CHAPTER ONE: INTRODUCTION

"Chronic illness is like gravity. It always exists."

Joan C. Barth, Ph.D. (1996)

The technical and scientific advances that occurred in medicine during the past century have profoundly impacted the treatment of serious chronic illnesses in the United States. Today, medical conditions that were at one time in our history considered terminal may be treatable if not curable. Families of persons with chronic illnesses, as a result, often manage treatment demands over the life span of their loved ones. In many instances the management of chronic illness requires adherence to complex, time-consuming, and uncomfortable regimens.

When a chronically ill person is a child, parents assume responsibility for the coordination of medical routines, symptom monitoring, and regular medical visits as they lead their families through life with chronic illness. Parents must learn to cope with the chronic condition. That coping process includes making adjustments that benefit the affected child as well as other children in the family (Austin, 1993). Families expend a wide range of emotional energy that is often draining and empowering at the same time: they learn to live with emotions that seem on the surface to contradict one another but on a deeper level create the full human experience of illness (McDaniel, Hepworth, & Doherty, 1997).

The prominent themes in family illness stories are described as universal human struggles (McDaniel, et al., 1997). Yet, this researcher identified only a few studies that explored African American parents as participants in chronic childhood illness research (Williams, 1993; Yoos & McMullen, 1999). Even more obviously absent from research regarding illness experiences are studies that examine African American fathers and their experiences parenting their chronically ill children.

African American men in this country are part of a unique historical and social collective. The decisions they make regarding how they choose to be involved in the care of their child with a chronic illness may likewise be unique. The association between race, ethnicity, and the delivery of health-care services in this country has been well documented in recent findings by the Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care (Smedley, Stith, & Nelson, 2002). The study found that "patients' race and ethnicity significantly predict the quality and intensity of care they receive" (p. 62). Researchers concluded:

Racial and ethnic disparities in healthcare exist. These disparities are consistent and extensive across a range of medical conditions and healthcare services, are associated with worse health outcomes, and occur independently of insurance status, income, and education, among other factors that influence access to healthcare (p.62).

Therefore, this qualitative research study is a critical exploration of how African American fathers experience parental involvement and participation in the care of their chronically ill children.

<div align="center">Statement of the Problem and Its Setting</div>

The Center for Disease Control's National Center for Chronic Disease Prevention and Health Promotion broadly defines chronic disease as "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely (2000)." That definition is derived from an investigation by a National Commission on Chronic Illness (1956) that concluded the following:

Chronic disease comprises all impairments or deviations from normal which have one or more of the following characteristics: are permanent; leave residual disability; are caused by non-reversible pathological alteration; require special training of the patient for rehabilitation; may be expected to require a long period of supervision, observation, or care (p. 2).

Later, Mattsson (1972) extended the definition of chronic illness in the following way:

Chronic illness refers to a disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life span despite impaired physical and mental functioning. Such a disease frequently shows periods of acute exacerbations requiring intensive attention (p. 801).

Currently, according to *The National Health Interview Survey* (1997), 8 percent of children ages 5 to 17 were limited in their activities (going to school, playing, and any other activities of children) because of one or more chronic health conditions, compared with 3 percent of children younger than 5. From 1984 to 1997, the survey health indicators show that activity limitations due to chronic childhood illness increased from 9 to 11 percent among children ages 5 to17 in families living below the poverty line. Among children in the same age range in families at or above the poverty line, activity limitation increased from 6 to 8 percent. The conditions reported in this survey usually last more than 3 months and include such chronic

conditions as asthma, diabetes, and hearing impairment (Forum on Child and Family Statistics, 2002).

Until recently when researchers studied families with chronically ill children, fathers were largely excluded from studies. Quittner and DiGirolamo (1998) asserted that exclusion of fathers from studies has limited the ability to "provide direct links to clinical interventions" (p.78) in support of family adaptation to chronic childhood illness. In his book on the influence fathers have on children, Hamilton (1977) postulated that the omission of fathers from studies seemed to involve one or two assumptions: fathers do not play a significant part in the family or fathers' attitudes and behavior are adequately represented by the mother. Furthermore, at least two reasons have been suggested to explain the consistent imbalance of familial respondents and the tendency to focus on the mother-child dyad: first, mothers are the primary caretakers of chronically ill children, particularly medical care routines, and second, mothers are the child's main representative to health-care providers (Drotar, Crawford, & Bush, 1984). In such studies, according to McKeever (1981), maternal responses are assumed equal to paternal responses and contribute to the assumption that mothers and fathers always operate as a team and respond identically in their parental roles.

During the final decade of the 20th century and into this millennium, research documented the effects of father involvement on child outcomes (De Luccie & Davis, 1991; Hawkins & Palkovitz, 1999; Marsiglio, 1993) and included the Department of Health and Human Services Fatherhood Initiative (1995). Hawkins and Palkovitz (1999) explained that the term "father involvement" has an established meaning of "temporal and directly observable interaction between fathers and children" and encompasses how the father "affects his child and how his child affects him" (p. 17). Although the amount and depth of father involvement research has increased, research into the contributions that African American men make on behalf of their families' well-being and development remains limited. Allen and Connor (1997) said the following:

> Without accurate information, negative stereotypes depicting African American men as neglectful, abusive, dependent, or absent proliferate. In the social sciences, the reluctance to undertake credible scholarship about African American fathers may be the result of many researchers' misconceptions about African American men. Researchers'

misgivings about black men's suitability for or interest in family life often emerge from the deeper societal ambivalence about ethnicity and "race relations" (pp. 58-59).

