know what to do until they asked me permission to have her tested for HIV. When the test came back they told me it was positive.

This mother who was herself unsuspecting and symptom-free at the time of finding out about her child's diagnosis was also faced with her own diagnosis for HIV infection and rejected herself. At that moment, it was upsetting for her to realize that she had transmitted the HIV infection to her daughter. "If she [child] has this illness, I must have it myself, too, because I was the one who delivered her. I don't know why it never occurred to them to do that test." Similarly, a mother of a 10-year-old child said, "She [the child] was having fatigue, fatigue, and
fatigue. Then in her sixth pneumonia, I decided to take her to another doctor. After two weeks of being in uncertainty and expecting a miracle, they told us that she had that thing [the HIV illness]." Some families were surprised by being the last ones to find out about this illness. As one father said, "I didn't look for this. I didn't know what was happening to her [his ex-partner]." Another mother said, "Sometimes the most interested person about what's going on is the last one to find out."

Some parents were faced with the diagnosis when their ex-partners were at the end stage of the illness spectrum. For ex-partners, the task to disclose their illness seemed critically important before they died since their own physical deterioration made it impossible to avoid disclosure. When reflecting on the time he faced the illness of his ex-partner, a father indicated, "Before she passed away, however, all her family, many of them, knew that she had that condition. Then before she died, in the final stage, then she sent for me and told me, look, this is what is happening." The fear was a significant factor that kept this ex-partner from revealing the illness. As this father explained, "She was afraid of me. She was afraid I would commit suicide; she was afraid."

The experience of facing the HIV diagnosis appeared in some couple's lives when they were dealing with two major challenges: the pregnancy of their first baby and the husband's hospitalization. In describing the experience, the mother said,
"I was at that time seven months pregnant. My husband was hospitalized because he was bleeding through his prostate. The doctors did all possible tests but they couldn't find anything wrong until they decided to test him for HIV, and it came back positive. We found out about this illness together, everything at the same moment." This mother also reviewed the first moment she decided to share her diagnosis looking for support and guidance: It was so hard, I was so worry [sic] that I shared my feelings with my gynecology [sic]. The need to share her feelings and diagnosis with her own gynecologist carried the consequences of rejection: "In response he told me that he didn't take care of patients with AIDS. I was left in the air."

Only one mother suspected that her husband had the illness. Nonetheless, she also expressed surprise when she actually was told. The conditions that led her to suspect her spouse's illness were (a) her husband's lifestyle, (b) his history of previous sexually transmitted disease, and (c) his alcohol intake problem. This mother remembered the changes her husband experienced that made her more suspicious about the HIV illness:

I observed him without appetite, he didn't want to eat, he became fatigued just by walking only two steps, and of course in one month he lost 30 pounds. I told him, Don't try to hide this from me, sooner or later I'm going to find out.

This mother confirmed her suspicion after her husband died, and the test performed on him at the hospital came back positive.
Reflecting on the confirmatory test, this mother stated, "I suspected; he couldn't hide this from me. I took my children and we were all together tested for HIV."

Reacting to the Diagnosis

The reacting phase is defined as the participants' responses to the HIV/AIDS diagnosis and its meanings to them. Responses to the diagnosis ranged on a continuum from responses common among people dealing with different life-threatening illnesses, including initial shock followed by denial, feelings of loneliness, anger, disbelief, and sadness, to more intense and more negative responses that seem to be unique to people confronting the HIV phenomena: a sense of shame, feelings of being labeled as different, and a sense of being infectious. A mother described her feelings of shock and anger after receiving her daughter's diagnosis and realizing the possibility of being exposed herself to the HIV/AIDS illness:

I waited two weeks. These two weeks were the most...
Two weeks where I couldn't sleep. Two weeks of anguish. I felt ill. I couldn't look at him [her spouse] or talk. I was in shock. He was in shock. There were no words to say... We rejected each other. I thought, "if you [spouse] have tried to hurt me so badly, I will kill you."

Another father described the struggle that erupted at the moment he faced the fact of the illness:

For me it was hard, hard, really hard... No...no, I
couldn't. I was completely out of myself; my mind wasn't clear. I couldn't believe it. I couldn't accept that something like this was happening to me...

I felt lonely.

Suicidal thoughts appeared at this stage. The same father considered suicide as a way to get out of this painful reality. As he explained, "I had bad thoughts when I found out what was happening. I thought about doing something bad to get out of this situation. I thought about suicide because, why me? Why is this happening to me?" Within the family circle the illness caused his mother to suffer greatly. The same father added, "There was a lot of suffering in my mother, a lot. She was out of control. I'm her son; she is [his child] her granddaughter. It was necessary to take her to the psychologist."

One mother, who was pregnant at the time she found out about the HIV diagnosis, went through a self-destructive period when she was initially told: "I did a lot of bad things not to have this child. I didn't care. I just wanted to die when I knew about this, I was so angry." Similarly, another mother experienced shock and resistance when her child was diagnosed: "I was alone at the hospital. I got hysterical, and I called my husband at his work. At first, I didn't want to be tested; I couldn't. For me it was better not knowing. The only person in my life was my husband."

One child's reactions to an HIV diagnosis for himself was a frightening experience, especially when the test was performed in
the context of a realistic concern. He had received a transfusion from his father, who had recently died from AIDS complications. This fourteen-year-old child shared his experience of going for his test results: "Then we went to the clinic. They called us, and I took a seat. Then I started crying because I didn't know the result yet... I wasn't expecting it... I wasn't expecting it." Following the diagnosis, this child experienced difficulty in his school performance. His mother explained, "Knowing about this thing scared him. He reflected his fears by lowering his grades." His sister demonstrated sorrow about what was happening to her brother: "I felt sad, and sometimes I'm still feeling sad when I think that it was my father who infected both [her mother and brother]."

Denial is still evident 3 years later in the life of one of the fathers as a way of coping with the overwhelming reality of the illness: "To this date I don't think she [his daughter] has this illness, but according to the doctor, it is true. It is still affecting us."

The negative and intense responses experienced by participants seemed to result from the personal meanings they have attached to the HIV/AIDS illness and the stigmatized meaning that society has created for the illness. At a personal level, the HIV/AIDS illness is viewed by some participants as a terrible condition. As one mother described it, "This is a mortal illness. It is really sad to see people dying from this illness. AIDS has four sad small letters" A father stated, "When you talk
about this illness, you always talk about death." Another father commented, "This is something evil."

There is a persistent awareness among participants about the consequences of having this illness. Having this condition with no cure means life expectancy rapidly declines and physical changes occur fast. A father described his perception about the illness: "This illness is the last. It has no cure. With this illness the person loses his life faster" Similarly, another father stated, "I have seen many people deteriorating. I don't like to go to CLETS [clinic]. Everytime I go there I come back depressed. I see how the illness is deteriorating people."

A primary concern for a child was her sister's life expectancy: "Daddy, how long is she going to live?" One mother's concluded about the illness, "It's death. There is no other definition. Your days are numbered; you know your destiny." A nurse shared her perspective of the consequences of having physical changes:

As much as possible we try to keep them healthy. But we know that sooner or later they are going to deteriorate. This is the most painful process for them and for ourselves because once they start deteriorating, we know what the end is going to be. One mother who has AIDS has become preoccupied with her physical status and said, "I can't make decisions. I'm exhausted. I have many things to do but I'm exhausted. I'm depressed with fatigue, and I don't like that. I feel bad. What I have is not very
pleasant. I'm worried, like I'm going to die."

Dealing with the illness is hard and difficult. To some participants it represents a burden or yugo, meaning something they have been forced to go through. As one mother put it, "Since this thing [illness] happened, everything is difficult; there's nothing easy here." One father explained,

Not knowing about the illness, I was living a normal life. Then after learning about my daughter's condition things changed...Going through this is not easy. I have a burden. Since 1990 I'm under this yugo dealing with my daughter. Ashe & Rampersad (1993) wrote, "I know that once it happened, my life and the lives of my family would be changed forever, and almost certainly for the worse...The quality of one's life changes irrevocably with something like this" (p.7, 17).

For a large segment of Puerto Rican society, the myths of contagion and the deeply stigmatized meaning associated with the HIV/AIDS illness have persisted. HIV/AIDS has a socially constructed image and engages particular attitudes. The illness is connected to certain groups in the community such as homosexuals, injecting drug user, bisexuals and promiscuous persons. Society considers those persons with HIV/AIDS to be responsible for this illness and more deserving of what is happening to them. As one father explained, "They blame you for this. They want you to feel guilty for this situation." People who suffer from HIV/AIDS are placed into socially constructed
categories of being inferior, deviant, and ultimately
discreditable. It doesn't matter if participants fit or not in
those categories. They are also labeled by society to make them
appear different and separate from others. As one father stated,
"It is like you have a label. This person has this [illness],
and he can't live with the society."

A sense of shame is demonstrated when the participants
themselves associate the illness with people who do drugs,
meaning that the illness belongs to others and not to themselves.
Two participants expressed their fears of being linked to and
labeled as deviants in the community. As one mother explained,

> When I went to the medical center, I saw a lot of
people there. The majority were grandmothers with
their grandchildren because their daughters were
addicts. There are few cases like mine. That's why I
don't like to go there. You feel labeled. It is like
you have it painted on your forehead.

