ADJUSTMENT AND COPING OF AFRICAN AMERICAN PARENTS OF CHILDREN
WITH SEVERE CEREBRAL PALSY

By

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ABSTRACT

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The aim of this dissertation is to understand the lived experiences of fifteen African American parents of children ages five to eighteen with severe cerebral palsy. Although very few in number, current and historical research studies that have focused on racial differences in the prevalence of cerebral palsy have consistently shown that African Americans have a higher prevalence ratio and that the prevalence of severe cerebral palsy was 70% higher in Black children than white children. Unfortunately however, there remains a considerable gap in the literature relative to African American parents of children with severe cerebral palsy. This dissertation explores adjustment and coping of these families, how they are impacted by caring for a child with severe cerebral palsy, and the support systems they utilize.

The main objectives of this exploratory study were to elicit the attitudes, opinions, and experiences of the participants through in-depth interviewing. Interview questions and demographic surveys were developed and explored three key domains – health, cultural and religious values, and support systems. The study was designed and conducted from a phenomenological perspective. A thematic coding method based on grounded theory was chosen to analyze the qualitative data. Two surveys were used to compile demographic profiles of the parent participants and their children with severe cerebral palsy.

Significant themes that emerged from the data were self-reliance, caregiver strengths, caregiver burden, and mistrust. Results from the findings indicated that parents rarely sought support from others for assistance, despite feeling overwhelmed and limited. A second

significant finding was that although the vast majority of the sample identified Christianity as a religious affiliation, they seldom attended their place of worship and received little to no support from their faith community. However, parents also reported the significance of their religious beliefs in coping with their child's severe cerebral palsy and giving meaning and purpose to their lives. Findings also indicated that racial discrimination and cultural incompetence and insensitivity contributed to mistrust of professional service providers and the underutilization of formal support services. Even though these parents encounter numerous challenges and complex life circumstances, they have developed positive adjustment and coping skills. Parents view their child as a "gift" and their role as their child's primary caregiver as "rewarding". Knowledge gained from these fifteen study participants about their lived experiences and reflections of their role as caregivers not only contributes to the literature, but has implications for social work practice, future research, and the religious community.

DEDICATION

To my beloved daughter, Alexy,
thank you for blessing me with your beautiful smile, gentle-spirit, and unconditional love.
You are my inspiration.

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I can't begin to express my gratitude enough to all the people who were instrumental in helping me to complete this dissertation. I have been fortunate to share this academic journey with so many talented, generous, and genuinely caring people. This dissertation would not have been completed without the love and prayers of my family and friends, the guidance and support of the MSU School of Social Work administrators, faculty and staff, and community members who believed in the value of my work.

I want to first thank God for his mercy and goodness. I am so blessed to know your love and to receive your grace. I know through you all things are possible and I am so honored to give witness to your never-ending love.

I especially want to thank my husband, hero, and best friend, Ellington. You have always supported my ambitions, and without hesitation. You sacrificed so much in order for me to pursue my doctoral studies. You encouraged me in so many ways, especially when you would say, "don't worry; you got this" or "you and me". Thanks for always being there for me, for being my greatest supporter. It is because of you I live my dream. I love you. You are my rock.

To my children Alexy and AJ, thank you so much for your understanding and patience. Alexy, your hugs and kisses always brighten my day. AJ, I can't thank you enough for "hanging out" with me at the library and for all the joy you bring to my life. I love you both dearly and am truly blessed to be your mother.

To my mama Deloise, I thank you for giving me a strong foundation in life. You taught me the value of hard work and modeled self-determination. You helped me to see

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CHAPTER 1

INTRODUCTION

Cerebral palsy is the most common motor disability in childhood, affecting approximately 1 in 303 8-year-old children in the United States (Yeargin-Allsopp et al, 2008). It is a non-progressive neurological disorder that is caused by damage to one or more specific areas of the brain. The prevalence of cerebral palsy is found to be highest in Black, non-Hispanic children at 4.2 cases per 1,000, compared with 3.3 cases per 1,000 among white, non-Hispanic children (Yeargin-Allsopp et al, 2008). The prevalence of severe cerebral palsy is approximately 70% higher in Black children than white children (Maenner et al, 2012). Unfortunately however, there remains a considerable gap in the literature relative to African American parents of children with severe cerebral palsy. This dissertation explores adjustment and coping of these families, how they are impacted by caring for a child with severe cerebral palsy, and the support systems they utilize. It is hoped that knowledge gained from this study will assist professionals in their efforts to better identify and understand cultural differences and how those differences impact quality of care and level of service for African American children with severe cerebral palsy and their families.

Format of the Dissertation

This dissertation is organized into five chapters. Chapter one is the contextualizing section that explains the research problem and questions arising from the problem. It states the purpose and significance of the study and presents the conceptual framework applied to the study. This section also provides definitions of the significant terms and concepts used in the study.

Chapter two is a literature review outline of topic areas relative to the historical background of cerebral palsy, its classification levels, and African American children with cerebral palsy. Attitudes toward cerebral palsy, impact of cerebral palsy, and adjustment and coping are also discussed. Extended family and religion among African Americans concludes this literature review outline. This chapter is an interwoven discussion of the results of historical and current studies that focus on children with cerebral palsy, families of children with disabilities, research methods for disability studies, and African American culture. This chapter will provide an understanding of the history, philosophies, and practices of addressing the needs of children with cerebral palsy.

The methodology of the study is discussed in chapter three. This will entail a description of the research questions, theoretical framework, and targeted sample population. The measurement tools used for data collection are presented and discussed. A detailed description is given of the procedure for collecting and analyzing data. The researcher also reflects on trustworthiness and the role of the researcher.

Chapter four reports the results of the study. The demographic profile of the sample and summaries of the qualitative analyses are presented. Additionally, observations by the researcher taken from field notes are also discussed.

Chapter five is the discussions section which concludes and summarizes the study. The implications for social work practice, future research, and religious communities are addressed. The limitations of the study are acknowledged, in addition to the researcher's reflections about the study. This final section of the dissertation reiterates the study findings with emphasis on the expressed experiences of the families and relates those experiences to the understanding of how

this sample of African American parents adjust to and cope with caring for a child with severe cerebral palsy.

Statement of the Problem

Culture has implications for how families define and experience disability, how families experience their interactions with the formal service system, and how parental child rearing values develop (Balcazar, Suarez-Balcazar, & Taylor-Ritzler, 2009; Rogers-Dulan & Blacher, 1995). While there is significant research on the impact of caring for a child with a disability, major gaps exist in the literature specific to African American parents of children with cerebral palsy (Britner et al., 2003; Copeland, 2005; Huang & Coker, 2010; Patterson & Blum, 1993). Using four databases (ERIC, JSTOR, MEDLINE, and ProQuest), this researcher conducted a review of health-related journals published between 2000 and 2009. The following key words were used for the search: African American, Black, children, cerebral palsy, families, and parents. The search revealed no articles relating directly to African American parents of children with cerebral palsy. Many scholars have argued that it is imperative that future disability research differentiate the experience of African Americans caring for a child with a severe disability from that of white families (Atkin, 1991; Harry, 2002; Huang & Coker, 2010). This argument is also supported among disability scholars who understand disability as a social construct, variably defined across cultures (Ferguson, 2001; Olkin, 1999).