Prior to the mid-1970s, research literature focused specifically on the plight of African American men and tended to investigate their dysfunctional, pathological contributions within families (Gordon, Gordon & Nembhard, 1994). A shift away from pathology-focused research and toward research on the strengths of African American families began in the late 1960s and continued through the early 1980s (Billingsley, 1968; Boyd-Franklin, 1989; Hill, 1972; H. P. McAdoo, 1978). Consequently, literature emerged on the well-functioning of father-present families (Allen, 1981; Amato & Rivera, 1999; Bowman, 1990; Grief, Hrabowksi & Maton, 1998; J. L. McAdoo, 1981). Nonetheless, Gordon, et. al (1994) conclude that African American males in the literature continues to be limited in scope:

> It is primarily a literature of the failures and dysfunctional behavior of Black males, and it is greatly over-representative of Black males in the inner cities. This focus neglects the majority of the Black male population and fails to more fully address age, class, gender and geographical issues. It is the absence of appropriate attention to a broad range of adaptations and maladaptations found in this population that is perhaps the greatest weakness of this literature (p. 552).

More expansive and diverse scholarship on the manner in which men are involved in their families has been widely recommended (Allen & Conner, 1997, Hawkins & Palkovitz, 1999; Mintz, 1998). Furthermore, paternal involvement investigations that consider race, class, culture, and ethnicity are particularly important because differences in cultural conceptions of masculinity and cultural differences in male standards have also been associated with gender-related attitudes, stress, and conflicts (Wade, 1995).

The human experience of illness, therefore, is yet another intersecting quandary to the constructs of race, gender and culture. McGoldrick (1993) states that illness behavior is governed by cultural rules. Those culture-specific rules are demonstrated, for example, by patients' differences in their attitudes toward complaining (some ethnic groups require it; others disapprove of it), in the accuracy of their ability to describe their preferred solution to being in pain, and in their attitudes toward doctors. Additionally, beliefs about control, communication patterns about illness, decisions about who participates in the care-taking system, hospital vigils,

and rituals associated with healing are other examples of culture specific illness beliefs (Imber-Black, 1991).

<div align="center">Purpose of the Study and Significance</div>

The purpose of this study is to investigate how African American fathers participate, cope with, and manage the chronic illnesses of their children, to explore how they believe they are perceived in their work on behalf of their families, and to discover how they experience paternal involvement in light of their family's circumstance. The study further aims to inform clinical practice through insights gained from fathers' descriptions and advice.

James May in the documentary video *Equal Partners, African-American Fathers and Systems of Health Care*, posed the following questions:

> In a world where the predominantly white health care community overwhelmingly deals with women, how does the African-American male fit in? What is his experience in a medical world that probably believes it treats him well (National Fathers Network, 1996)?

Descriptive accounts of how African American men define their experiences are important for several reasons: (1) the public's perception of African American fathers is often negative and reflective of a deficit model, which leaves clinicians with an unbalanced view of families; (2) fathers in general and African American fathers in particular remain an elusive research target in research regarding chronic childhood illness (Holder & Turner-Musa, 1998; Knarl & Deitrick, 1987); and (3) clinicians traditionally have had difficulty engaging men in treatment, particularly men of color (Grief, Hrabowski, & Maton, 1998).

The versatility of qualitative methods is a good match for examinations of diverse family forms and experiences because the focus is not on identifying structural or demographic trends in families, but rather on the process by which families create, sustain, and discuss their own realities (Daly, 1992). The intent of this qualitative study is to begin, with a small exploritory intensive inquiry into the participation of African American fathers in families with chronically ill children, to fill in the existing gap in research by focusing on experiences within as well as between families and outside systems (Gilgun, 1992).

This study offers abundant opportunities for illuminating the process of father participation that occurs while managing a variety of stressors. It is of value to clinicians and others who work directly with children and families living with chronic illness, plus scholars,

and students of related disciplines as well. According to Knarl and Deatrick, (1987) studies that are "subjective active" in their approach to chronic illness research are relevant to clinical practice in the following ways:

1. Readers of subjective accounts learn of family definitions and experiences and are often challenged to explore the assumptions and biases they carry and are also challenged to examine ways to better understand and to work effectively with families;

2. The variety of active definitions and approaches to managing life with chronic illness generates an awareness that supports collaborative work and aids clinicians and families in their effort to define specific needs and interventions; and

3. From the identification of specific needs can come a variety of new services developed on behalf of the entire family system (pp. 303-304).

<u>Person of the Researcher</u>

To this research project, I bring a unique lens. I am married to an African American man. At an early age, our child was diagnosed with a chronic illness. I have therefore been intimately involved in a family system impacted by chronic childhood illness. The background experience that I bring to this project offers a considerable capacity to understand and to investigate this complex and dynamic family process. The theoretical sensitivity that I possess allows for the development of a theory that is grounded, conceptually dense, more integrated than if sensitivity were lacking (Strauss & Corbin, 1990). Although there are advantages to the insider status as a source of theoretical sensitivity, Strauss and Corbin (1990) alert researchers to some potential "blinders" that may result from insider experience: difficulty seeing the routine and obvious in fresh, new and imaginative ways or assuming sameness of experiences. To these "blocks" they recommend that researchers periodically step back and ask questions of the data collected, maintain an attitude of skepticism regarding theoretical explanations or categories, and follow solid research procedures. I have incorporated those strategies into the design and implementation of this investigation.