Similarly, another mother expressed her fear of being identified
in the neighborhood: "If you don't mind, I would like not to
mention the HIV/AIDS word while I read this paper because people
outside can hear me and nobody around here knows." Another
father said, "I couldn't accept that I had something to do with a
person like that, with that...I am not the kind of person who
does drugs. Never. We never had drug habits. I have a poor but
honest family."

One prominent response among participants is a sense of
being infectious, a belief that a person is capable of transmitting the illness or endangering others. This sense of being infectious occurred mostly between parents and children even when there was no basis for concern. Parents were constantly watching the interaction of the sick child who was playing with other children. A mother of a 3-year-old child explained, "I have to watch him. He is small and he doesn't know what he is doing wrong and may be unsafe. If he puts something in his mouth and another child tries to get it, you know." Another mother expressed similar concerns: "I have to watch her; she is terrible. She likes to take things and put them in her brother's mouth. She is very little and doesn't know what she is doing."

There are restrictions placed on a 10-year-old child who doesn't know about her own diagnosis. Her mother, who fears infection with HIV and worries that the other children will contract the illness, watches the girl constantly and never leaves her alone with her brothers who are HIV negative. How the sense of being infectious is experienced in this family unit is best described by her own husband:

She is the one who is afraid. She is afraid, I don't know. For example, if she has to go to the doctor or something like that she always says, take the children with you or take her [the daughter]. When she is not present, she always tries to keep them separated. When she is present she lets the children play with her only
in games where she doesn't have to worry that something will happen. She is afraid that if she [the daughter] cuts herself and her brothers try to help, something will happen.

Revealing the Illness

Once families learned about the HIV diagnosis, the process of revealing the illness to others begins. The process of revealing the illness consists of two decisions: Telling others and avoiding information about the illness. Both decisions were observed to be happening simultaneously and through time within the context of the family unit and outside the family unit, including relatives and friends.

Telling Others

Telling others means sharing information about what is happening within the family unit. Many parents make the decision to tell others on a voluntary basis. However, in one family unit the circumstances forced one mother to do it. Within the context of the family unit, parents were faced with telling their children about the illness which generated anxiety and guilty feelings. Although stressful, some parents found that talking about the illness to all of their children provided a sense of trust and security. As one mother explained, "I always like to tell the truth to my children. We are a very close family. I talked to them and I said this is what's happening." One of her children said, "Mommy told me that she and my brother have the HIV virus. She doesn't want us to feel that she was hiding

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things from us because she never does that." Another father stated, "I sat down with them and explained the situation. I don't want them to find out from the outside. I wanted to tell them myself."

When parents decided to share information, their children needed to understand how the illness appeared in the family and how long their parents or siblings are going to live. For one mother, telling her child about the illness occurred at a time when she was under a lot of pressure, and the child was constantly asking questions about the pills his sick sister was taking, the treatments, and appointments: "I didn't think about it, I just told him what was happening. I felt really bad after that." She decided to withhold information about the illness from her other daughter: "If I tell her, it will be worse." Oyler (1988), writing about the moment she talked to her children about HIV/AIDS, said, "So I talked to them about it for a few minutes...Only this time we had to be careful not to frighten them. And the honest truth by itself seemed too frightening."

The fatal aspects of the illness are continuously portrayed through television and reinforced by people. The HIV/AIDS illness is tied to drug users, the homosexual community, and sexuality through mass media. As one mother explained, "Television has influence on people. They learn that you can die from this. That you can be contaminated, and you are going to die." One mother noted, "What he sees on television are people dying because they were addicts before. Watching these people in
their late stage of the illness affected him, but I explained how we became infected. I told him, your sister has AIDS, your father and I have the virus, not the disease. We would be able to live five, ten, or fifteen years." Another child spoke about what her mother told her when she questioned her about the mode of contagion:

My mother told me that she got it through a sexual relationship and my brother through a blood transfusion. I feel really bad because other people think that you can only get the HIV just because you went to bed with many people. That's not true.

Another child was very explicit regarding what his mother taught him about the transmission modes:

I can get this by having sex and from a used syringe. If they [people] offer me a syringe, I must say no because that syringe was used and that's bad. If one man who has HIV goes to bed with another man or woman, they can catch this, too.

As a distinct characteristic, all of the families reached out to one of their key relatives or friends to tell them about the illness. Understandably, participants were unable to keep something like this to themselves. The HIV illness is one of those illnesses that cries out for revelation, just to tell someone (Ashe & Rampersad, 1993). The decision of telling others is based mainly on three factors: the parents' need for (a) relief, (b) support, and (c) help. Trust and a sense of feeling
safe also were two related conditions for parents' decisions to
tell others. When discussing the need to share the illness with
a sister, one mother explained, "I told her to relieve myself.
My sister is everything for me." Another mother explained, "I
told my mother, a friend, my cousin, and sister-in- law, who is a
nurse. I did it because these people helped me when I needed it.
Now they can help and I trust them."

Similarly, another father said, "I told my mother, father,
sister, an uncle who lives with us, and my two sons. There is no
comparison. I can count on them." Of all the families
interviewed, this father was the only one who took the risk to
share information about his five-year-old's illness with
officials from the child's school:

It wasn't necessary, but I told them because besides me
they are now the people most close to her. I talked
to the social worker and principal and explained the
child's condition. So far, I haven't seen any
rejection, no rumors, nothing.

Few parents have been telling others through time. For some
of them the result of telling others represented the loss of
friends and relatives through rejection and isolation. Based on
their own experiences and the experience of other families, some
parents have decided to cope in a more secretive way with the
illness to protect themselves. With feelings of resentment and
disappointment, a mother who was rejected reflected: "I talked
about this [illness] with friends, but some of them are gone.
Now, they're interested in others. Why am I going to call them now? What am I going to tell them?" Similarly, a mother explained: "She [the child] hasn't heard anything from her grandfather. Since he knew about her illness, he stopped visiting her." This mother disclosed her experience of losing her job of almost 23 years after telling her boss about her daughter's illness:

My problems with the company started when I told my boss what was happening.... Maybe he thought I was sick or something. They fired me... I called him and I tried to explain that I wasn't the one with AIDS, but my child was. I was in shock.

Avoiding Information

Avoiding information represents the opposite of telling others. It means that parents decide to keep silent and withhold information from others within and outside the family unit. Confidentiality, secrecy, and control of rumors are three components of the decision to avoid information. The three components are viewed as self-protective strategies for parents to preserve some sense of normality and control over their lives and to protect the children's feelings from negative judgments, rejection, ridicule and discriminatory acts. The families' decision of avoiding information and the implementation of confidentiality, secrecy, and control of rumors strategies confirmed that they have internalized the stigmatized social meaning attached to this illness and the negative consequences.
for people who suffer from it. As one father explained, "But the sadness of this situation is that people reject you, you know... With this [illness] they think the worst. That they can be contaminated with it. They don't understand how the situation is." Similarly, another mother described her perception, "With this illness nobody loves you, everybody rejects you." The same mother stated, "She [the child] was rejected at the hospital... When I came back from home there was a big label on her door."

Oyler (1988) wrote, "They wanted to stare at us but didn't know where to look. They wanted to ostracize us but they didn't know how to find us. They don't understand it yet."

Confidentiality.

Confidentiality is a major concern for families. Two general informants agreed that AIDS make families subject to rejection and isolation. Association with people with HIV/AIDS infection was perceived as stigmatizing. The social worker of the unit, for example, has experienced rejection from people in the community when resources are requested for families. Phrases such as "I don't spend money in that way with patients" or "I don't have money" have been heard by her. The general informants corroborated the families' sense of vulnerability to being rejected and isolated, and encouraged them to keep the illness only within some intimate networks. One nurse from the unit described the sense of vulnerability experienced by families:

When the illness is within the family unit, the
suffering is centralized. But once they decide to share it with other people in the society, they know that they are going to be rejected. They are not prepared for that, to confront rejection. They are not prepared; neither are we.

Speaking of confidentiality, the social worker said, "The confidentiality is something we must keep for the family. We have parents who live with their extended family and nobody knows about the diagnosis. Sometimes we are the only people who know about the diagnosis."

One father explained, "It was there [the unit] that I was oriented that I have the right to keep this confidential." Another mother indicated, "They [the clinic] told me not to share this with anybody else..."

Secrecy.

Parents perceive that secrecy is needed because of the social stigma surrounding HIV/AIDS and by the internal sense that others would want to avoid contact. Children are viewed as more vulnerable, and parents struggle with what they are going to do if other people find out about the illness, especially at school and in the neighborhood, where children spend most of their time on a daily basis. A mother is concerned about how her children will be treated by other children and adults:

It is not because of me. I don't want to see them being rejected; they are children. It doesn't matter if only one has the illness, they [people] reject the
others, too. They reject the others although they are negative. That's why I told them, "Don't say anything at school."

A father felt the same feelings about his sick child: "There are a lot of people who don't have enough knowledge of that [illness]. I don't want to see her being rejected or something."

Children share similar views with their parents. Phrases used by some of them to describe their parents' anticipatory worries are, "She is afraid that they [friends] will go away from me and call me fag..." "She doesn't want other to make fun of me or anything." "They [people] don't understand. They think you can catch this." "Don't touch me." One child quoted another child as saying, "I don't like children who have AIDS."