The absence of the experience, perceptions, and opinions of African Americans in disability research can be attributed to cultural distrust, lack of information and understanding of the research study, and insufficient recruitment efforts by researchers (Beresford, Sloper, Baldwin, & Newman, 1996; Breland-Noble, Bell, & Nicolas, 2006; Green, Bischoff, Coleman,

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Sperry, & Robinson-Zanartu, 2007; Mason, 2005; Woodcock & Tregasjus, 2008). Harry (2002) explains barriers to cultural studies as follow:

> Blindness to culture has been hard to change because the disability advocacy movement was framed as a lobby on behalf of a new minority group, people with disabilities. The defining feature of this group was disability, not racial or cultural identity (p. 133).

Suggested strategies for preventing inadequate study of ethnic-racial minority groups include partnering with community organizations serving minorities with disabilities; and involvement of ethnic minority investigators on the research team, Institutional Review Boards, research funding agencies, and journal editorial boards (Gil & Bob, 1999; Huang & Coker, 2010; Mason, 2005; Papadopoulus & Lees, 2002).

Since disability research has characteristically underrepresented African Americans, there is little research addressing culturally appropriate treatment and services for African American children with severe cerebral palsy and their families. As African Americans are at a greater risk for cerebral palsy and severity of the condition, professionals must develop an understanding of African Americans' values, norms, and way of life that influence how they adjust to and cope with caring for a child with severe cerebral palsy**.** Without a basic understanding of how cerebral palsy and its severity impacts African American parents, professionals are less able to accurately discern what is needed in order to provide best practices and most effective interventions for the child and their family.

Purpose of the Study

Based on the assumption that cultural beliefs and values influence African American parents in how they care for a child with a severe disability, greater knowledge of these families

would allow for the improvement of existing services and the development of new strategies to sustain caregivers in their vital roles. The primary purpose of this study is to contribute to knowledge about African American parents of children with severe cerebral palsy. The rationale for this study is threefold. First, there is essentially no information in the literature regarding African American parents of children with severe cerebral palsy. Second, it is not clear to what extent cultural values and beliefs impact on the provision of care and perceptions of the child with severe cerebral palsy. And lastly, it is not clear what formal and informal supports are desired or used by African American parents caring for children with severe cerebral palsy.

This information will assist professionals in their efforts to better identify and understand cultural differences and how those differences impact quality of care and level of service. But most importantly, this information is crucial as children with severe cerebral palsy are living longer and being cared for in their home environment. The additional challenges inherent in caring for these children will gravely impact their quality of life and ability to reach their maximum potential. Therefore, this information may also be useful for African American parents. The developed research questions and design of the study will generate knowledge that may improve quality of life for African American children with severe cerebral palsy and their caregivers.

This study inquires about concepts and use terms that may have multiple meanings or interpretations. In order to give clarity and discuss the study with consistency, definitions of terms that will apply for this study are necessary.

Definition of Terms

For the purpose of this study the following definitions will apply:

1. Adaptation – a dynamic and ongoing process in which the family's ability to modify its rules, roles, and structure in response to changes, pressures, stressful situations, to negotiate differences and make decisions during times of crisis (Turnball, Summers, & Brotherson, 1986).

2. African American family - used interchangeably with Black family, is an intimate association of persons of African descent who are related to one another by a variety of means, including blood, marriage, formal adoption, informal adoption, or by appropriation; sustained by a history of common residence in America; and deeply embedded in a network of social structures both internal and external to itself (Billingsley, 1992).

3. Coping ability – efforts, both action-oriented and intrapsychic to manage environmental and internal demands and conflicts among them, which tax or exceed a person's resources (Shapiro, 1983).

4. Culture – totality of thought and practice by which a people creates itself, celebrates, sustains, and develops itself, and introduces itself to history and humanity (McAdoo, 2007).

5. Cultural competence – understanding the importance of social and cultural influences on health beliefs and behaviors; and devising interventions that take these issues into account to assure quality health care delivery (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003).

6. Cultural sensitivity – sensitive to the ways in which other members' values and perceptions differ from one's own (Rosenjack Burcham, 2002)

7. Extended Family - consists of a multigenerational interdependent kinship system held together basically by a sense of obligation to the welfare of members of the kin network (Martin & Martin, 1985).

8. Fictive kinship - is the caregiving and mutual-aid relationship among nonrelated Blacks that exists because of their common ancestry, history, and social plight (Martin & Martin, 1985).

9. Formal Support – refers to services provided by agencies and professionals; and includes emotional, technical, and service support (Agosta & Melda, 1995).

10. Informal Support – refers to the assistance people receive because of their relationships with their primary groups such as one's immediate family, friends, neighbors, fellow churchgoers or clergy, and coworkers (Agosta & Melda, 1995).

11. Parent – biological or legal primary caregiver of minor child with severe cerebral palsy.

12. Religion/religious connectedness – provide shared rituals, narratives, symbols and guidance through scriptures, prayer and modes of social support.

13. Severe Cerebral Palsy – neurological disorder affecting body movement and muscle coordination to the extent children are totally dependent (Lagunju & Adedokun, 2008).

14. Stress – occurs when an individual perceives a discrepancy between the demands of a situation and their ability to cope with those demands (Kelso, French, & Fernandez, 2005).

Conceptual Framework

Only a few researchers have foregrounded culture as they explored families and the assets they bring in caring for their child with a disability (Kozleski et al, 2008). Two of the more noteworthy scholars are Rogers-Dulan and Blacher (1995). Their model, *African American Families, Religion, and Disability,* acknowledges the interactive influences of culture, religion, and family structure. This model was used as the conceptual framework for this dissertation study because it allowed the researcher to focus on parents' perceptions of the meaning they ascribe to their experience of parenting a child with severe cerebral palsy.

After recognizing the lack of empirical evidence on the impact of a child with disabilities on African American families and the influence that religion and ethnicity exert on families who have a child with disabilities, Rogers-Dulan and Blacher (1995) developed the model. In proposing a conceptual framework for understanding the coping strategies of African American families, they referred to an African American cultural style which is composed of three key factors: religious connectedness, culture/ethnicity, and family structure and functions. They argued that these factors influence the interpretations, coping resources, and adjustment of African American families with children with disabilities. The model shown in Figure 1 illustrates two spheres of influence on family adjustment.

The social context (culture/ethnicity, religious connectedness, and family structure) as part of the outer sphere influences the link among the elements in the inner sphere (interpretation, coping resources, and adjustment). The elements of the model were based on the assumption that "the presence of a child with disabilities will not change the fundamental values held by individuals" (p. 230). They also note ways in which religious connectedness may

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enhance social, material and psychological resources; social and material assistance may be

provided by the church and its members.