<u>Theoretical Framework</u>

Stress and coping theory is the framework that is used in this study. This theoretical base provides a broad base from which questions are posed and responses are examined. The stress and coping framework considers multidirectional non-linear conceptualizations of individual

adjustment within the family system, the family emotional transactions involved in the adjustment to illness, and the process of disease in the context of family life-stage development (McCubbin & Thompson, 1987). Phases that families go through as they manage stressors are described as factors that influence family adaptation at given points in the process. This model is based on Hill's ABCX Model (Hill, 1949), which was developed to describe families' responses to war separation and reunion. The family's definition of the stressor event (the C factor) interacts with the stressor (the A factor) and the family's resources for facing the crisis (the B factor). The interaction of factors is used to explain whether the family experiences a crisis (the X factor). The model proposes that family demands interact with family adaptive resources and family definition to produce coping behaviors. The outcome of these coping behaviors leads to adaptation (Austin, 1993). The Double ABC-X Model of Family Adaptation and Adjustment (McCubbin & Patterson, 1985) identifies that factors both within the family and outside the family influence how well families adapt to a chronic stressor, such as chronic illness in a child (Austin, 1993). In the Double ABCX Model, the coping process (both cognitive and behavioral strategies) is a key aspect in understanding a family's response to a stressful life event: the family's perception of the stressor event, the family's perception of the pile-up, and the family's perceptions of its resources. Stress, then, has been defined as "specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.141) or "hardships of the situation or event itself" (Hill, 1949, p.9). The coping strategies that individuals employ have been classified as problem-focused (efforts to modify the source of the problem) or emotion-focused coping (efforts to reduce emotional distress) (Folkman & Lazarus, 1980).

Research Questions

This study examines how African American fathers experience their contributions to the development of their chronically ill child and their family. The primary objective was to investigate, based on the stress and coping theoretical frame, how African American fathers participate, cope with, and manage their child's chronic illness; how they believe they are perceived in their work on behalf of their families; how they experience paternal involvement in light of their family's circumstance; and how clinical practice can be informed by their experiences.

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I developed questions to address family demands, definitions, resources, and coping strategies. The interviews were based on information drawn from a pilot study that involved an African American father of a chronically ill child and from the research literature. Following are the areas covered and the questions addressed:

1. Tasks, responsibilities, and expectations related to father participation: What are the daily familial and social contexts within which coping takes place?

2. Demands and stressors participants experience and the variance they experience over time: What are the coping processes that occur as participants are involved in their families?

3. Resources (internal and external), coping strategies, and constraints to adaptation defined by participants: What are the historical appraisals of paternal involvement and family illness experience within which the coping process takes place?

CHAPTER TWO: LITERATURE REVIEW

Introduction

This study explores African American fathers and their experiences parenting their children with chronic illnesses. I found a limited amount of research that specifically explores parenting by African American fathers and an even smaller amount of research regarding African American fathers of children with chronic illness. Therefore, the following review of literature provides a broad overview of research and knowledge that applies to substantive areas involved in this qualitative investigation. I will proceed with a brief review of several areas of parenting research: research regarding African American family functioning; research regarding African American family functioning with a particular focus on paternal involvement; research regarding positive father involvement; and research that investigates father involvement within families where there is a child living with a chronic illness.

African American Family Research

Many researchers have documented historical trends in African American family research and have described a propensity to present the African American family from a pathology perspective with particular focus on the cause and effects of maladaptive behaviors versus the trend to investigate adaptive behaviors and family functioning from a strengths-based point of view (Billingsley, 1968; H. P. McAdoo, 1978; J. L. McAdoo, 1997). J. L.McAdoo (1981), an investigator who explored families through a strength-based lens, made several observations regarding prior studies of African American families:

- Negative interaction patterns observed were drawn from economically deficient, socially vulnerable, and problematic family structures;
- Vulnerable Black families were usually compared with economically stable white middle-income families; and
- No studies were found that examined the interaction patterns within middle-income Black families (p. 115).

Nearly 20 years later, Hill (1999) identified that researchers within this body of literature tended to misuse the concept of class in the design and analysis of studies of African American families. He reported, for example, that many studies equated class with culture and that distinctions were not made between class adaptations that reflect current situations and cultural adaptations that are transmitted inter-generationally. In addition, Hill stated that class and race

were often confused. Comparison between Blacks and Whites, for example, often failed to control for socioeconomic status and for diversity of values, behaviors, and attitudes among and within groups.

Staples (1974) and Allen (1978) also examined trends in African American family research and evaluated how theories and frameworks have informed those studies over time. Allen (1978) identified a trend of three theoretical perspectives that has occurred in African American family research: a cultural deviant perspective, a cultural equivalent perspective, and a cultural variant perspective. He described that a cultural deviant perspective is one in which the attributes observed in African American families are compared to attributes in White families and negative meanings are attached to the differences. A cultural equivalent perspective depicts White cultural norms as the standard to which African American families are evaluated based on their ability to adopt those lifestyles. A cultural variant research orientation describes the African American family in terms of their unique functioning. In this qualitative investigation, it is possible that themes may emerge that suggests functioning unique to African American culture.

Hill (1972), for example, explored aspects of African American family functioning and observed traits unique to culture. His observations drew from the established work conducted through out the 20th century and included some unpublished studies that highlighted family's strengths and resiliencies. Hill identified traits in African American families that were present in other ethnic and racial groups, yet functioned differently within African American families because of their unique history of slavery and other forms of racial oppression: strong kinship bonds, strong work orientation, adaptability of family roles, strong achievement orientation, and strong religious orientation. The study concluded that these traits promoted stability in the family and were effective coping strategies utilized by middle-income and low-income African American families.

Kin network support is an example of a culture specific trait examined in research (H. P. McAdoo, 1982). She conducted an investigation of the relationship between stress, economic mobility, and kin network support in upwardly mobile African American families. The majority of participants in her study viewed themselves as middle class (74 percent), while a smaller percentage self-reported as working class (19 percent) and an even smaller percentage considered themselves upper class (7 percent). Three hundred and five parents (174 mothers and

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131 fathers) completed personal data sheets and two-hour interviews regarding the presence of stress and the use of specific cultural patterns as a source of support. She found that families under high stress appeared to be more dependent on the kin network and fathers experiencing more stress reported greater contact with family members. When families incurred significant life changes, they received assistance from kin. Help from kin appeared to arise from kin network concern for a family member's need. Only 26 percent of high stressed families received no help from families. In addition, families actively involved in organizations that reinforced their culture were under less stress. While parents under greater stress were more involved in integrated or almost all White groups.