To maintain secrecy, there are some parents dealing with HIV/AIDS infection by discussing the child's illness under the context of the opportunistic infection, such as pneumonia, or under asthma or cancer. As one father said, "The children don't know. We told them that their sister has asthma and also a problem in one of her lungs." His present spouse, sharing the same view, said, "When the child mother's died of that illness we told the child that she died from cancer. That's what we have been telling our children and the neighbor." A mother who has encountered questions from her daughter explained: "She asked questions about her sister's pills. Because the child suffers from asthma, I keep telling her that the pills are for that problem." Similarly, a father said, "I told at work that my
child has cancer. You know what could happen with this illness."

If the illness is revealed, some parents fear about their children's reactions. From a father's perspective, telling the illness to his daughter seemed to have a special meaning:

We are afraid because we don't know how she is going to react... There are a lot of people that after a diagnosis of cancer have tried to kill themselves, something like that... She might use this [illness] as a weapon and try to take revenge on herself or other people, or something."

Another mother expressed her feelings to justify her decision to keep silent about the illness: "Many people have died of knowing that they have AIDS. Not because of the illness but because of depression. In other words, knowing has caused more harm than the illness." A father trying to avoid burdening his daughter said, "Yes, exactly, because I don't want to hurt her feelings. I don't want to do that. I don't want to put her through this kind of test yet. I could mess up her head. I would like to wait." Although family members from one family unit have a religious connection with a particular church in their community, their sense of vulnerability of being rejected and isolated kept them from reaching out for the church's support. The mother from this family unit stated, "I haven't said anything in my congregation. I don't want to say anything because of my children."
Controlling rumors.

The self-protective strategy of controlling rumors has become part of the daily life of families. Parents have learned and teach their children how to react to relatives' and friends' comments concerning the family situation. Each family unit has unique ways of controlling rumors. A father stated his experience with rumors: "Through rumors, people have tried to hurt me. Few people had come to ask me directly. What the majority does is just whispering behind you." For him, one way of controlling rumors is to talk clearly to people. The characteristics of talking clearly are (a) giving information about the illness as far as he knows and (b) putting things in clear perspective, directly to the point. Talking clearly helps him to feel liberated. Being liberated means being able to confront the situation. As he explained,

When somebody tries to tell me something, I like to explain how things are as far as I know. As far as I know I try to set things clear, clearly and to the point...I take the opportunity to set things clear and tell them that up to these days, things are in this way, in this way clearly.

Another father faced with the decision to tell or avoid information controlled rumors through leaving doubts in the person who asked. This father explained, "I think her [the child's] maternal grandfather told others about this thing [illness]. One time the school principal told me about what
other people have been saying about my daughter. I told her, "Well you know more than me. I left her in doubt. We haven't said anything directly in the school." Similarly, a mother taught her children about what to tell people if the issue of the illness arises. Describing what his mother taught him, a child said,

If somebody asks questions, I can answer but I don't have to tell them that I have it... None of them needs to know what I have. This is something personal... If they ask about my appointments I would say, "It is none of your business."

Living with Concerns

Living with concerns is present in the families' daily life once they have found out about the HIV/AIDS illness. Parents' descriptions of their own worries converged in three main categories: (a) worry over their children, (b) limited or no income, and (c) being in uncertainty.

Worry Over their Children

It seems clear that children are central forces in the lives of all of the parents. Since children are in the middle of this experience with the HIV/AIDS illness, a great deal of concern is expressed by some parents about what will happen to them. A mother expressed increased feelings of worry and guilt in relation to her children. Since she perceived herself dying first, her worry centered on who in her family would take care of her four children after her death. This mother described her concern about the children's future:
They are going to be alone because I don't have anybody on whom I can count and leave them. I have my mother who is a sick person, a sister who works and also has four children of her own. I have a brother in the United States who doesn't know what's happening. They can't take care of four children at the same time. It will be necessary for me to divide them.

Another mother who also perceived herself dying first has been making plans with a relative. "We have been making plans about the person who will take care of him [the child]. He has an aunt. She is the best person because she is special. She loves the child, and the child loves her very much. I don't want to fail him." One mother wants to be around her children until they are able to be on their own. "I just pray to God to be with them until they are grown." As an integral part of the process to prepare the children for the future, this mother has been teaching them how to think independently, how to make better decisions for their own benefit, and how to deal with issues such as sexuality. Having a fourteen year old HIV positive son, this mother has emphasized the issue of sexuality. As this mother explained,

He likes girls. I have to prepare myself because he is going to ask me, "Mommy why can others do it and I can't?" I told him, "You have to protect yourself and protect the person you selected, a person who understands the situation and is able to know how to
deal with you. You have to think about those things."

Siblings within this family unit also appeared to be worried about their brother. Siblings are now assuming new responsibilities to care for their oldest brother. As part of her new responsibilities, the sister explained the things she does for him:

I like to care for my brother. There are moments when mommy forgets to give him the medicines. When this happens, I do it. I watch him at school because sometimes he doesn't like to eat lunch. Mommy wants me to watch him and make sure that he eats at lunch time.

This sister agreed that she also acts as a mediator between her mother and brother: 'Sometimes I told him, 'If you have something to say or ask, go to mommy and say it. Try to see her as a friend. You don't have to see her as your mother all the time.'

Similarly, the other brother in this family expressed the following feelings: 'I want him well. I like when he takes his vitamins and pills...Sometimes when he doesn't want to take them and pretends to be sleeping we bring them to his room. If he is sleeping, we spill water over his face to wake him up.'

Limited or No Income

Having limited or no income involves financial effects experienced by participants as consequences of having to deal with the HIV/AIDS illness. Some parents who were working could no longer work. Monetary needs have increased for participants, and the majority of them are recipients of Medicaid. The
family's daily life dealing with the HIV/AIDS phenomenon appears to be mostly centered around multiple appointments to follow and multiple medications and therapies to take. Obtaining child care for children when needed is a problem for some parents. Most of the time they bring all their children when they have to go to medical appointments. Money is needed for transportation, for meals, for daily expenses, and sometimes for medicines and therapies not available at the moment. Parents often are in need of the social worker and staff members to find economic resources. Parents expressed worry about how the financial crises affected their family. A mother with four small children explained, "We have been living together in this small place. The child is always sick. The only one who is working now is my husband. I was working, but because of her [the child], I quit the job I had in a clinic. The amount he earns is not enough for six mouths in this house; it is too much. I spend a lot every time I go with all of them to the medical center."

One mother illustrated the financial and physical changes the illness has created for her:

I used to go to the discotheque, to take care of myself more. I had my long nails. I had money to buy Estee Lauder products. Now I don't care how I look. Now everything is different. I depend on Social Security. I have no motivation to buy clothes. Everything you see is because my mother bought it for me.

Similarly, another mother's view was, "We are on Social Security,
receiving just seven hundred dollars for five members in this family. We pay three hundreds dollars for this house, gas, water...why?" Having a child hospitalized for almost two months became a financial stress for a family unit. One mother told about needing to ask for financial help in order to pay her credit cards to buy diapers for her child:

I haven't received any money from work since two months ago because I asked for a leave of absence to take care of him [the child]. I'm going to talk to my family to see how they can help me. I know they will pay temporarily for some of my credit cards. We are spending a lot of money on diapers because he needs to be changed frequently.

Caring for a child, especially a sick one, caused some parents to be noncompliant with their own treatments and appointments. A mother receiving psychiatric help expressed her reason for not taking the antidepressive as prescribed: "I haven't taken the antidepressive because I don't want it. If I take it they stop me. I can't be still having many things to do with my child and husband. Now, he [the husband] also needs dialysis. I also need to update the Medicaid." Similarly, another mother who missed many of her appointments stated, "She [the child] and the baby have many appointments. Some of them are at the same time I have mine. They need to see the doctor and I'm going to change my appointment."
Being in Uncertainty

Being in uncertainty represents the participants' inability to adequately anticipate the outcomes. Not knowing the outcomes was stressful in two areas: (a) stress from the effects of drug treatments on their children and themselves and (b) stress from the lack of definitive HIV status through testing and monitoring.

A mother whose child is under a research protocol explained,

He is now in a new protocol, but he was in another that caused problems with the liver. I gave some thoughts before include him in this one, because I don't want him to be affected. At the beginning of the treatment he doesn't want to eat. But now he is doing fine. I think he is in the other group, where they give sugar...This is bad because he is not having the same chance other children have.

This mother's husband was taking Zidovidine (AZT) and because he experienced side effects, it was necessary to stop it. The same mother described what happened: "He was taking AZT but started having adverse symptoms. He is now taking Didanosine(ddI) but also complains that this medication is affecting his sight. He keeps saying that he is already tired of all of these things."

Another mother who is HIV positive and got pregnant became preoccupied with her baby and the effects AZT has caused him:

When I was five months pregnant my spouse told me about his worries. He was worried that the baby would come with problems. At least if something happened, he
would be treated early. I didn't take AZT as they told me to. The doctors don't know for sure, but they think that it was the AZT that made his bone marrow lazy. Now he has low hemoglobin. I still have to take him for evaluation. So far, he is still negative.