Figure 1

Religion, Ethnicity, and Disability: African American Families Framework

CULTURE
ETHNICITY
* Values
* Behavior

Interpretation
* Opportunity to give
* Growth & development
* Another challenge
* Punishment
* Threat/burden/loss

Coping Resources
* Social
* Psychological
* Utilitarian
* Health

Adjustment
Outcomes related to the
social/adaptation processes
(e.g. placement tendency, stress)

RELIGIOUS
CONNECTEDNESS
* Personal & family life
* Socialization
* Non group modes
* Institutional activities
* Support

FAMILY STRUCTURE
Nuclear/Extended
FUNCTIONS
* Family relations
* Individual identity
* Childcare/training
* Economic
* Home/household
* Social

Scholars have repeatedly expressed that cultural beliefs can affect the manner in which

families adapt to each other and to a family member with a disability and can influence the

utilization of trust in caregivers and caregiving institutions (Abbott & Merredith, 1986; Atkin,

1991; Belgrave, 1998; Beresford, Sloper, Baldwin, & Newman, 1996; Copeland, 2005; Gupta &

Singhal, 2004; Harry, 2002; Hill, 2003; McAdoo, 2007). Culture also influences how families

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seek help and support. Adams (2008) tested the Rogers-Dulan and Blacher model in her

dissertation research that focused on the factors that influence African American mothers'

decision to keep home or place their profoundly disabled child. She found that when kinship

bonds are increased, the likelihood of placement was decreased. She also reported that although

the central value of religion may apply to African American mothers, those beliefs have no

relationship to the decision one makes whether to homecare or place the child who is profoundly

disabled.

The Rogers-Dulan and Blacher's (1995) model is an appropriate and well-suited

framework for examining and understanding adjustment and coping of African American parents

of children with severe cerebral palsy. With this model as the framework for this study, the

following pre-conceptual map was designed to demonstrate the influence of culture, religion,

health, and social support on outcomes of African American parents of children with severe

cerebral palsy.

Table 1: Pre-conceptual Map

THEME	RESEARCH QUESTION	INTERVIEW QUESTION	ASSUMPTIONS
Cultural Beliefs and Challenges	What kind of positive and negative statements do African American parents make about caring for a child with severe cerebral palsy?	What are some of the challenges you experience that you think are unique to African American parents caring for a child with a severe disability?	Cultural beliefs that disability is a sin (punishment from God) and a burden.
		What are some of your most rewarding/memorable experiences?	Child overcomes barriers/limitations and exceeds expectations.
		Have you or your child ever been treated differently because of your race? If so, please explain.	Culturally insensitive care from professionals.
		Do you believe the individuals providing professional services to you and your child are culturally competent?	Professionals do not value cultural beliefs or integrate into treatment plans.

Table 1 (cont'd)

		How were you told of your child's diagnosis and what was that experience like for you?	Physician direct and overwhelming.
Health	What types of health problems do African American parents experience as a result of caring for a child with severe cerebral palsy?	Can you describe a typical day of care for your child?	Disruption in family routine/norms Overwhelming care – physically demanding
		Has your health declined since you began caring for your child? If so, please explain.	More frequent headaches, backaches, high levels of stress, and depression.
		Do you have any medical problems that interfere with your ability to care for your child?	Chronic muscle and back problems make it difficult to lift and carry child.
Social Support	What types of informal and formal community resources are utilized by African American parents of a child with severe cerebral palsy?	Do you have a religious affiliation? If so, how would you rate their level of support to you and your child?	Religious connectedness and dependency.
		Describe your support circle. Who do you identify as most supportive? And why?	Nuclear and extended family most supportive.
		Are there community resources you would like to utilize but have not been able to? If so, please explain.	No or limited access to recreational facilities, neighborhood parks, and other leisure activities.

Through the application of this conceptual framework, different aspects of culture including family's religious beliefs and attitudes toward disability were examined. Furthermore, use of this model allowed for an in-depth exploration of the experiences of these parents and how they are impacted by their child's disability.

Significance of the Study

Researchers have undoubtedly overlooked the influence of culture on caring for a child with cerebral palsy (Britner et al., 2003; Copeland, 2005; Huang & Coker, 2010; Patterson & Blum, 1993); therefore this study has merit. This study is significant for a host of reasons. It has

the potential to close gaps in the literature by presenting the perceptions and experiences of African American parents of children with severe cerebral palsy, which is critical as African Americans are at a greater risk for cerebral palsy and the severity of the condition.

This study contributes to the field of social work in that it may help social workers improve service delivery and develop therapeutic interventions which can ultimately contribute to quality of life for African American children with severe cerebral palsy and their caregivers. Social workers are actively supporting advocacy, education, policy, and research specific to childhood disabilities (i.e. cerebral palsy, autism). Therefore, they must gain an extensive understanding of the unique characteristics and strengths of African American parents of children with severe disabilities in order to develop comprehensive treatment plans and delivery of service that reflects cultural competence and sensitivity.

An additional value of this research is that African American parents may feel valued in sharing their experiences; and viewed as experts on caring for their child with severe cerebral palsy. As noted by de Geeter, Poppes, and Vlaskamp (2002), "Parents of children with disabilities are increasingly considered as experts in the field of care. Their expertise can deliver an important contribution towards planning their child's care and education" (p. 443). The National Association for the Education of African American Children with Learning Disabilities (NAEAACLD) is one of a few nationally recognized organizations focusing on African American children with disabilities. Founded in 2000 by a mother and her two sons, NAEAACLD's mission is to link information and resources provided by an established network of individuals and organizations experienced in minority research and special education with parents, educators, social service agencies, psychologists, hospitals, churches, lawyers, and other organizations ("About NAEAACLD", 2008). This study has the potential to be a resource for

NAEAACLD and other related organizations such as The National Black Disability Coalition (NDBC).

NBDC is a response to the need for Blacks with disabilities in America to organize around issues of mutual concern and use their collective strength to address disability issues with an emphasis on people who live in poverty. They seek to achieve collective power and inclusion for Black people with disabilities within families, faith organizations and the greater disability community.

CHAPTER 2

LITERATURE REVIEW

Literature and research studies were explored from peer-reviewed journal articles, books, and doctoral dissertations that focused on cerebral palsy, its impact, parent adjustment and coping, and the influence of extended family and religion. The pathology, etiology, and epistemological aspects of cerebral palsy give an overview of the condition. The impact of cerebral palsy on caregiver health, financial stability, and family dynamics are discussed, along with the factors that contribute to adjustment and coping. The influence of extended family and religion in the African American community is also part of this chapter's discussion on the history, philosophies, and practices addressing the needs of children with cerebral palsy.