In another example of culture specific research, Hill (1999) expanded his 1972 study of family structure and functioning. He explored indigenous cultural strengths plus several mainstream coping strategies and identified factors internal and external to African American families that impact functioning and resiliency. Egalitarian family role, for example, was a coping strategy within resilient families that enhanced the family's social and economic viability. In addition he noted the involvement of fathers in resilient African American families and suggested future research about the nature and extent of contact that children in two-parent households have with their fathers.

Similarly, others have contributed to what is understood about culture specific traits that are used as sources of strength and strategies for coping well in African American families: extended family, role flexibility, healthy enmeshment, religion and spirituality, nonverbal communication (Boyd-Franklin, 1989); value of learning, quest for autonomy, self-help and mutual aid orientation, family life and collective action, community self-help (Billingsley, 1992).

Of studies that consider culture specific traits, a number have explored African American fathers within that context. Still other studies have examined fathers in roles as economic providers and decision-makers, and in terms of parenting styles. In the next section, I review studies of African American cultural influence on paternal functioning, involvement, coping styles, and resources within families.

<div align="center">African American Culture and Fathers</div>

Cochran (1997), in her review of recent African American father research, documented a shift in literature from negative and distorted views of fathers to a more "balanced and representative portrayal" (p. 340). She attributed the shift to the following: (1) the use of middle-

class men among subjects analyzed; (2) the documentation of "varying attitudes, degrees of involvement and responsibilities" assumed by men; and, (3) the use of "theoretical models that seek to explain the socio-cultural framework" of experiences observed (p. 340). This shift, she found, contributes more comprehensively to what is understood about the "internal and external factors that influence the experience of fatherhood" (p. 346).

Bowman (1990), for example, conducted research that investigated culture as a resource for fathers in their role as economic providers. A national sample of 372 African American fathers participated in a multiple classification analysis. This multivariate study, guided by the role-strain adaptation model, examined the process of role adaptation and the adaptive cultural resource of African American husbands-fathers. The findings suggested that global satisfaction among husband-fathers was reduced by provider role strain but enhanced by indigenous cultural resources. The joint effects of five provider role strain predictors on global family satisfaction emerged as less devastating if husband-fathers were members of very close rather than less close families. The absence of very close family ties increased negative effects of both husband and father role discouragement. In very close families, harmful provider role strain effects were restricted to objective employment difficulty, primary provider discouragement, and anxiety about family economic subsistence. Discouragement as a primary provider had a more negative effect when families were perceived as very close, rather than not very close. Objective unemployment and family economic worries were negatively associated with family life satisfaction regardless of family closeness.

In another study by Bowman (1993), husband-fathers were asked to consider the extent to which they retain adaptive cultural resources as a source of empowerment in the face of discouraging provider role difficulties. Husband-fathers answered regarding their perceptions of adaptive ethnic resources: closeness of family bonds, para-kin friendship bonds, racial consciousness or system-blame ideology, and religious beliefs. According to responses, 64 percent resided in two-earner households; 63 percent perceived families as close; 67 percent retained strong para-kin friendships; 68 percent expressed consciousness of racial barriers; 84 percent reported being "fairly" religious and 37 percent reported a "very high" level of religious commitment.

Although culture specific aspects of parenting are important to research regarding African American fathers, Allen and Connor (1997) warn that while it is an error to ignore the

possibility of "unique positive or negative consequences of ethnic-group membership" (p. 58), it is also an error to assume that "ethnicity has the same effect on all members of a given ethnic group" (p. 58).

Recently, some research has explored the participation of African American fathers and the impact of parenting beliefs and behaviors on the development of children and families. Before reviewing some of those studies, I will briefly review aspects of paternal involvement research. This large and expanding body of literature is foundational to the study of men in their families, and it provides an entrée into literature on paternal involvement, chronic childhood illness stressors and the impact on families.

<u>Father Involvement</u>

Biller (1993) and Pleck (1997), in reviews of the literature regarding the impact of father involvement and noninvolvement on child outcomes, noted trends to explore father participation as a unique form of parenting (Snarey, 1993) and also to explore father participation in terms of positive involvement (Lamb, Pleck, & Levine, 1986). Hawkins & Palkovitz (1999) agree that researchers of father involvement have shifted their investigations from father absent explorations to what they describe as a trend among scholars to expand the conceptualizations of father involvement.

In order to gain a greater understanding of paternal contributions that are unique forms of parent involvement, many factors regarding participation have been considered in the literature (Christiansen & Palkovitz, 1998; Deluccie, 1996). Palkovitz (1996), for example, suggests that father involvement be considered within three domains: cognitive involvement, affective involvement, and behavioral involvement. Within those contexts, he suggests that involvement can be understood in terms of appropriateness, observability, degree, time invested, salience, proximity, and directness of involvement.

Others suggest that a complete understanding of men's involvement in their families consider additional dimensions. An example of one such dimension is the impact of parenting alliances on the amount of paternal involvement. McBride and Rane (1998) involved 89 predominantly White, Midwestern middle-class mothers and fathers in a study that measured paternal involvement, parenting alliance, and marital quality. The data were collected from self-reports and interviews. Results indicate that an important predictor of paternal involvement was parents' assessments of parenting alliances. When parents were not in agreement about

parenting strategies, fathers were less involved. Fathers who believed their wives had confidence in their abilities to parent were more involved with and responsible for their children. Although this finding is not generalizable to other populations, this study raises important questions about African American parents, the identification of egalitarian parental roles as a coping strategy within families, and how alliances support paternal involvement.