For participants who are HIV negative, one of the biggest stressors is being subject to continuous testing and monitoring. Although being tested is one strategy that could help to reduce uncertainty, it also creates anxiety in participants, since being tested is a constant reminder that something bad could appear. One husband described his spouse's feelings when she faced the testing and monitoring procedures: "She is afraid, afraid. We have been tested three times and we are still negative. But she is still afraid of the illness." Just the knowledge of having exposed the children to the HIV induced a mother take them to be tested. This mother said,

I talked to them and said, "You were negative, but I still have to take both of you to be tested again. It is a routine test to see how you are doing. If the test is negative, perfect. Your brother and I need to be under treatment for the rest of our lives.

The experience of being in uncertainty is best described by one father interviewed:

It doesn't matter if you want it or not. You are waiting in tension for something, for something bad to happen. This is something you can't avoid. You worry
for something bad to happen. You are always worried. The same father added, "They told me to be tested in five years, but I thought, let me do it annually. I have been tested four times. I have the test results at home. Thank God all of them were negative."

Seeking Balance

Living with the HIV/AIDS illness required from families a constant seeking of balance. The phase of seeking balance is characterized by a continuous process where coping strategies are incorporated into the family functioning to get control and to accommodate the illness in their lives. Coping strategies are patterns of thought and behavior used in response to the demands the illness has created. There are three major categories of coping strategies that play an important role in helping parents in the process of seeking balance: (a) faith system, (b) making changes in life perspective/thinking positively, and (c) keeping busy.

Faith System

Faith in God has become stronger in the lives of all of the families following the HIV diagnosis. Faith has been functioning in several ways among them. The word "test" is mentioned by participants, meaning that it was God's will for them to confront this illness. One mother said, "The Lord sent this test to us. I know this is a test from him." God is viewed as sending this illness, but at the same time God is a source of strength, support, and comfort to them.
As one mother put it,

I know I'm here with a purpose. God is the only one who gives and takes life. I pray, "Lord, give me strength because you are the only who can". God is always present and because of that we need to depend on him. We need to keep the faith because that's the last thing we lose. As human beings, that's the last thing we lose.

To cope with the experience, one father spoke directly to God. As this father explained,

I didn't talk to anybody, I just talked to God. I asked... I told, God "If this is part of my life, if I must confront a situation like this, here I am." I must keep myself going until God wills because God doesn't give you more than you can handle.

As part of their faith system, parents keep expecting a miracle to happen. As parents, they try to put their energies into doing everything they can to provide a better life to the child. One mother said, "A miracle could happen. I don't want him to lose weight. That's why I'm constantly watching him. I don't want him to miss any of his appointments. I always give him the medicines on time...So far he is doing fine."

One father reflected,

She is special. I keep my hope that maybe today or tomorrow we will have the cure for this fatal illness. She will have everything. You know, that the cure will be here soon. I
want to see her completely happy. I have other children that I also love dearly, but who needs the most is her, who needs the most is her.

After her child's diagnosis was confirmed, one mother started attending church. At this point in time, the church has been a source of strength for her:

Since her illness, I started visiting the church. Nobody would understand without having the same experience I'm going through. Being in the same position. I told the minister in my church. He has been helping me to go through this.

Making Changes in Life Perspective/Thinking Positively

In three families, the coping strategies of making changes in life perspectives/thinking positively were also described by participants as ways to deal with the HIV/AIDS experience. Both coping strategies occurred together as participants sought balance to the challenges the illness created in their lives. Implementing these coping strategies facilitates the participants' finding purpose and meaning in life in facing the HIV/AIDS illness. By finding purpose and meaning in life, things and relationships are viewed now by participants as more significant and important. One father summarized the experience of how his life perspective and system of thoughts changed in the face of this illness:

This illness changed me a lot. Now things are more important. I start relating with the child...Now it is
different. She was born with a label of a fatal illness. I try to live with the good things. I realize that doing good is the best way to go through this. Doing good things to my children, to my neighbor....I try to think positively, to remember good things. I try to surround myself with people who gave me a hand. I try to get the good things from people, things good for my soul.

Similarly, a mother of three small children described her feelings as evidence of growth and new ways of focusing on life:

Because I have this condition I'm not going to lay down and die. My children will be affected. If I hadn't been positive, I'd have been dead. I told myself, "No, there are many beautiful things in life. Life has beautiful things." I told my children, "Let share until God's wills." There is a word I use to say to them: "I can, I can." Let's keep doing good and worthwhile things.

After suffering his second hospitalization and being very ill, a father came to terms with the importance of changing lifestyles to improve his health. As he explained, "I'm not going to smoke or drink anymore. There is an activity in September, but I'm just going to play dominoes. If they want to drink, it's up to them."

Keeping Busy

The coping strategy of keeping busy was used by participants
to block out worries and negative thoughts associated with their illness experiences. Participants kept themselves busy implementing activities that helped them feel in control and get some relief. One mother stated,

Sometimes when I'm in the park with my children, I'm physically with them but my mind is in another place. When I don't have things to do, I think about this thing [illness]. But immediately, when I catch myself thinking in that way, I try to do something like listen to music or play with my children. When I keep my mind busy I feel happy. I don't want to show my children that I'm depressed. I don't want to do that.

One of her children who is HIV positive expressed the consequences that might happen if he gave thoughts to the illness: "I try not to think about that [illness]. If I think, it could be worse. It could bring fatal things...like leaving the house or hurting somebody." When worried with negative thoughts and sadness, he described his engagement in several activities that helped him deal with his feelings: "I go to my room to listen to the radio, to sleep, or to play Nintendo. Sometimes, I just go outside to get some fresh air, or I take a cold bath with the hose outside the house."

One mother spoke of the difficulties she had in keeping HIV/AIDS out of her mind. Caring for the children and working around the house distracted her from focusing on the experience. As she explained, "I think about this twenty four hours a day. I
can't avoid it. My husband said that I worry too much, but I have to because I have many things to do." Her husband commented, "I told her not to think too much on this. I try not to do it. She too is always doing things around the house until late at night."

Being able to find a new job is part of a mother's strategy to get additional income and distract herself from what is happening. This mother explained, "I started selling hot dogs a few weeks ago. I'm earning some money and at the same time, I'm distracting myself outside."

Summary

When the diagnosis of HIV/AIDS is revealed to families, the impact is significant for all its members. The stigmatized meaning of the illness continually influences family functioning. There is clear evidence that families' responses towards HIV/AIDS are based on the stigmatized meaning this illness has for them. Families are constantly dealing with a sense of vulnerability to being rejected and isolated. To manage this sense of vulnerability, protecting the family emerges as the dominant core process of functioning.

Analysis of data resulted in the identification of five phases related to the dominant core process of protecting the family which is illustrated in Figure 1: (a) facing the diagnosis, (b) reacting to the diagnosis, (c) revealing the illness, (d) living with concerns, and (e) seeking balance. Data analysis demonstrated that once families faced the HIV/AIDS
Figure 1. Protecting the Family the Substantive Theory of Family Functioning for Families of Children with HIV/AIDS Illness

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diagnosis as a consequence of having a sick child, husband, or ex-partner(s), their responses ranged from common responses seen in other life-threatening events to unique responses characteristic of people confronting the HIV/AIDS illness.

Once families are confronted with the dilemma of revealing the illness, a decision-making process that involves telling others or avoiding information takes place. Either approach is painful and stressful for families to make. Families are confronted with concerns involving the children, financial aspects, and uncertainty.

In seeking balance, families provide evidence of growth in the face of HIV/AIDS. In the process of seeking balance, families implement a series of coping strategies aimed to get control over the illness and their lives including having a faith system, making changes in life perspective/thinking positively, and keeping busy. Seeking balance seems to be a dynamic and continuous process in the lives of these families.
CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

In this chapter, the substantive theory of family functioning as derived from the family perceptions and experiences is discussed and reviewed in five phases. This theory provides nursing with a practical model from which to view the process of family functioning for families of children with HIV/AIDS infection. In addition, the findings of this study are related to previous studies and current literature of families dealing with the HIV/AIDS phenomenon. Finally, implications for nursing practice and recommendations for further research are discussed.

Summary of Findings

Protecting the family is the substantive theory of family functioning for families of children with HIV/AIDS illness. The grounded theory describes the movement of families through five related phases: (a) facing the diagnosis, (b) reacting to the diagnosis, (c) revealing the illness, (d) living with concerns, and (e) seeking balance. The process begins with the first phase, facing the diagnosis. For families, facing the diagnosis happens either when a child, husband, or ex-partner confronts health problems. Facing the diagnosis of HIV/AIDS brings new threats and challenges to family life. Included in the theory is a constant sense of vulnerability to being rejected and isolated.
This sense of vulnerability is continuous, as reflected in each of the phases. Coping with the illness and the increasing challenges exerted a heavy force on all family units. Protecting the family as a process of family functioning becomes of paramount importance for families to handle this sense of vulnerability and to help them feel control over their lives. Protecting the family is reflected not only in the context of the health care setting, but also on a day-to-day basis at home, school, and in the neighborhood.

By reacting, families experience a series of responses to the HIV/AIDS illness and its meanings. Upon learning the diagnosis, families experience some of the classic coping stages associated with a life-threatening crisis process. Responses such as shock, anger, denial, depression, and acceptance are similar to those stages described by Kubler-Ross (1987). However, families also experience intense, negative, and unique responses not observed with other life-threatening illnesses when dealing with the HIV/AIDS stigma. Reacting to the stigma, families experience a sense of shame, feelings of been labeled as different, and a sense of being infectious.