Cerebral Palsy Overview

The United Cerebral Palsy Research and Educational Foundation estimates that nearly 8,000 infants, and 1,200 to 1,500 pre-school age children are diagnosed with cerebral palsy every year in the United States (Krigger, 2006; Rodriques & Patterson, 2007). According to the federal government's Centers for Disease Control and Prevention (CDC), each year about 10,000 babies born in the United States will develop cerebral palsy (National Institute of Neurological Disorders and Stroke, 2006). The CDC has estimated that the lifetime cost to care for an individual with cerebral palsy is nearly one million dollars.

Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development before, during, or shortly after birth; or during infancy. Cerebral palsy is a non-progressive neurological disorder and although it is not curable, early intervention in the form of training and therapy can help to improve function. The main

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characteristic of cerebral palsy is the failure of communication between the body and the brain. Children with cerebral palsy are more likely to have associated conditions including mental retardation (52%), ophthalmologic defects (28%), hearing impairment (12%), speech and language disorders (38%), and additional oral-motor deficits (Ashwal et al., 2004).

Dr. William John Little (1861), an English orthopedic surgeon wrote the first medical description of cerebral palsy as " . . . deformities arising after birth from disorders of the nervous system -- disorders of nutrition, affecting the muscular and osseous structures, -- disorders from malposition and violence" (p. 243). After Little distinguished cerebral palsy, originally called 'cerebral paresis' as a disorder, the condition was referred to as "Little's Disease" for many years. The term *'cerebral palsy'* was coined in 1888 by William Osler, a Canadian physician who became a chief physician and professor at Johns Hopkins Hospital and School of Medicine. In 1897, with a background in neuropathology, Austrian neurologist Sigmund Freud challenged Dr. Little's and Dr. Osler's assertion that cerebral palsy resulted after birth in his publication titled, *Infantile Cerebral Paralyis,* and suggested that the disorder may have been caused during the brain's development in the womb (Kavčič & Vodušek, 2005). In 1947 the American Academy for Cerebral Palsy was established as a professional organization devoted to inter-disciplinary physician education. With a focus on the symptoms and cause of cerebral palsy, they redefined the disorder as any abnormal alteration of movement or motor function arising from defect, injury, or disease of the nervous tissues contained in the cranial cavity (Kirk, Gallagher, & Anastasiow, 2003).

Research continues to conclude that in most cases, it is unclear what actually caused the injury to the brain or what could have been done to prevent it. However, in general, there are two problems that can cause cerebral palsy, developmental brain malformation or neurological

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damage to the child's developing brain. Developmental brain malformation may occur when the

fetus' brain fails to develop the usual number of brain cells, communication between brain cells

is impaired, or brain cells do not migrate to the areas they are supposed to (Geralis, 1998).

Failure of the brain to develop properly may be linked to genetic disorders, chromosome

abnormalities with genetic material, or faulty blood supply to the brain (Stanley, Blair, &

Alberman, 2000). Neurological damage to the brain may be the result of an injury before,

during, or after birth. Types of problems that can lead to brain injuries include encephalitis or

meningitis, metabolic disorders, head trauma, toxic injuries, bleeding in the brain, or lack of

oxygen to the brain (Nissenkorn, Michelson, Ben-Zeev, & Lerman-Sagie, 2001).

Classification of Cerebral Palsy

Minear (1956) introduced a classification of cerebral palsy that described the areas of the

body impacted and the extent of severity. Cerebral palsy may be classified as monoplegia,

affecting only one limb; diplegia, affecting a child's legs; hemiplegia, one side of the child's

body is affected; and quadriplegia, the most severe form of cerebral palsy that affects the whole

body. This model of classifying cerebral palsy is still widely used today (Hutton, Colver,

Mackie, & Rosenbloom, 2000; Lagunju & Adedokun, 2008; World Health Organization, 2001).

Also used commonly throughout the world today is the Gross Motor Function

Classification System (GMFCS). It is a five level classification system that describes the motor

involvement of children with cerebral palsy on the basis of their functional abilities and their

need for assistive technology and wheeled mobility. GMFCS was developed in 1997 at the

CanChild Centre for Childhood Disability Research of the McMaster University in response to

the need to have a standardized system for classifying the severity of movement among children

with cerebral palsy (Palisano et al, 1997). Distinctions between the five levels are based on

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functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement (Rosenbaum et al, 2007). Children at Level 1 are performing movement transitions without limitations. Level 3 denote a need for assistive mobility devices. Children at Level 5 have no means of independent mobility.

The most compelling distinction between the two classification systems is that GMFCS measures functional status, what the child is able to do. In contrast, Minear's system focuses on limitations, examining how the child is not able to perform. But there are certainly many commonalities between the two as well. Children with quadriplegia cerebral palsy or classified at Level 5 of the GMFCS are described as completely dependent, characteristically non-verbal, non-ambulatory, incontinent, and unable to eat orally (Lagunju & Adedokun, 2008). Sadly, the prevalence of quadriplegia or Level 5 classification is higher in Black children (Maenner et al, 2012). Research has shown that neither race nor ethnicity is the root cause for the disparity. But found that social determinants may contribute to the higher prevalence of severe cerebral palsy among African American children.

African American Children with Cerebral Palsy

Severe cerebral palsy is more common in poorer, more rural, and less educated populations (Britner, Morog, Pianta, & Marvin, 2003). The significance of these findings is even greater when related to the African American population. The United States Bureau of the Census (2008) reported that of all children under the age of eighteen living in poverty in 2008, African American children were the largest subgroup by race at 33.9%. Regarding family structure, the Children's Defense Fund (2012) reported that 51% of Black children live with only their mother and the median income for a Black female-headed household with one or more

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children was $21,082. When discussing overall health outcomes, they also reported that African American children are more likely than white children to be uninsured, to have no regular source of health care, unmet medical needs, delayed medical care, had no dental visits in two or more years, and are more than five times as likely to have to rely on hospital emergency rooms for non-emergency medical care.

Although very few in number, current and historical research studies that have focused on racial differences in the prevalence of cerebral palsy have consistently shown that African Americans have a higher prevalence ratio (Bhasin, Brocksen, Avchen, & Braun, 2006; Haerer, Anderson, & Schoenberg, 1984; Murphy, Boyle, Schendel, Decoufle & Yeargin-Allsopp, 1998). Yeargin-Allsopp et al. (2008) conducted a comprehensive study of cerebral palsy among 8-year-old children living in northern Alabama, metropolitan Atlanta, and southeastern Wisconsin. They found the prevalence of cerebral palsy to be highest in Black, non-Hispanic children at 4.2 cases per 1,000, compared with 3.3 cases per 1,000 among white, non-Hispanic children. Their findings also noted that children born to families of lower and middle socio-economic status had a higher prevalence of cerebral palsy than did children born to families of higher socio-economic status.