In an essay, Mintz (1998) discusses other important dimensions of involvement. He contends that the manner in which men are involved in the family varies greatly along and across lines of race, ethnicity, class, and religion. He suggests that the complex changes in men's family roles and family involvement are strongly linked to the economic and cultural shifts that have occurred over time. Mintz further suggests that men's definitions of their commitment to their families and roles within their families can be understood within the historical context that frames their public achievement, as well as their private lives as fathers.

Lamb (1998) agrees that men's familial roles have followed complex paths. He states that "successful fatherhood should be defined relative to the specific socioeconomic, cultural, ethnic, and historical niches in which individual men and women together define their needs and roles, whether in or out of enduring relationships" (p.50). Similarly, Burton and Snyder (1998) suggest that in order to gain a more complete understanding of the impact of social, economic, and demographic forces on men's family roles, it is imperative that discussions not exclude the connectedness of men's lives across ethnic or racial groups. Pursuits toward an understanding of the manner in which family and work roles emerge for men, they contend, should consider that "men of different ethnic or racial groups may have unique historical experiences, but it is the unique combinations of these experiences across race and ethnicity that produce the outcomes we see in their work and family roles" (p.38). The results of more expansive and diverse scholarship, Hawkins and Palkovitz (1999) suggest, will "produce clearer and stronger, as well as subtler, connections between father involvement and children's outcomes and father's development" (p. 25).

Many factors have been studied to better understand connections between father involvement and child outcomes. Although associations have been observed, the impact of socioeconomic characteristics on paternal involvement is one example of complex and inconclusive findings. The following studies demonstrate contrasting findings with respect to the race and ethnicity of fathers.

A recent analysis, for example, used data from a national probability sample to examine positive paternal involvement and whether that involvement is associated with child outcomes at home and at school (Amato & Rivera, 1999). The sample consisted of 994 two-parent families with children aged 5-18 and analyzed fathers' (791 White fathers, 117 African American fathers, and 86 Latino fathers) reports of positive involvement in terms of time spent with children, the frequency of support expressed in response to their children, and overall closeness ratings of their relationship. This analysis incorporated mothers' reports of children's behavior problems in order to control for same source bias. Controls for the quality of the effects of the mother-child relationship were part of the analysis. Amato and Rivera found that father time, father support and father closeness were negatively associated with children's behavior problems. Their analysis indicated that if fathers reported being highly involved in their children's lives, then mothers reported relatively few child behavior problems. The association between father's and mother's positive involvement and children's behavioral problems were found to have an independent and significant association and held across three cultural and racial lines. In addition, parents' level of education, in this study, was positively associated with father involvement.

Similarly, another study found there was no relationship between the ethnicity of fathers and their involvement with their children (Fagan, 1998). Fagan's study examined ethnicity as a factor, as well as several other dimensions of paternal involvement: (1) whether unemployed fathers or fathers who work fewer hours outside the home are more involved with children; (2) whether family income was positively associated with paternal involvement; and (3) whether fathers with higher levels of self-esteem and greater nurturing skills were more involved parents (Fagan, 1998). Sixty African American and 25 Puerto Rican low-income fathers of preschool aged Head Start children participated in telephone and face-to-face interviews regarding factors of involvement: direct interaction, play, outings, reading, and responsibility for Head Start. The results of data indicated that father's involvement was not influenced by availability. The unemployed fathers and fathers who spent more time at home were more accessible to their children. These fathers were not found to be more involved. In addition, more nurturing fathers were not more accessible and did not spend more time playing, going on outings, or reading to their children. These fathers did, however, engage in a higher level of direct interaction with

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children. Family income, according to these findings, was found to have a positive relationship to father's direct interaction, play, and outings but not to reading, responsibility, or accessibility.

Family income and education, though, were not significantly associated with paternal care-giving activities in a study by Hossain and Roopnarine (1994). Sixty-three African American middle- to lower-middle income fathers were assessed regarding their care-giving involvement with infants as a function of their wife's full- or part-time employment and as a function of father's functional style within the family, support received, father's education, and income. All participants were from two-parent families. The amount of time that African American fathers were found to spend in child-care involvement (42 percent as much time spent as mothers) was similar to reports by Euro-American fathers regarding time spent in primary care-giving activities. Interestingly, this study found that father's involvement in feeding and comforting infants was significantly associated with fathers' assessments of their ability to communicate effectively within the family and to their commitment to their family.

In an earlier study, Allen (1981) found that African American fathers were more involved within their families than were White fathers. His investigation of 130 middle-class families' interpersonal dynamics compared the socioeconomic characteristics of African American and White families with differences in child-rearing practices and relationships. According to Allen's findings, wives perceived that African American husbands were as involved in child-care and childrearing as they were involved. While 47 percent of White wives claimed their husbands gave more help than average, a larger percentage of African American wives, 63 percent, perceived their husbands' gave more help than average. African American fathers commonly cited the spouse as a helpful childrearing resource. The findings also indicated that African American fathers used verbal rewards and material rewards more frequently than their wives. In addition, the African American fathers expected independence in the son's behavior at a much older age than mothers and White fathers.

The findings of a more recent study suggest that race and ethnicity and cultural ideologies are a function of father's involvement. Toth and Xu (1999) researched behavioral, affective, and cognitive involvement. They examined African American, White, and Hispanic fathers and whether involvement varied by race, culture, and ethnicity. Within the cognitive involvement domain, African American and Hispanic fathers were more involved than were White fathers.