The basic tenet of symbolic interactionism is that meanings are developed from the social interaction with individuals or human groups in society (Blumer, 1969). Families, as part of the interactive social system, have internalized the stigmatized meaning attached to HIV/AIDS illness and society's negative stereotypes and perceptions. HIV/AIDS is viewed as an illness
acquired through certain unaccepted behaviors. Stigmatization as a complex process of social interaction leads to rejection of persons with certain deviant behaviors or aberrant characteristics (Volinn, 1983). Dealing with a culturally marked illness, families are linked to such characteristics or behaviors. Families express their fears of being stigmatized and therefore subject to rejection and isolation from relatives and friends. The stigma generated by society is continually apparent, playing a major role in families' interactions with others in the health care system, school, home, and neighborhood. Findings are consistent with those of previous studies that suggest that fears of been stigmatized and the consequences of the stigma are central to families dealing with HIV/AIDS illness (Dolan & Nokes, 1992; Lester, 1991; Rose, 1993). As an integral part of living with HIV/AIDS, families seem to be unable to transcend the stigma generated at all system levels, from the societal to the familial to the personal level.

The phase of revealing the illness consists of families making decisions whether or not to reveal the illness to somebody else inside or outside the family unit. In revealing the illness, two major decisions are made by families: telling others or avoiding information. Families in this study made the decision of telling others because of their need for relief, support, and help. In order to tell others, families looked for people they could trust and with whom they were able to feel safe. There are families who were able to tell their children,
relatives, and friends. However, other families were reluctant to inform their children about the illness for fear of their reactions. As Kubler-Ross (1987) stated, "It is hard enough for an adult to cope with it [the HIV diagnosis], it's impossible to explain to a child (p. 43)."

In this study, only one family unit sought informal support from the church. Literature reports that because the fear of being subject to judgment, blame, and further stigmatization, organized religion is not always sought as a primary source of support (Cohen, 1993; Hutchinson & Kurth, 1991).

Walker (1991) reported that families are extremely vulnerable to the social consequences of revelation. After taking the risk of telling others about the illness, some families in this study experienced rejection and therefore the loss of friends, relatives, and jobs. Rose (1993) found that women who shared information with family members who had small children perceived tremendous rejection from them. Women were mistreated by families and felt alienated and isolated. In this study and others' reports (Andrew, Williams, & Neil, 1993; Oyler, 1988), the decision to tell others is not reported as a continuous process. Disclosure held the possibility of rejection, a risk that families do not want to take, mostly because children are in the middle of the experience.

In avoiding information, families indicated the implementation of three self-protective strategies: confidentiality, secrecy, and control of rumors in dealing with
the HIV phenomenon. Families in this study believe that these self-protective strategies are necessary to preserve a sense of normality; to maintain more control over their lives; and to protect the family, especially children, from outside harm. These findings confirmed that the psychosocial implications of HIV/AIDS are not similar to those found in families with other chronic illnesses. Families dealing with other chronic illnesses are not faced with the need for confidentiality, secrecy, and controlling rumors in dealing with the illness. In addition, families confronting the HIV/AIDS lack, in the majority of cases, the empathy and compassion that typically would be offered if dealing with other chronic illnesses.

Living with concerns, the fourth phase, consists of families' worries over the children, limited or no income, and being in uncertainty. For families, their children are central in their lives. Since children are viewed as a way of continuing life, a great deal of concern was expressed about who would take care of them after the parents' death. Andrew, Williams, & Neil (1993) reported similar findings in a study with mothers of children with HIV/AIDS infection. They found that mothers expressed increased feelings of anxiety centered on the fact that they may die before their children are grown, and the surviving children will need eventual placement. For families, being there for the children and spending time and energy caring for them is necessary to feel a sense of connection and accomplishment.

In this study, some mothers tended to be noncompliant with
their treatment. This finding is similar to what Rose (1993) reported for African-American women where the mother's role is central. The elements of a lack of self-care and a greater focus towards others may also represent a cultural norm for Puerto Rican mothers, who traditionally center their life around the family, sacrificing their own needs for those of others.

The feelings and thoughts of children who knew about the diagnosis were also explored. Siblings reported worries about the health status of the sick member, increased closeness, and emphasized feelings of responsibility for the care of this member. Nehring, Malm, & Harris (1993) indicated that it is common for unaffected siblings to worry about their family member's illness and to function as parental caregivers.

Financial difficulties in dealing with this illness were also identified by the families as a major concern. The majority of these families are highly dependent on Medicaid and Social Security benefits for financial support. They are also in need of a range of health-care services to maintain child and family functioning. The cost of treatment for HIV/AIDS infection and for its long term complications is high. The present indirect cost of an adult and child with HIV/AIDS in Puerto Rico is $80,000 and $56,000, respectively (Shepard, 1990).

Families reported that having to go to multiple appointments at the medical center with their children and the need to pay for transportation, meals, and sometimes for expensive medicines and treatments were significant stressors. In order to meet their
financial needs, some families found they must turn to the social worker, staff members, and their families for assistance.

In this study, two major sources of uncertainty were expressed by families: not knowing the outcome of the treatment's effectiveness on children and/or themselves, and the lack of a definitive HIV status. The families' sense of uncertainty is influenced by the fact that there is no known cure for the HIV/AIDS infection and because many treatments protocols are experimental. Captain & Selder (1991) found that the sources of uncertainty for women participating in a support group consisted of the unpredictable nature and course of the illness, the isolation and stigma experienced, and the doubtful future. Similarly, after conducting a study with ten homosexual and bisexual men, Gaskins & Brown (1992) reported that living with the uncertainty of not knowing what to expect as a result of being infected with HIV is persistent in the lives of these men. Uncertainty is experienced as a continuous process. Regardless of their sense of uncertainty, some families find it necessary to participate in clinical trials as a way to manage their feelings and to maintain hope that a cure will be found.

At present, there is an antibody test available which can detect exposure to HIV. To manage uncertainty, some families find it necessary to be tested to detect whether or not they have been exposed to the virus. Internal anxieties and fears are created every time families are tested for antibodies to HIV, since something bad could appear and they are unable to predict...
it. For families, uncertainty is an important concern because they cannot definitely know where they stand with this illness.

The last phase of the model is seeking balance. In this phase, families implemented a series of coping strategies to accommodate the illness into their lives and to respond to the demand the illness has created. The three major coping strategies helping families in seeking balance were (a) faith system, (b) making changes in life perspective/thinking positively, and (c) keeping busy. In this study, all families agreed that the presence of God is a source of support and relief for coping with the illness experience. Spirituality, as an essential aspect of this culture, is helping families in their quest to take control of their lives. Families placed their faith and trust in God as a higher power from whom to receive strength and comfort. Giving spiritual meaning to the illness enabled families to focus on living rather than dying from HIV/AIDS illness.

Making changes in life perspective/thinking positively took place when families believe that there is meaning and purpose in what is currently happening to them. In the face of HIV/AIDS, families are living and learning through the illness experience. They are using it as an opportunity to grow instead of being victimized. The re-evaluation of life perspective and the utilization of positive thinking have provided families the opportunity to move through the experience and see things and relationships as more significant and important.
By keeping busy, families maintain a sense of control by avoiding negative thoughts. Caring for the children, doing things within and outside the house allow these families to block from their minds the emotional distress that HIV/AIDS engenders.

Implications for Nursing Practice

HIV/AIDS has become a family phenomenon rather than an individual situation. It is clear that a direct relationship exists between the nature of family functioning and specific aspects of the HIV/AIDS phenomenon in the family. Families of children with HIV/AIDS find challenges not observed in dealing with other chronic illnesses. HIV/AIDS is a life-threatening illness with no cure and a stigma attached to it. Since the illness is socially attached to certain groups, families saw themselves as being vulnerable to stigmatization as a consequence of being linked to such groups. Fears and concerns of being stigmatized and of eventual rejection and isolation are central to the families of children with HIV/AIDS. Protecting the family is of paramount importance in every context where families interact on a daily basis.

Vulnerability and protecting the family are two important concepts in the nursing care of families dealing with the HIV/AIDS illness. Families' feelings of vulnerability and their need for protection should be addressed by nurses and others working with families once the diagnosis is received. Being able to explore and make an initial assessment of the sense of vulnerability as part of the entire family response to the
HIV/AIDS diagnosis will assist in the identification of stressors, needs, and resources within the family to cope with those feelings. The more nurses and members of the interdisciplinary health care team know about this sense of vulnerability and what families experience from their own perspective, the more they will be able to create intervention strategies to assist families in protecting themselves and others in the family.

Facing the diagnosis of HIV/AIDS triggers an emotional crisis in which a number of responses are experienced. Many of the emotional reactions are intense and negative, reflecting the social beliefs and attitudes prevailing about this illness and the meanings attached to it. It was evident that, regardless of the time of diagnosis, feelings of shame, being labeled as different, and being infectious remained present within these families.

Establishment of support groups to assist families in dealing with those feelings and to normalize the impact of the illness on family life need to be considered. Being able to provide a safe place to talk about all aspects of their lives in dealing with HIV/AIDS is necessary. In a support group especially created for families of children with HIV/AIDS, Cradles, Sussman, Berthaud & Sunderland (1992) found that participating families had the opportunity to deal with their losses and to minimize their sense of shame, depression, fears, anxiety, and isolation. It would be of great help to develop
support groups for families within the clinic setting and examine how beneficial it is for them to vent their feelings, meanings, concerns, and uncertainties in dealing with the HIV/AIDS experience.