The Maenner et al (2012) study which sought to determine whether the greater prevalence of cerebral palsy among United States non-Hispanic Black children persists across all levels of functional limitations, resulted in similar findings. They examined data of 476 eight-year-olds with cerebral palsy previously identified through the Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring Network. Their results revealed that prevalence of mild cerebral palsy was similar for Black and white children, whereas the prevalence of severe cerebral palsy was 70% higher in Black children than white children. And

although it was not the scope of their study to determine causal relationships between perinatal factors and motor outcomes; they found no evidence that the increased severity of motor limitations among Black children was associated with selected maternal or birth characteristics. However, they did suggest that, "Other factors, such as disparities in access to care, maternal age, substance abuse, or other pathologic processes, may contribute to the associations of preterm delivery or low birth weight with cerebral palsy" (p. 39).

LaVeist (1996) argues that race or ethnicity is not the root cause for the higher incidence of disability among African Americans, but rather is "fundamentally a measure of exposure to health risks" (p. 24). Low birth weight (babies who weigh less than 5.8 pounds) is one of several factors of pregnancy or birth associated with an increased risk for cerebral palsy (Cummins, Nelson, Grether, & Velie, 1993; Stevenson et al, 2006; Winter, Autry, Boyle, & Yeargin-Allsopp, 2002). In 2008, 13.7 percent of African American infants were low birth weight, compared with 8.2 percent of Asian and Pacific Islanders, 7.4 percent of American Indians and Alaska Natives, 7.2 percent of non-Hispanic whites, and 7.0 percent of Hispanic infants (Martin, Hamilton, Sutton, & Ventura, 2010).

Wu et al. (2011) conducted a study to determine if birth weight accounts for ethnic disparities in the prevalence of cerebral palsy and whether socioeconomic factors impact cerebral palsy within racial and ethnic groups. They compared maternal and infant characteristics among 8,397 infants with cerebral palsy who qualified for services from the California Department of Health Services. Their findings were consistent with previous research and revealed that Black infants were 29% more likely to have cerebral palsy than white infants. It was also noted that women of all ethnicities who did not receive any prenatal care were twice as likely to have infants with cerebral palsy relative to women with early onset of prenatal care.

Several studies have stressed the importance of prenatal care to reduce the risk of low

birth weight and subsequently, cerebral palsy. However, Collins, David, Handler, Wall and

Andes' (2004) study explain the racial disparity in low birth weight as, "the reported lifelong

accumulated experiences of interpersonal racial discrimination by African American women" (p.

2137). The negative effects of racial discrimination can certainly contribute to racial differences

in disease. Copeland (2005) also links poverty, substandard housing and neighborhood

conditions, and insufficient availability of and access to quality health care to poor health

outcomes among African Americans. Health disparities among racial groups are also apparent

within the disabled population. African Americans with disabilities typically receive fewer

comprehensive services, lack of affordable health services, limited availability of bilingual health

providers, limited knowledge about resources, and communication and cultural barriers to

obtaining meaningful information and support from local agencies (Balcazar, Suarez-Balcazar,

Taylor-Ritzler, 2009; Brach & Fraser, 2000; Lillie-Blanton & Hudman, 2001; National Council

on Disability, 2003).

Attitudes Toward Cerebral Palsy

The opinion shared by many developed societies that children with disabilities were

either a burden or curse on society prevailed for centuries. Religion played a significant role in

influencing those worldwide views. Clapton and Fitzgerald (1997) explain that the roots of

understanding bodily difference have been grounded in biblical references and persons with

disabilities were seen as the result of evil spirits, the devil, witchcraft or God's displeasure.

Based on this belief, individuals with disabilities were viewed as sinful, impure, undesirable, and

unfitting. Historically, the response of many societies to infants and children with disabilities

was annihilation and isolation.

Ancient Greeks euthanized obviously disabled newborn infants by exposure, placing them in clay pots and leaving by the roadside to die (Warner, 2006). Greek law dictated that a newborn baby was not really a child until seven days after birth, allowing for the disposal of an imperfect child. In Sparta, any infant or toddler considered unfit for citizenship or warrior status was either drowned or abandoned in the wilderness of the Taygetus Mountains (p. 17). In Europe, Roman Emperor Loonicatus Marcus Commodus, son of Marcus Aurelius is said to have targeted bow and arrows on physically disabled children and in the 15th century, the Church sanctioned the extermination of disabled persons (Durant, 1944). Martin Luther, who initiated the Protestant Reformation in the 1500's, endorsed the killings of disabled babies because they were "incarnations of the devil" (Coleridge, 1993).

Although with greater restraint, these negative attitudes and deplorable practices were exercised even in the twentieth century. In 1907 the United States adopted the Eugenics Movement, which legally permitted the forcible sterilization, and in some cases, euthanasia of children with disabilities (Laughlin, 1922). Children with disabilities were also systematically removed from their families and placed in institutional settings for care (Williams, 1969); a practice which continued well into the mid-1970's.

A current study examined factors influencing young adults' perceptions of children with cerebral palsy. Using vignettes describing pre-school aged children with cerebral palsy and a healthy child, 180 college students reported their attitudes toward these children on the Ratings of the Child Questionnaire. Results revealed that young adults held less positive perceptions of children with cerebral palsy compared with a healthy child; women endorsed more positive perceptions for all children than men; and knowledge about cerebral palsy and wanting to work with children were related to positive perceptions of children with cerebral palsy (Nabors &

Lehmkuhl, 2005). Westbrook, Legge, and Pennay's (1993) study of the attitudes of people toward 20 disability groups found that people with AIDS, mental retardation, psychiatric illness and cerebral palsy were the least accepted of the disability groups.

Several research studies have also revealed that attitudes toward cerebral palsy appear to differ between ethnic groups (Harry, 2008; Mir & Tovey, 2003; Patterson & Blum, 1993). McCallion, Janicki and Grant-Griffin (1997) conducted a series of focus group meetings with African American, Chinese American, Haitian American, Latino American, Korean American and Native American communities to discuss the cultural issues in caring for persons with a developmental disability. They reported that some families did not seek and would not accept help from their community. Instead they tried to hide the person with a disability because of the shame they felt. And although there was variation within each culture, Native Americans and African Americans were less likely to hide the person with a disability.

Impact of Cerebral Palsy

Caring for a child with severe cerebral palsy can impose rigorous stress on parents, which can impact parents' mental and physical health. LeClere and Kowaleski (1994) proclaim "childhood illness and disability is, perhaps, the most disruptive of family-related health events because it is unusual and falls outside of the normative life course of most families" (p. 458). Raina et al (2005) support this claim by stating, "Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence" (p. e627). As it has been since the de-institutionalization movement of the 1960s, most children with cerebral palsy, regardless of the severity, live at home with their families. There is extensive evidence that the presence of a child with a disability in the home creates a crisis for caregivers and other family

members (Albrecht, 1995; Farber, 1959; Howe, 2006; Lavin, 2001; Reichman, Corman, & Noonan, 2008; Singer & Farkas, 1989). Trute and Hiebert-Murphy's (2002) study on the impact of a child with developmental disabilities confirmed "the importance of the marital relationship in predicting parenting stress, which, in turn, is highly correlated with overall family adjustment" (p. 278). Their findings were consistent with other studies focused on divorce rates among parents of children with disabilities (Abbott & Meredith, 1986; Risdal & Singer, 2004).