Grief, Hrabowski and Maton (1998) explored the parenting practices of 29 African American fathers of academically successful sons. From this qualitative study emerged six parenting approaches utilized by participants: open, consistent and strong communication; positive racial and male gender identification; community resources; limit-setting; discipline; and high expectations. Similarly, in a small ethnographic study of eight urban African American fathers of kindergartners, fathers studied maintained relationships with children that were warm, nurturing and characterized by open communication (Bright & Williams, 1996). Two recurring themes reported by fathers in this study were "their desire to teach their offspring a strong sense of responsibility" (p.255) and to prepare their children to "negotiate potential barriers to Black achievement" (p.255).

In summary, recent findings suggests many factors influence father involvement including socioeconomic status. The small numbers of studies that have examined the effects of father involvement in non-white populations have yielded varied results. One explanation for this may be that a small number of contexts are represented thus far. African American fathers' participation in families with infants may differ from father participation with preschoolers or adolescents, for example. Other factors that may influence involvement include the following: socioeconomic characteristics; father's motivation to parent as influenced by his developmental history, personality, or beliefs; father's self-perceived parental skill level and self-confidence; father's support system; and parental stress (Pleck, 1997).

Therefore, it is important that this study's examination of five African American father-child relationships consider the unique contexts in which each contributes to the development of their child. The next section will explore additional research of fathers involved in the care of their families living with chronic childhood illness.

<div align="center">Paternal Coping and Family Adjustment</div>

The impact of chronic childhood illness on family systems has been widely investigated and findings demonstrate that "both mothers and fathers of ill children have higher percentile rankings on many distress subscales than do parents of healthy children" (Hauenstein, 1990, p. 357). In her review of studies of parents of children with chronic illness compared to control groups of healthy children, Hauenstein (1990) found that mothers and fathers of children with chronic illness were found (1) to experience more emotional distress, (2) to have few social resources, and (3) to name more family problems. She found that the different distress measures

used by researchers yield a variety of results that fail to explain non-linear complexities of parent experiences. One such example she questioned was the relationship between chronic childhood illness and marital dissatisfaction. In many instances, she noted, "significant parental distress can occur without affecting marital quality" (p. 360).

In addition, Hauenstein (1990) called attention to the exclusion of fathers in this body of research. This is a common practice noted in research regarding children with chronic illness. "Parent reports" typically represent small if any number of father observations. When they include fathers as informants, data collected tend to be collapsed into larger numbers of mother responses. This practice results in our knowing about parent's reports in children with chronic illness to be a primary reflection of mother's perceptions (Thompson, & Gustafson, 1996, p.80). Therefore, some have reported the lack of clarity that remains regarding how fathers, who are reported to experience fewer emotional problems than mothers in their adjustment to chronic childhood illness, contribute to the favorable or unfavorable adjustment of other family members (Chaney, Mullins, Frank, et al., 1997).

For example, the longitudinal study conducted by Chaney, et al. (1997) assessed global measures of parental adjustment. Their findings indicate that fathers and mothers of chronically ill children with insulin-dependent diabetes exhibited comparable levels of adjustment. Research on just how fathers managed chronic childhood illness was conducted in a study of 100 families who have a child with cystic fibrosis (McCubbin, H., McCubbin, M., Patterson, Cauble, Wilson, & Warwick, 1983). Three parental coping patterns emerged from the investigation: (1) maintaining family integration, cooperation, and an optimistic definition of the situation; (2) maintaining social support, self-esteem, and psychological stability; and, (3) understanding the medical situation through communication with other parents and consultation with the medical staff. Fathers were found to demonstrate two coping patterns. Both coping patterns were system-maintenance dimensions of family life and were associated with family organization, cohesiveness, conflict, organization, and control. Father's coping efforts were directed at integration, cooperation and optimism and efforts at medical communication and consultation. In addition, improvements in the cystic fibrosis child's health appeared to be associated with the father's effort to maintain social support, self-esteem ,and psychological stability. Furthermore, positive correlations were indicated between family income and the father's coping efforts and the age of the cystic fibrosis child and the father's coping efforts. The higher the family income,

the greater the father's coping efforts were directed at keeping the family together and becoming involved in medical consultation. In addition, the older the cystic fibrosis child, the greater the likelihood of father's involvement in the medical aspect of child-care.

Other examples were found that examined how fathers are involved in and cope with chronic childhood illness in the family. A qualitative study compared parents' reports of stressors and coping strategies to the reports of professionals (Horn, Feldman, & Ploof, 1995). The results suggested although stressors among participants were universal, coping strategies were personal. Participants to this study included thirteen mothers and five fathers from thirteen families hospitalized for at least thirteen days along with eleven professionals involved in the delivery of care. Each participated in semi-structured interviews with open-ended questions regarding stressors and strategies for coping. Of thirteen categories reported, the top seven coping strategies were common to more than half of the participants while the other strategies appeared particular to individual families. The top strategies included "gaining information, obtaining support from hospital staff, reprioritizing, normalizing, obtaining support from family and friends, obtaining support from families having a similar experience, relying on inner strengths and beliefs" (p.118). Health care professionals reported on families with whom they found it difficult to collaborate. They described personal challenges with "reactive families who readily showed strong emotions, overwhelmed families, demanding families, unavailable families and families different in terms of religion or culture (p. 120)."

In another qualitative study that investigated how fathers and mothers mastered parenting children with special needs, parents were interviewed about their daily challenges and struggles (Snell & Rosen, 1997). Researchers found that parents maintained the view that they were doing what parents typically do yet they approached their tasks and responsibilities with a "heightened sense of purpose and intentionality." Parents' thoughts and behaviors were essential parts of their mastery process. That process often included "worldview shifts" that parents made in order to meet their child's care needs.