The decision-making process around disclosing the HIV/AIDS diagnosis is difficult for families. Families are concerned with secrecy, confidentiality, and control of rumors because they want to protect the family, especially the children. Families' rights for privacy and confidentiality are unquestionable and must be protected. This does not mean that something cannot be done to decrease families' concerns about these issues. Anticipatory guidance could be an important strategy to assist families in the decision-making process.

Nurses and the health care team can create a model of intervention to assist families as they struggle to identify and decide in which circumstances it is appropriate or desirable to disclose information. To create the model, it will be helpful to initially design educational programs in which families' rights and the benefits and disadvantages of revealing the illness or keeping it concealed are addressed. The families then could be formally assisted in such areas. Such interventions would empower families with adequate knowledge and skills in the decision-making process.

Families need continuous assistance in management of concerns associated with the future of the children. Helping families to plan for their children could be a healing experience.
for all members of the family unit. The need to help a family plan its future while they are capable of participating has been suggested by Walker (1991). In order to provide adequate guidance in the children's planning process, it is essential to identify resources within and outside the family unit. The potential impact of grandparents or the extended family assuming the caregiver responsibilities require attention. Special attention must be paid to the actual tendency of grandparents to assume the caregivers' role, since many of them are experiencing chronic illnesses themselves, and it could be a burden to take care of a sick child who requires continuous attention. Potential caregivers should have continuous access to services and resources such as training, agency support systems, and financial support for illness management.

In seeking balance, families provided evidence of being actively involved in the fight against HIV/AIDS, incorporating changes, strategies, and positive attitudes towards life and relationships. An understanding of families' coping strategies would benefit nurses and members of the health care team, since families are seen as living systems trying to take charge of their lives. Nurses and others should use the strength of these families as models to empower other families in the clinical unit. Long-term survivors with HIV/AIDS have been identified as people able to fight and take the illness experience as an opportunity for learning and growing (Carson, 1993; Hall & Allan, 1991). Families could be resources to share with other families.
their positive coping strategies in seeking balance regardless of
the HIV/AIDS experience.

Recommendations for Future Research

The findings that have been uncovered by this study
demonstrated that the diagnosis of HIV/AIDS infection invariably
has profound effects on family functioning of Puerto Rican
families with children. The following are a list of
recommendations for future family nursing research.

1. It is recommended to consider a longitudinal
qualitative study involving families, in a wider variety of
settings, and a multidisciplinary research team. Collecting data,
taking into consideration these aspects, could contribute to
further validate, clarify, and expand the substantive theory of
family functioning.

2. Further exploration is needed of the perceptions and
feelings of siblings and of the children with HIV/AIDS infection,
since only four children were interviewed in this study. The
study of their perceptions, problems, needs, developmental
responses, and strategies could provide a fuller understanding of
the HIV/AIDS experience from their own perspective.

3. Research to study the effectiveness of educational
programs and support groups for families confronting the HIV/AIDS
phenomenon needs to be conducted.

4. Families experience much stress related to financial
costs for daily expenses and illness management. The development
of studies to assess the impact of the financial burden in family
functioning is necessary. Such studies should provide justification to request additional financial resources to assist families in meeting their needs.

5. Another grounded study could be developed among family units including biological families, extended families, and foster parents.
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APPENDIX A

Letter of Approval Institutional Review Boards
MEMORANDUM

DATE: February 24, 1993

TO: Yvonne Sterling, Ph.D.
Department of Nursing

FROM: Lynette R. Elliott, M.B.A., Coordinator
LSUMC Institutional Review Board

RE: Institutional Review Board (IRB) Filing System

The LSUMC Institutional Review Board records, located in the Office of the Chancellor, are now filed by IRB identification numbers. When corresponding about an IRB Project, it is necessary to include both the title of the project and the IRB Identification Number.

Identification Number _2115_ has been issued for your project entitled:

_The Family's Perceptions of Immunodeficiency Virus (HIV)/AIDS Phenomenon and Its Impact on Family Functioning of Puerto Rican Families with Children: A Grounded Approach_

Please retain this identification number and refer to it when corresponding about this project.
May 25, 1993

Dr. Marta Rivero  
Nursing School  
College of Health Related Professions  
Medical Sciences Campus  

Dear Dr. Rivero:

RE: THE FAMILY'S PERCEPTIONS OF IMMUNODEFICIENCY VIRUS (HIV)/AIDS PHENOMENON AND ITS IMPACT ON FAMILY FUNCTIONING OF PUERTO RICAN FAMILIES WITH CHILDREN, (NEW STUDY)

I am pleased to inform you that the above mentioned protocol was approved by our Committee in the meeting that was held on May 20, 1993.

Please remember that a yearly submission of a progress report is necessary for the continuation of this important study.

Cordially yours,

Alan M. Preston, Ph.D.  
Acting Chairman

AMP/cdc

Enclosure
APPENDIX B
FAMILY DEMOGRAPHIC FORM

Families' Perceptions of Immunodeficiency Virus HIV/AIDS Phenomenon and Its Impact on Family Functioning of Puerto Rican Families With Children: A Grounded Approach

DATE OF INTERVIEW _______________ CODE NUMBER ___

FAMILY MEMBER (S) PRESENT:  Mother _______ Father _______
Age _________  Age ___________

MARITAL STATUS: Single ______ Married ______ Divorced ______
Separated ______ Widowed ______

HIGHEST GRADE COMPLETED: Mother _____________ Father ___________

OCCUPATION: Mother __________________ Employed: Yes ___ No ___
Father ___________________ Employed: Yes ___ No ___

WHEN DIAGNOSED FOR HIV/AIDS: Mother _______ Father _______
Child _______ Sex ___ Age ___

Other Family Members:
1. ___________ Sex _____ Age ___
2. ___________ Sex _____ Age ___
3. ___________ Sex _____ Age ___

HIV CLASSIFICATION STATUS: Mother __________ Father __________
Child _______ Sex ___ Age ___

Other Family Members:
1. ___________ Sex ___ Age ___
2. ___________ Sex ___ Age ___
3. ____________________ Sex _____ Age _____

**NUMBER OF PEOPLE LIVING IN YOUR HOME**

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<tr>
<th>Relationship</th>
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**Additional Notes:**

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APPENDIX C
INITIAL INTERVIEW GUIDE

Families' Perceptions of Immunodeficiency Virus HIV/AIDS
Phenomenon and Its Impact on Family Functioning of Puerto Rican
Families With Children: A Grounded Approach

(A) Tell me about the child's visit to the doctor today.

__________________________

__________________________

(B) What did you and the doctor discuss about the child?

__________________________

__________________________

(C) What kind of treatments does your child receive in this
clinic? ________________, ________________, ________________

(D) How long has your child been receiving services at the
clinic? How frequent are the appointments?

__________________________

__________________________

(E) What are some of the things you do here in the clinic when
your child has an appointment? What is your day like?

__________________________

__________________________

__________________________

(F) Do you miss out on things when you go with your child to the
clinic? Tell about it ________________________________
APPENDIX D

DESCRIPTIVE QUESTIONS TO PARENTS

Families' Perceptions of Immunodeficiency Virus HIV/AIDS Phenomenon and Its Impact on Family Functioning of Puerto Rican Families With Children: A Grounded Approach

  (A) How has your child being doing since I saw you at the clinic?

  (B) How long ago was your child's condition first diagnosed?

  (C) Think back to when your child was diagnosed as having HIV infection and tell me:

      1. Who told you?
      2. Where you were told?
      3. What was your reaction?
      4. What did you do?
      5. To whom did you turn for support?
      6. Why did you tell this person?
      7. What was his/her reaction?
      8. Whom did you not tell?
      9. What were the reasons to not tell?

  (D) How would you describe your family life right now?

  (E) Tell me how you and your family are managing this illness.

  (F) How does having HIV/AIDS illness in your family affect
the kinds of people you and your family associate with?

(G) If I followed you through a typical day in your home, what would I see you and your family doing? Or what activities or things would I see happening?

(H) What would you say are your major concerns dealing with this illness?
APPENDIX E
DESCRIPTIVE QUESTIONS TO CHILDREN

Families' Perceptions of Immunodeficiency Virus HIV/AIDS Phenomenon and Its Impact on Family Functioning of Puerto Rican Families With Children: A Grounded Approach

(A) Tell me what grade are you in?

(B) What are some of the things you like to do at school? At home?

(C) Tell me what are some of the things that you like to do with your friends?

(D) What are some of the things you usually do in the clinic when you have an appointment?

(E) Let's talk about the day you were told about what was happening to you, sister, or brother.

   (1) Who told you?

   (2) What did they tell you?

   (3) What do you think were the reasons this person had to tell you about the illness?

   (4) How do you feel in knowing that you, sister, or brother has this illness?

(F) Tell how different you feel from other children.

(G) What things do you do when you feel sad?

(H) What things worry you about your family now?

(I) What things do you do to help your mother, father,
sister, or brother?

(J) How difficult is it for you to keep the illness a secret from other people?