Families containing children with disabilities must cope with greater financial stress, more frequent disruptions of family routines, more marital problems, and reduced social and leisure activities outside the family in comparison to families with children without disabilities (McDaniel, Hepworth, & Doherty, 1992; Seligman & Darling, 2007; Singer & Farkas, 1989). Poor children have particularly high rates of disability, with at least some evidence that not only does poverty increase the incidence and severity of disability but also that a child's disability may impoverish the family even more (Perrin, 2002). The out-of-pocket expenses of parenting children with disabilities were two to three times higher than the expenses associated with parenting children without disabilities (Parish & Cloud, 2006). According to the Centers for Disease Control (2004), the average lifetime costs for persons with cerebral palsy were $921,000 in 2003. This is a $121,000 increase from the estimated lifetime cost of $800,000 in 2000. The Centers for Disease Control also reported that based on the value of a dollar in 2005, the medical costs for children with cerebral palsy alone were 10 times higher than for children without cerebral palsy or intellectual disability, which amounts to $16,721 versus $1,674.

Children with severe cerebral palsy are completely dependent and require round-the-clock care. Community supports commonly available to parents of typically developing children such as child care and after-school programs are not always options for parents with exceptional

care responsibilities (Rosenzweig & Brennan, 2008). This level of care can impose rigorous stress on parents, which can impact their mental and physical health.

Parents of children with cerebral palsy have more back pain, migraine headaches and stomach/intestinal ulcers, and higher overall distress compared with other parents (Brehaut et al., 2004). Caregivers and family members of children with cerebral palsy are equally at risk of depression and isolation (Krigger, 2006; Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Yau & Li-Tsang, 1999). Children with severe disabilities may never achieve developmental milestones, as a result parents may experience renewed anxiety or sadness (Fewell & Vadasy, 1986). Perryman (2005) noted, "Beyond the daily toil, parents confronted with their child's diagnosis must also face the reality of a different future than the one they had imagined for their child and themselves" (p. 597).

Breuhat et al. (2004) conducted a study on the physical and psychological health of 468 primary caregivers of children with cerebral palsy in Ontario, Canada. Findings of the study revealed that a greater proportion of the caregiver sample reported indications of emotional problems (e.g. unhappy or little interest in life) and cognitive problems (i.e. difficulty with memory or problem-solving) (p. e188). Self-completed questionnaires and face-to-face interviews measured social support, family functioning, and frequency of contacts, distress, and emotional and cognitive problems. Physical health variables measured included chronic conditions, vision, hearing, and mobility problems, and experience of pain. Results revealed that caregivers of children with disabilities are likely to have lower incomes; and report poorer psychological and more physical health problems.

Although there is significant research on the impact of caring for a child with a disability, major gaps exist in the literature specific to African American parents of children with

disabilities (Copeland, 2005; Ha, Greenberg, & Seltzer, 2011; Huang & Coker, 2010; Patterson & Blum, 1993). Britner et al. (2003) noted that most studies of children with cerebral palsy involve homogenous samples; white families of similar financial status. Peters (2007) noted that "When the research population involves both Black and white parents, the research design, typically, compares Blacks with whites and comparative statistics are used. Rarely is the research ethnomethodological and descriptive" (p. 204).

The few studies comparing emotional distress and acceptance of a disability among ethnic groups have consistently found greater resilience among ethnic minority families as compared to white families (Harry, 2002). Mary's (1990) study compared initial reactions of African American, Latino, and Anglo-American mothers to having a child with mental retardation. She interviewed 20 African American, 20 Latino, and 20 Caucasian mothers of children with disabilities age six years to explore their feelings and reactions toward a child with disabilities. Trends revealed that Latino mothers reported an attitude of self-sacrifice toward a child with disabilities and greater spousal denial of disabilities more often than African American and Caucasian mothers. African American mothers reported feeling less overwhelmed by having a child with disabilities than did Caucasian and Latino mothers. These findings were consistent with Flynt and Wood's (1989) study of 90 mothers of children with moderate mental retardation. They found that African American mothers had lower perceived family stress levels than white mothers. They also found that African American mothers had a greater tendency to use coping strategies that centered on resources and social support within the family. Findings from additional studies showed that African Americans report lower levels of caregiving burden, lower levels of grief, lower levels of depression, anger, and hostility, and higher levels of

caregiver satisfaction than whites (Hines-Martin, 1992; Hinrichsen & Ramirez, 1992; Pruchno, Hines Patrick, & Burant, 1997).

Parents' Adjustment and Coping

Seligman and Darling (1997) made an important distinction between the reaction of parents whose child was diagnosed with a developmental disability shortly after birth and those whose child was diagnosed later in infancy or childhood. They noted that parents who knew their child's diagnosis from the beginning were better able to adjust. They further noted that the family's ability to cope depended on how they define their situation, their child's disability, and their available social supports.

The birth of a child with cerebral palsy can cause major changes in family patterns that create a series of reactions, adaptations, transitions, and readjustments dictated by numerous factors such as normal developmental stages, parents' education, the severity of the disability, ongoing medical issues, and economic resources and crises (Carpenter, 1998; Garmezy, 1991; Lin, 2000; Turnbull & Turnbull, 1990). Research about families in stressful circumstances has progressed from being deficit-oriented to investigating factors that promote health, well-being, quality of life, protective features, resilience, and empowerment (Dunst, 2002; Dunst, Trivette, & Deal, 1994; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). Studies that have given attention to factors that generate positive perceptions of coping have shown that there can be positive and potentially rewarding aspects of providing care for a child with a disability (Glenn, Cunningham, Poole, Reeves, & Weindling, 2008; Kenny & McGilloway, 2007; Scorgie & Sobsey, 2000; Skinner, Bailey, Correa, & Rodriguez, 1998). Research also suggests that families believe their lives had increased meaning and enrichment as a result of their experience with their children (Gupta & Singhal, 2004; Hornby, 1992; Mullins, 1987).

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Lin (2000) examined coping and adaptation of 274 family members of individuals with cerebral palsy. Descriptive results indicated that five factors were associated with family coping: positive family appraisal, support from others, spiritual support, personal growth, and advocacy. Raina et al (2005) study found that better family functioning was associated with caregivers' perception of his or her general health and well-being, social support from family and friends, and ability to manage stress. Alston and Turner (1994) gave attention to the role of family and noted that "extended family relationships, including fictive kin, provide an important source of support for African American families" (p. 379).

Ha, Greenberg, and Seltzer (2011) conducted a study examining the extent to which positive and negative social interactions with family members other than the spouse moderate the impact of child's disability on adaptation. The researchers hypothesized that "positive interactions will enhance parents' ability to cope with the stress of having a child with a disability, while negative interactions with other family members would exacerbate the stress of having a child with a disability on parental well-being" (p. 406). They found that parents who have lower levels of positive support from family members are more likely to have negative mental health profiles, and those who have higher levels of positive family support are more likely to have positive mental health profiles. In addition to Ha et al. (2011) study, Table 2 summarizes two other studies that examined the coping of African American parents caring for children with disabilities.