Some studies found involved only fathers in research designs and considered strategies for coping. In a study of boys with hemophilia and their fathers, interviews and observations indicated that fathers used denial and repression as a coping strategy but were found not to withdraw emotionally or physically from their sons (Mattson & Gross, 1966). Another study involved observations of children with hemophilia and their fathers. The observations of a

normative sample of fathers and children were compared to the observations of fathers of children with hemophilia. Findings indicated that fathers of the chronically ill children were more involved and more protective in comparison with the norm sample (Markova, MacDonald & Forbes, 1980).

A pilot study examined racial differences in perceived social support of African American and White families living with chronic childhood illness (Williams, 1993). Data was obtained during structured interviews and from an inventory of networks. Twenty-one Blacks (16 mothers, 4 fathers, and 1 aunt) and seventeen Whites (12 mothers, 3 fathers, 1 grandmother and 1 aunt) responded to questions about types of support received, who provided support, need for reciprocity of support and unhelpful support behaviors. This investigation found differences between groups in perceptions of support and descriptions of support. White participants reported that they primarily received affective support from spouse, family, and friends. The majority of African American participants received instrumental assistance (help with siblings, financial help, and groceries). One difference noted in this study was that six African American participants discussed that they received no help while at home and five African American participants received no help during hospitalizations. This differed from White participants. White participants did not describe managing illness without support. Both African American and White parents described that it was important that they "be viewed as competent regarding the care of their children" (p. 1514). Across racial lines, participants found it nonsupportive and insulting when their knowledge of their child's status was discounted or they perceived they were disrespected. In addition, participants were asked whether they perceived that the help they received was spontaneously offered or whether they had to point out their difficulties and ask for help. All White participants except one described that they received spontaneous help. Black participants, on the other hand, reported receiving spontaneous help only 57 percent of the time. Although this study does not seek to describe racial differences it is likely to describe some racial experiences. In addition, it is anticipated that data may emerge regarding help seeking behaviors and support systems that are helpful and unhelpful to fathers.

While some research urges exploration of helpful and unhelpful fathering under circumstances in which families face challenging and stressful family events (Amato, 1998), others recognize the unique opportunity to do so through investigations of families with chronically ill children (Hauenstein, 1990). The next chapter of this investigation presents the

methods used to study the unique voices and personal accounts of fathers involved in the complex task of parenting within the context of chronic childhood illness.

CHAPTER THREE: METHODS

Introduction

This study examined the participation of African American fathers in the lives of their children with chronic illness. The idea for the study emerged from personal experience. My family began a journey into the world of childhood chronic illness when our 4- month old began manifesting health-related distress. Nine years later, I was introduced to a video documentary on this very subject (May, 1996). Very provocative questions were asked that stimulated my personal and professional curiosity regarding research on father participation and chronic childhood illness. With the help of Dr. Sandra Stith, advisor to this study and members of my committee, I began to formulate a researchable question and to conduct a pilot study designed to assist me in the development of a project proposal. The following section describes methods used to conduct this qualitative study of five African American fathers and their experiences as parents of children diagnosed with chronic illness.

Study Design

Before I settled on the design for this study and submitted the proposal for this research, I conducted a pilot study that explored the experience of an African American father of a child with chronic illness. Data from that study and data from related literature helped to narrow and focus this study. The pilot study afforded me the opportunity to consider the role of the researcher and the various sensitivities I bring to this study. Theoretical sensitivity according to Strauss and Corbin (1990) involves a personal quality of the researcher: knowledge of the literature and personal and professional experience, for example. This important aspect of qualitative research, they further explain, enables the researcher to "see the research situation and its associated data in new ways and to explore the data's potential for developing theory (p. 44). Therefore, once I completed the pilot study, I considered my initial impressions and explored with my committee ways to approach data collection. I was particularly interested in refinements that would help me build rapport with participants, structure and deliver interview questions effectively, and ask questions pertinent to the population studied. My goal was to explore participants' experiences in a manner that allowed them opportunity to fully share their views of the world and meanings of their fathering experience.

I used a multiple-case study qualitative design. Accounts were obtained through open-ended, semi-structured interviews. The study was aimed at description, and it proceeded according to the inductive approach. The focus was not on identifying structural or demographic trends in families, but rather on the process by which participants create, sustain and discuss their own realities (Daly, 1992). Stress and coping theoretical framework guided this qualitative study.

I chose a qualitative design because it was a suitable match for this small-scale intensive inquiry into the participation of African American fathers in families with chronically ill children. The amount, richness and depth of data acquired by the very nature of qualitative designs help to fill in existing gaps in research through a focus on experiences within as well as between families and outside systems (Gilgun, 1992). In addition, the versatility of qualitative methods is a good match for the examination of diverse family forms and experiences.

<u>Participants and the Recruitment Process</u>

The men recruited into this study were referred from clinic directors, physicians, mental health workers, and colleagues. The referring sources were informed that this study was considering recruits perceived as involved, resilient parents who cope well with chronic illness in their families. A letter of recruitment was created for the purpose of soliciting participants (Appendix A). Before I forwarded the letter to referring sources or candidates, I made inquiries to potential referring sources and informed them of this qualitative research project and the intent of the study. Sources were asked whether they could recommend any African American fathers who matched the criteria and might be interested in participation. Sources with potential candidates in mind contacted the potential participants regarding their interest and willingness to hear more about the study. Three men responded affirmatively to the referral sources and granted permission to be contacted by telephone. One source referred a candidate I knew prior to the study. I contacted another candidate directly in response to a recommendation that he would likely have a potential interest.