(K) What do you think could happen if somebody else knows what is it happening in your family?
APPENDIX F

Letter of Approval Hospital
Marta Rivero Méndez, RN, MSN
Candidata Doctoral LSU
Nueva Orleans y
Catedrática Auxiliar
Escuela de Enfermería
Recinto de Ciencias Médicas

Estimada Srta. Rivero:

Reciba nuestro saludo.

Deseamos notificarle nuestra autorización para llevar a cabo el siguiente estudio en las facilidades del "Proyecto Gamma" del Hospital Pediátrico Universitario: Estudio exploratorio sobre las percepciones y experiencias que tienen las familias puertorriqueñas con niños afectados por el Virus de Inmunodeficiencia Humana (VIH) y con el diagnóstico del Síndrome de Inmunodeficiencia Adquirida (SIDA) y el impacto que tiene este fenómeno en el funcionamiento familiar.

Entendemos que la realización de dicha investigación aportará al continuo mejoramiento de la calidad del cuidado de Enfermería ofrecido a estos pacientes y sus familias. Con este propósito, agradeceremos se suministre a nuestra Institution los hallazgos del mismo.

Estamos a su disposición para cualquier ayuda o colaboración que estime necesaria durante la investigación. Le deseamos además el mayor de los éxitos en sus estudios doctorales.

Cordialmente

Sra. María J. Aguilar Pérez, RN, MSN
Directora Asociada en Educación
Servicio de Enfermería

MJA/car

cf: Sra. Carmen Rivera, RN

Vo.Bo. Sra. Leticia Fuentes Negrón, RN, MSN
Directora
Servicio de Enfermería
6 de mayo de 1993

Sra. Leticia Fuentes, R.N., M.S.N.
Directora, Servicios de Enfermería
Hospital Pediátrico Universitario
Centro Médico, Rio Piedras

RE: "Estudio de Investigación sobre Percepción y Experiencias que tienen los Familias Puertorriqueñas con Niños Infectados por VIH y SIDA"
Investigadora:
Sra. Marta Rivero, R.N., M.S.N.

El documento enviado por la Sra. Marta Rivero fue evaluado y tiene la aprobación para que el estudio se realice en el Programa.
Agradeceré que se comunique a la Sra. Rivero esta decisión.

Atentamente,

[Carmen M. Rivera, R.N., M.P.H.]
Coordinadora
Proyecto Gamma-ACTU
APPENDIX G

CONSENT FORM

Louisiana State University Medical Center in New Orleans

1. STUDY TITLE
The Families' Perceptions of Immunodeficiency Virus (HIV)/AIDS Phenomenon and its Impact on Family Functioning of Puerto Rican Families With Children: A Grounded Approach

2. PERFORMANCE SITES
Data will be collected in two clinical settings localized in San Juan, Puerto Rico. The settings are the University Pediatric Hospital and the San Juan City Hospital/Pediatric AIDS Programs San Juan, Puerto Rico. Data also will be collected in the participants' homes or a mutually selected location.

3. NAMES AND PHONES NUMBERS OF INVESTIGATORS
INVESTIGATOR: Marta Rivero, R.N., M.S.N.
   Telephone: (Home) Ext. (Office)
FACULTY MEMBER: Yvonne M. Sterling, R.N., DNSc
   Telephone: (Home) (Office)

4. PURPOSE OF STUDY
The purpose of this exploratory study is to help nurses to understand about the Puerto Rican families' perceptions of their experiences and processes of daily functioning with a child who has Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) infection.

5. PARTICIPANT INCLUSION CRITERIA
   (a) Families composed of two or more family members living
in the same household with at least one biological caregiver (mother or father) who is responsible for a child under 13 years of age diagnosed for HIV/AIDS will be included in the study.

(b) Families members living in the same household with the ability to read and write Spanish will be included in the study.

6. PARTICIPANT EXCLUSION CRITERIA
(a) Families will be excluded if their child's diagnosis has not been determined yet.
(b) Participants who cannot read and write Spanish will be excluded from the study.

7. DESCRIPTION OF STUDY
The investigator anticipates that 5 to 10 families will be participants in this study and that they will be interviewed and observed two or three times over a period of 5 to 6 months. The interviews lasting about 1 hour will be conducted at the hospital clinic, in the participant's home or a mutually selected location where answers can be given privately. The investigator will interview participants about their activities in the setting where they are receiving health services. Participants also will be interviewed about their experiences and daily functioning with a child with HIV/AIDS. The investigator will make arrangements to visit the participant's home for certain period of times during this study to observe the family through a typical day. The investigator has plans to negotiate in advance with each family how many hours she will spend in their home. The interviews will be audiotaped. Upon request, the participant can listen to the tape and edit any part of the tape. The investigator will inform each participant that the content of the interviews and observations will remain confidential. The family member
will be informed that the investigator is obligated to report any illegal activity observed or reported such as child abuse and drug use. Only numbers, not names will be used on the tapes. All audiotapes will be erased after the information given by the participant has been typed from the tape. The written notes without the participant's name will be maintained for future study. Participants will have the opportunity to review the overall transcriptions of the interviews and observations in order to assure that what was written accurately represent what they said and what I observed.

8. BENEFITS TO PARTICIPANTS
Possible benefits of the study are:
(a) That nurses may gain increased understanding of participant's everyday life, their personal feelings, concerns, problems, and needs dealing with the HIV/AIDS infection.
(b) Participants may receive some benefits in discussing their feelings and concerns with the investigator. Otherwise, there may be no real benefits for participating in this study.

9. RISKS TO PARTICIPANTS
There are no known risks to the participants, however participation in this study may involve:
(a) Possible fatigue at being interviewed.
(b) Possible feelings of anxiety either because of face-to-face questioning, the investigator's observations, or the recording process.

10. ALTERNATIVES TO PARTICIPATION IN THE STUDY
The alternative for the participant is not to participate in this study.
11. PARTICIPANT'S REMOVAL Not applicable to this study

12. PARTICIPANT'S RIGHT OF REFUSAL TO PARTICIPATE OR WITHDRAWAL
The participation in this study is entirely voluntary. The study's participants are free to refuse to participate or free to withdraw from this research study at any time without jeopardizing in any way their health care treatment and benefits in this institution in the present or future.

13. PARTICIPANT'S RIGHT TO PRIVACY
The information shared with the investigator will not be released to any member of the participant's family or any member of the health care team. The privacy of participants will be protected and their name will not be used in any manner whatsoever. Any information collected from participants will be combined into a report and will be used exclusively for research purposes, and may be published and presented at conferences. The consent form signed by the participant and their family members will be kept in a safe, inaccessible place in the investigator's home and separate from the audiotapes and the interview transcriptions to protect the privacy of participants and the confidential nature of the study. The investigator also will use a number to identify each audiotape, interview transcriptions, and written notes. No names will be used.

14. RELEASE OF INFORMATION
You agree to permit the sponsoring agency to review your medical records at any time.

15. FINANCIAL INFORMATION
Participants will not be paid for their participation in this study. In addition, there are no final costs associated with their participation. I understand that in the event of physical and/or mental injury resulting from this research
study, no financial compensation is available, but I will receive medical treatment free of charge at the University Hospital or at any other hospital designed by the Chancellor of the Medical Sciences Campus of the University of Puerto Rico. The cost of unforeseen complications must be met by the participant.

16. SIGNATURE
The study has been discussed with me, and all questions concerning it also have been answered. I understand that I have the right to ask the investigator any questions which may arise during the course of the study and that answers to the questions will be provided. I understand that I may receive a copy of the results of this study upon request from the principal investigator. I understand that if I have any questions about patient rights or other concerns, I may contact Dr. Enrique Velez Garcia, President of the Institutional Review Board, at [blank] Ext. [blank] I agree with the terms above and acknowledge I have been given a copy of the consent form.

__________________________  ______________________
Signature of Participant      Date

__________________________  ______________________
Signature of Witness         Date

"The study participant is a child and I certify that I am his/her legal guardian"

__________________________  ______________________  ______________________
Legal Guardian Name          Legal Guardian Signature  Date

__________________________  ______________________
Child's Name and Age         Child's Signature       Date

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Reason for not obtaining child assent:

________________________________________

________________________________________

________________________________________
1. TITULO DEL ESTUDIO:

Estudio exploratorio sobre las percepciones y experiencias que tienen las familias puertorriqueñas con niños afectados por el Virus de Inmunodeficiencia Humana (VIH) y con el diagnóstico de Síndrome de Inmunodeficiencia Adquirida (SIDA) y el impacto que tiene este fenómeno en el funcionamiento familiar.

2. ESCENARIOS SELECCIONADOS PARA LA INVESTIGACION:

La información para este estudio será colectada en San Juan, Puerto Rico en dos unidades clínicas que proveen servicios a la población pediátrica afectada por VIH/SIDA. Las unidades clínicas están localizadas en el Hospital Pediatrúctico Universitario y en el Hospital Municipal de la Capital. Información también será colectada en los hogares de los participantes o lugares mutuamente seleccionados entre participantes e investigadora.