Table 2: Studies on Adaptation and Coping of African American Parents of Children with
Disabilities

STUDY	PURPOSE	SAMPLE	RESULTS
Ha, Greenberg & Seltzer (2011)	To examine the extent to which the impact of parenting a child with a disability on African American parents' well-being differs depending on the level of positive and negative social interactions with family members other than spouses.	192 African American parents living in Milwaukee, WI - 48 parents of children with a disability and 144 comparison group parents of nondisabled children.	Parents who have lower levels of positive support from family members are more likely than the comparison group to have negative mental health profiles, and those who have higher levels of positive family support are more likely than comparison group parents to have positive mental health profiles.
Magana & Smith (2006)	To compare the health of older mothers who were co-residing with a child who had a developmental disability to the health of same age mothers without caregiving responsibilities.	162 Latina and Black American women who co-reside with a child who has a developmental disability and 2,754 Latina and Black American women who do not co-reside with a child with a disability.	For both groups, older adult caregivers were more likely to report having limitations from arthritis than their noncaregiving counterparts. Caregiving was associated with more depressive symptoms for Latinas, but this relationship was not found for Black American women.
Picket et al (1993)	To compare the coping mastery ability and self-esteem scores of Black and white parents of severely mentally ill offspring to determine the different effects of caregiving on these 2 groups of parents.	24 African American parents and 185 white parents of adults with serious mental illness.	African American parents had higher levels of coping mastery and self-esteem and lower levels of depression.

As is true with all racial and ethnic groups, there is a great deal of variability among

African Americans in parenting children with and without disabilities. However, research

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findings have revealed characteristics of common practices and beliefs among African American families. Decision-making and parenting roles in Black families may be shared not only by mothers and fathers but also with grandparents and relatives from the extended family network (Barbarin, 1983; Boyd-Franklin, 1989; McAdoo, 2007; Stack, 1974). As previously noted, adjustment and coping of African American parents of children with severe cerebral palsy is greatly influenced by socioeconomic status, family support, and cultural beliefs. Traditional practices within the African American family are deeply rooted in African philosophies that emphasize family unity and the vital role of extended family.

Extended Family

Nguzo Saba is a communitarian African philosophy consisting of seven principles that represent "the best of African thought and practice in constant exchange with the world" (Karenga & Karenga, 2007). The first principle Umoja, Swahili for "unity" is to strive for and maintain unity in the family, community, nation and race. This philosophy was clearly demonstrated in the cultural values and practices of traditional African societies. According to Martin and Martin (1985),

> The helping tradition among African people was stronger that no one could go
> hungry while others hoarded food, and no one could be denied shelter if others
> had space to spare. A person was brought before the public court not just for
> offenses such as thievery but for being selfish and unneighborly, and especially
> for treating productive assets as if they were his or her private property and using
> them in ways not consonant with the general welfare of the people. (p. 12)

The belief that mutual aid was necessary for survival influenced the development of the Black extended family, a kinship bond where one did not have to be a relative by blood or marriage to

receive support.   Membership of the Black extended family is often referred to as fictive kinship – everybody is treated like a relative. Hill (1998) characterizes the Black extended family as, "perhaps the most enduring cultural strength that has enhanced the functioning of Black families since their days in Africa" (p. 22). For families caring for a child with a disability, there seems to be an even greater demand for support from the Black extended family.

This researcher did not identify in the literature any previous studies that focused primarily on the role of fictive kin in caring for children with cerebral palsy. However, research has consistently recognized the role of Black extended family as an informal support system to vulnerable and fragile families (Gibson, 1982; Hill, 2003; Kivett, 1993; McAdoo, 2007; Rogers-Dulan & Blacher, 1985; Taylor, 1985). Uttal (1999) conducted an exploratory analysis on racial and ethnic differences in views on the appropriateness of using kin-based care. She interviewed 31 employed mothers (17 white, 7 African American, and 7 Mexican American) of children ranging in age from newborn to six. Her results revealed that white mothers viewed using kin for child care as an inappropriate and undesirable practice. Mexican American and African American mothers viewed it as an appropriate practice. Two of the African American participants reported that their extended families provided care for their children for long periods of time, even though they lived hundreds of mile away.

Booth-LaForce and Kelly (2004) conducted a longitudinal study of childcare for 89 children with developmental disabilities, of which six were diagnosed with cerebral palsy. They found that care by a relative was the highest quality of care for the child with a disability. They also reported that for one-third of the study participants, severity of a child's disability proved to be an important factor in making childcare decisions. The racial or ethnic backgrounds were not

noted, however, this study presents findings recognizing the value many families place on kin-based care for children with disabilities.

In whatever unique way each family develops patterns of interactions, it is clearly evident that the role of extended family members is not limited to financial support or childcare, but also includes advice and information sharing, emotional support, and social participation. Family members may attend doctor visits along with the parents for emotional support, as well as to become informed of the child's diagnosis and prognosis. They may also provide a social outlet for the parent such as family or social gatherings. Members of the extended family providing support may view it as a sense of obligation, as prescribed in the Nguzo Saba. This can be a particularly valuable support as isolation can be one of the most stressful aspects of caring for a child with a disability (Beresford, Sloper, Baldwin, & Newman, 1996; Green, 2003). The sense of family connectedness and community support is also evident in religious practices. African American parents also seek solace in their religious orientation.

African Americans and Religion

Historical and current statistics show that African Americans engage in religious activities more frequently and express higher levels of religious beliefs than any other racial group in the United States. The Pew Research Center (2009) conducted the Religious Landscape Survey on more than 35,000 people in 2007 and found that 79% of African Americans say religion is very important in their lives while 56% of all U.S. adults said the same. The survey also found that 87% of African Americans belong to one religious group or another. Hill (2003) outlines five strengths inherent in the African American family - strong kinship bonds, strong work orientation, adaptability of family roles, strong achievement orientation, and strong religious orientation. He also states that high achievement and religious orientations have been

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used as mechanisms for survival and advancement for African Americans throughout the history

of the United States.

Africans and African Americans held supernatural beliefs about the causes of disabling

conditions and that the individual and/or ancestors did something to bring on the condition

(Belgrave, 1998; Masasa, Irwin-Carruthers, & Faure, 2005). Healers known as *root doctors,*

conjure man or woman were used to treat and cure physical, mental and social conditions. For

many Blacks, illness was viewed as the work of the devil, and Conjure was associated with the

universal contest between the forces of good and evil (Chireau, 1997). This viewpoint and

others like it are linked directly to the belief that there is ultimately a spiritual explanation for

every human misfortune (Tsey, 1997). Traditional and religious beliefs have certainly been used

to explain the cause or development of a disability. However, there is also evidence that the

certainty that the individual with a disability will be 'restored to health' is also based on religious

beliefs. Groce (1993) states,

> in some African-American house-holds, particularly those that are strongly
>
> affiliated with the church, hope for even the most critically ill child is encouraged,
>
> with parents hearing from both family and friends that maybe a miracle will occur
>
> or that maybe the doctors are wrong (p. 1050).