Once telephone contact was made, I explained the purpose of the study and how it would proceed if they volunteered to participate. Fathers were told the study was a qualitative project and that they would be asked to participate in one, two-hour interview at a site convenient to them. Once they agreed to volunteer, I asked questions to determine whether or not they were eligible to participate (Appendix B). Next, arrangements were made for the interview.

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The five participants in this study ranged in age from 30 to 81. Participant's household incomes were in the range of $50,000 per year or greater: one participant's household income was between $50,000 - $70,000 per year; two household incomes were between $70,000 - $90,000 per year; and, two participants had household incomes greater than $90,000 per year. All participants had attended college. Four were currently employed full time in professional capacities. One father was a retired college administrator. All participants were African American. They identified themselves racially in the following manner: two participants – African American; one participant – "Afro-American," one participant – "African American of Hispanic Origin," and one participant – "Black/ before that, Negro/ before that, Colored." Four participants were married. One was separated and the custodial parent of his only child.

The average number of children living at home was 1.6 per household. One child per household was identified as having a chronic illness and ranged in age from 6 to 48. The age at diagnosis averaged 3 years of age.   Two children were diagnosed with seizure disorders with other co-morbid illnesses, two were diagnosed with diabetes at age 5, and one child was diagnosed with a rare organ disorder that required transplantation. The demographic data for the participants and their families are displayed in Table 1. Participants' actual names were exchanged for pseudonyms in order to protect their privacy.

Table 1. Participant Demographic Data

	David	John	Isaiah	Lincoln	Dr. Edward
Age of father	36	47	30	47	81
Age of Child	6	21	6	10	48
Gender of Child	Male	Female	Male	Male	Female
Child's Age at Diagnosis	2	5	Birth	3	5
Child's Diagnosis	Seizure Disorder Autism Mitochondrial Disorder	Type I Diabetes	Seizure Disorder Mild Mental Retardation	Rare Organ Disorder	Diabetes Epilepsy
Number of Children at Home	2	3	1	2	0
Marital Status	Married	Married	Separated	Married	Married
Occupation	Military Officer	Safety & Training Supervisor	Technical Instructor	Physician	Retired College Administrator
Education	College Degree Plus	High School Graduate – Some College	College Graduate	Doctoral Degree Plus	Doctoral Degree Plus
Household Income	Between $70,000 - $90,000	Between $70,000 - $90,000	Between $50,000- $70,000	Greater than $90,000	Greater than $90,000
Participant Reported Race or Ethnicity	African American	Afro- American	African American	African American of Hispanic Origin	Black before that Negro before that Colored

<center>Data Collection and Analysis</center>

Participants chose to hold interviews at sites that accommodated their needs and were located conveniently. Two interviews were held in participants' homes. Three interviews were conducted at a neutral office location. One of those three interviews required additional time. The second part of that interview was completed at the participant's place of business.

The interview began with a description of the research project, an opportunity for questions about the project, and the completion of a consent form (Appendix C) and a family information sheet (see Appendix D). Next, an interview (Appendix E) was conducted. Because of the sensitive nature of information disclosed, each participant was informed that if at anytime he was uncomfortable with talking about a topic, he was free to choose not to respond and encouraged not to discuss any topics that made him anxious or topics he would prefer to remain private. According to Daly (1992), unanticipated disclosures may result from the inherent power imbalance between researcher and participants. As a result, it is important that qualitative researchers clarify research and therapy boundaries.

Once preliminary procedures were completed, the semi-structured open-ended interview explored how fathers experienced parental involvement and participation in the care of their chronically ill children. During the interviews, I posed questions that narrowed and focused the research question in accordance with discoveries regarding relevant or irrelevant fathering processes (Strauss & Corbin, 1990, p.38). The interviews lasted 150 minutes to 180 minutes. Each interview was audio taped. Prior to data analysis, I solicited a transcriptionist to transcribe one forth of the audio taped data (Appendix F). I transcribed the remaining data verbatim using a word processing system. In addition I reviewed the transcriptionist's hard copies with the corresponding taped interviews. Where necessary, I made corrections to the tapes and transcripts. Interview data resulted in more than 200 pages of transcribed data. Next, I downloaded text into QSR Nudist Vivo: a qualitative software package for analysis.

The data analysis began as soon as the collection of data began (Rafuls & Moon, 1996). I treated background sheets, as well as personal accounts as data. I used the constant comparative method of data analysis that is accomplished by categorizing, sorting and resorting, and coding and recording data. Open and axial coding of the transcripts was used to reveal patterns and themes that described the data. I began to code as I read transcripts and made notes, diagrams and lists of questions regarding themes, categories and emerging patterns. All interviews were

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electronically coded using broad, descriptive categories. After I coded the first two interviews, my advisor reviewed the list of categories, diagrams and the coded data. We collaborated throughout the process of analysis to discover and describe relationships within and across all interviews. I continued to code interviews based on our conversations and discoveries that occurred as I explored the data. Twenty-five percent of data was cross-coded by my advisor to assure balance and rigor to the data analysis and emerging concepts.

Once all five interviews were coded into broad categories, I reviewed the results and worked to narrow and focus findings further. I coded data further, this time by hand. As I coded, I revised diagrams, made notes of similarities and differences that emerged from the data. Through the process of analysis, data emerged which demonstrated relational and variation on themes and provided insight and understanding regarding fathering and how African American men experience parental involvement and participation in the care of their chronically ill children. Once the results were compiled, I forwarded draft copies to 4 participants for their review and invited fathers to respond with any concerns about the presentation of their experiences. I was unable to reestablish contact with one father due to changes in his contact information; therefore, he did not have the opportunity to review the results. Another participant had visual limitations that restricted his ability to review the results. None of the fathers responded back with concerns or comments.