3. NOMBRES Y TELEFONOS DE LOS INVESTIGADORES:

INVESTIGADOR: Marta Rivero, R.N., M.S.N.
Teléfono: [Redactar número]

MIEMBRO DE FACULTAD: Yvonne M. Sterling, R.N., DNSc
Teléfono: [Redactar número]

4. PROPOSITO DEL ESTUDIO:

El propósito de este estudio exploratorio es ayudar a las enfermeras y enfermeros a obtener un mejor entendimiento acerca de las percepciones y funcionamiento diario que tienen las familias puertorriqueñas manejando un niño que es positivo para el Virus de Inmunodeficiencia Humana (VIH) o que está diagnosticado con el Síndrome de Inmunodeficiencia Humana (SIDA).

5. CRITERIA PARA INCLUIR PARTICIPANTES:

(a) Serán incluidos en este estudio familias compuestas por dos o más miembros viviendo en el mismo hogar con al menos un padre o madre biológico responsable de un niño
menor de 13 años positivo para VIH/SIDA.
(b) Miembros de la familia viviendo en el mismo hogar con la habilidad de leer y escribir español serán incluidos en este estudio.

6. CRITERIA DE EXCLUSION DE PARTICIPANTES:
(a) Familias serán excluidas si el diagnóstico de su niño no ha sido determinado.
(b) Participantes que no sepan leer o escribir español serán excluidos de este estudio.

7. DESCRIPCION DEL ESTUDIO:
La investigadora anticipa que 5-10 familias participarán en este estudio y que serán entrevistadas y observadas 2-3 veces en un periodo de 5-6 meses. Las entrevistas pueden durar 1 hora y van a ser conducidas en las clínicas del hospital, en el hogar de los participantes o en un lugar mutuamente seleccionado donde se pueda conversar privadamente. La investigadora entrevistará a los participantes acerca sus actividades en la clínica donde el miembro de su familia está recibiendo servicios de salud. Los participantes también serán entrevistados acerca de sus experiencias y funcionamiento diario con un niño que es positivo para VIH o tiene un diagnóstico de SIDA. La investigadora hará arreglos anticipados con los participantes para visitar su hogar por ciertos periodos de tiempo para observar un día típico en su familia. La investigadora tiene planes de negociar con anticipación cuantas horas puede estar en los hogares de los participantes. Las entrevistas serán grabadas. Si el participante lo solicita podrá escuchar las grabaciones y editar o cambiar lo que desee. La investigadora informará a cada participante que el contenido de las entrevistas y observaciones serán confidenciales. El participante será informado de que la investigadora está obligada a reportar cualquier actividad ilegal observada o reportada tal como abuso de menores o uso de drogas. Solo números, no nombres serán utilizados para identificar las grabaciones. Las grabaciones serán borradas después que se hallan pasados por escrito. Las notas escritas sin el nombre del participante se guardarán para estudios futuros. Se le permitirá al participante revisar las notas escritas de las entrevistas y observaciones hechas por la investigadora para asegurar que lo que fue escrito realmente representa lo que dijeron y que las observaciones hechas fueron correctas.

8. BENEFICIOS A LOS PARTICIPANTES:
Los posibles beneficios en conducir este estudio son:
(a) Que las enfermeras y enfermeros puedan obtener un mejor entendimiento acerca de la vida diaria, los sentimientos, preocupaciones, problemas y necesidades de los participantes manejando la enfermedad VIH/SIDA.
(b) Los participantes pueden recibir ciertos beneficios al discutir sus sentimientos y preocupaciones con la investigadora. Aparte de lo señalado, posiblemente no existen beneficios reales al participar en este estudio.

9. RIESGOS HACIA LOS PARTICIPANTES:
No se anticipa ningun riesgo conocido para las personas que participen en este estudio, sin embargo la participación en este estudio puede causar:
(a) Posible cansancio al ser entrevistados.
(b) Algun grado de ansiedad al ser entrevistados cara a cara, al utilizar grabadora o ser observados.

10. ALTERNATIVAS PARA PARTICIPAR EN EL ESTUDIO:
La alternativa es que el participante no participe en este estudio.

11. REMOCION DE PARTICIPANTES: No es aplicable en este estudio.

12. DERECHOS DE REHUSAR PARTICIPACION O RETIRARSE DEL ESTUDIO:
Los participantes pueden libremente rehusar a participar en este estudio o retirarse libremente en cualquier momento sin que se le afecten los servicios de salud y beneficios que reciben en esta institución en el presente o en un futuro.

13. DERECHOS DE LOS PARTICIPANTES A LA PRIVACIDAD:
La información que el participante comparta con la investigadora no será dada a conocer a ningún miembro de su familia o miembros del equipo de salud. La privacidad de los participantes será protegida y bajo ningún concepto su nombre será revelado. Toda información colectada en este estudio será incorporada en un informe y será utilizado con propósitos investigativos, podría ser publicada y presentada en conferencias. La hoja de consentimiento firmada por el participante y miembros de su familia se mantendrá en un sitio seguro e inaccesible en el hogar de la investigadora, y separada de las grabaciones y notas escritas para proteger la privacidad y la confidencialidad de los participantes en este estudio. La investigadora utilizará un número para identificar las grabaciones, las transcripciones de las entrevistas y notas escritas.
Los nombres de los participantes no serán utilizados.

14. DIVULGACION DE INFORMACION:

Tu aceptas que la agencia que patrocina este estudio revise tu expediente médico en cualquier momento.

15. INFORMACION FINANCIERA:

Los participantes no recibirán ninguna compensación económica por participar en este estudio. En adición no existen costos finales asociados con su participación. Cualquier costo que halla por complicaciones imprevistas serán pagadas por el participante.

16. FIRMAS:

El estudio ha sido discutido conmigo, y todas mis preguntas relacionadas con el mismo han sido contestadas. Yo entiendo que tengo el derecho de hacer cualquier pregunta a la investigadora durante el transcurso del estudio y estas serán contestadas. Yo entiendo que si así lo requiero al investigador principal podré recibir copia de este estudio. Yo entiendo que si tengo cualquier pregunta sobre mis derechos como paciente o cualquier otra preocupación, Yo puedo llamar al Dr. Enrique Vélez García, Presidente del Comité de Derechos Humanos al (809) 758-2525 Ext. 1750. Yo estoy de acuerdo con los términos arriba señalados y admito que se me ha dado una copia de esta hoja de consentimiento.

Firma del Participante ___________________________ Fecha __________

Firma de Testigo ______________________________ Fecha __________

" El participante en este estudio es un niño y certifico que soy su guardian legal"

Nombre del Guardian Legal ___________________________ Firma del Guardian Legal ___________________________ Fecha __________

Nombre y Edad del Niño ___________________________ Firma del Niño ___________________________ Fecha __________
Razones para no otorgar el consentimiento del niño:

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CURRICULUM VITAE
Marta Rivero
University of Puerto Rico
Medical Sciences Campus
College of Health Related Professions
School of Nursing

PROFESSIONAL EDUCATION

1994
Louisiana State University Medical Center
New Orleans, Louisiana
Doctor of Nursing Science
November

Specialization: Parent and Child Nursing

Functional Area: Consultation

1981
Master of Nursing Science
University of Puerto Rico Medical Science Campus, School of Nursing

Specialization: Maternal and Child Nursing

Functional Area: Education

1976
Bachelor of Nursing Science
University of Puerto Rico Medical Science Campus School of Nursing.

PROFESSIONAL EXPERIENCE

1981-Present  Assistant Professor
Maternal and Child Nursing
University of Puerto Rico Medical Sciences Campus
School of Nursing.

1987-1989  Staff Nurse
Pediatric University Hospital, University of Puerto Rico, Medical Sciences Campus
Part-time nurse in Emergency Unit and General Pediatric areas.
1978-1979  Instructor
Medical Surgical Nursing
University of Puerto Rico Humacao Regional College
Department of Nursing.

1976-1978  Staff Nurse
Pediatric University Hospital, University of
Puerto Rico, Medical Sciences Campus.

PROFESSIONAL ACTIVITIES AND ORGANIZATIONS

1994-Present  President of the Editorial Board, College of
Professional Nurses, Puerto Rico.

1994-Present  Secretary of the Association of Residents Pradera-
Almira Inc. Cataño Puerto Rico.

1992  Volunteer for the Regional AIDS Interfaith Network
Louisiana, New Orleans.

1989-Present  Member of Louisiana State Nurses Association.

1990-Present  Member of Association of Nurses in AIDS Care
(ANAC).

1976-Present  Member of College of Professional Nurses,
Puerto Rico.

CERTIFICATION/LICENSES HELD

Louisiana State Board of Nursing Registered Nurse (Since 1989)

Puerto Rico Board of Nursing (Since 1976)

RESEARCH OR PUBLICATIONS

Rivero, M. (1994). Development of a Support Program as a Model of
Intervention in a Clinical Unit for Families of Children Affected
by the HIV/AIDS Infection. Funded by Fogarty International
Training Center, University of Miami, Miami, Florida

PARTICIPATION AT PROFESSIONAL CONFERENCES AND TRAINING

Poster Presentation:

Steele, N.F., Constans, T., Rivero, M. & Shroyer, L. Primary
Care for High Risk Infants: Program Development and Evaluation.
Presented at: Nursing Research: the Quest for Quality Outcomes.
Louisiana State University Medical Center, School of Nursing and
Epsilon Nu Chapter of Sigma Theta Tau International Honor Society. October 8, 1992.

Training


Graduate Clinical/Research Training to work with infants at-risk and their families. Human Development Center Louisiana State University Medical Center, School of Allied Professions. Summer, 1991.