The role of religion in the lives of families of children with disabilities has been the focus

of only a few studies (Fewell & Vadasy, 1986; Poston & Turnbull, 2004; Rutledge, Levin,

Larson, & Lyons, 1995; Tarakeshwar & Pargament, 2001). These studies have found that

religion plays a supportive role for some families, providing both practical and spiritual aid as

well as religious education and rituals that are meaningful and comforting to the family.

Literature on African American families further note that religious connectedness has influenced

African American families' adaptation to their child with disabilities (Hill, 2003; Ho, Rasheed, & Rasheed, 2004; McAdoo, 2007). Religion helps interpret the meaning of the disability, facilitates acceptance, and influences the decision to provide in-home care (Rogers-Dulan & Blacher, 1995). The model, *African American Families, Religion, and Disability*, emphasizes the importance of religion as a source of strength for African American families. The church not only serves as an effective means of stress management, "it encompasses social and economic activities, community services, and opportunities for self-expression and validation" (p. 231).

Summary of Literature Review

The literature discussed in this chapter lends insight into the nature of cerebral palsy, family stressors, and cultural values and beliefs as related to African American parents of children with severe cerebral palsy. The prevalence of cerebral palsy is highest among Black children and the prevalence of severe cerebral palsy was found to be 70% higher in Black children than white children. This remarkable disparity is not explained by maternal or birth characteristics. Instead, it is likely due to other factors such as racial discrimination, substandard housing and neighborhood conditions, and insufficient availability of and access to quality health care. Poverty greatly contributes to the higher incidence of severe cerebral palsy among African Americans. As reported in the 2008 Census report, of all children under the age of eighteen living in poverty, African American children were the largest subgroup by race.

The alarming statistics reported present a clear picture of the challenges African American parents of children with severe cerebral palsy face. Families must cope with greater financial stress, more frequent disruptions of family routines, more marital problems, and mental and physical health problems as a result of caring for a child with severe cerebral palsy. However, the literature revealed greater resilience among African American families when

compared to white families. Additionally, African American parents report lower levels of

caregiving burden, grief, depression, anger, and hostility, and higher levels of caregiver

satisfaction than white parents. African American parents have a greater tendency to use coping

strategies that centered on resources and social support within the family. They also tend to

depend on strong religious orientation for support.

African Americans engage in religious activities more frequently and express higher

levels of religious beliefs than any other racial group in the United States (Pew Research Center,

2009). Religious and cultural beliefs have been used to explain the causes and meaning of

disabilities, as well as to provide comfort and facilitate acceptance of the disability. The limited

studies that examined the role of religion in the lives of families caring for children with a

disability have found that religion provides a practical and spiritual aid to African American

families. It is a source of strength for families, an effective means of stress management.

CHAPTER 3

METHODOLOGY

Since the prevalence of cerebral palsy is higher among African American children and there is a considerable gap in the literature relative to this group, this study attempts to better understand the coping and adaptability of this phenomenon within this population. The main objectives of this exploratory study were to elicit the attitudes, opinions, and experiences of fifteen African American parents of children with severe cerebral palsy through in-depth interviewing. Influenced by Rogers-Dulan and Blacher's (1995) conceptual model, *African American Families, Religion, and Disability,* interview questions and demographic surveys explored three key domains – health, cultural and religious values, and support systems. Data from the measurement tools were analyzed using IBM SPSS 20, thematic coding, and NVivo 9. The role of the researcher also played a critical role in the design and implementation of the study. Using the guiding principles of Lincoln and Guba's (2000) trustworthiness model, the researcher consulted with colleagues and key informants, kept meticulously recorded notes, took caution in generalizing the findings, and provided a comprehensive description of all phases of the study.

Research Questions

The design of this study is guided by the following three research questions:

1. What types of health problems do African American parents experience as a result of caring for a child with severe cerebral palsy?

2. What kind of positive and negative statements do African American parents make about caring for a child with severe cerebral palsy that are influenced by cultural and religious values?

3. What types of informal and formal community resources do African American parents caring for a child with severe cerebral palsy utilize?

These research questions were influenced by the researcher's personal and professional experiences and are grounded in the literature review. The first question, *"What types of health problems do African American parents experience as a result of caring for a child with severe cerebral palsy?"* aims to understand the impact of caring for a child with severe cerebral palsy on the health of the caregiver. The question also attempts to understand what health challenges caregivers face that interfere with their ability to care for their child with severe cerebral palsy. As children with severe cerebral palsy are totally dependent on their caregivers, the natural process of their day-to-day care can be physically, emotionally, and mentally taxing. Without recognition of those demands, it would be impractical to assume a complete understanding of the adjustment and coping abilities of African American parents of children with severe cerebral palsy.

The second question, *"What kind of positive and negative statements do African American parents make about caring for a child with severe cerebral palsy that are influenced by their cultural and religious values?"* explored perceptions parents have about caring for a child with severe cerebral palsy with an emphasis on cultural and religious values. Although adaptive functioning of African American parents of children with severe cerebral palsy has not received sufficient attention, researchers have determined that culture and religion play a supportive role for many African American families (Hill, 2003; Ho, Rasheed, & Rasheed, 2004; McAdoo, 2007). Including this research question in the study permitted for an in-depth examination of the parents' reflections on their experiences not only as a parent of a child with severe cerebral palsy, but also as an African American.

The third question, *"What types of informal and formal community resources do African American parents caring for a child with severe cerebral palsy utilize?"* is intended to understand the formal and informal resources utilized by African American parents of children with severe cerebral palsy and their opinion of the effectiveness, cultural competence, and cultural sensitivity of those resources. This question also allows for the examination of the resources underutilized by African American parents and what factors influence usage or refusal of resources. This query is supported by the literature that shows a family's ability to adapt to a child's disability is influenced by the family's use of personal, family, and professional resources (Ha, Greenberg, & Seltzer, 2011; McAdoo, 2007; McCubbin & Patterson, 1983; Rogers-Dulan & Blacher, 1985).

Theoretical Framework

This study is intended to provide a better understanding of how African American parents of children with severe cerebral palsy adjust to and cope with caring for child with severe cerebral palsy, how cultural values impact on the provision of care for their child, and what resources they utilize for support. With these goals in mind, qualitative methodology was chosen for this study. O'Day and Killen (2002) describe one of the greatest strengths of qualitative methodology is its capacity to explain "what is going on" in complex situations involving interdependent individuals (p. 10). Qualitative methodology holds particular relevance in the field of minority research. Many researchers argue that it is better suited for investigating subjective meanings within a culture, understanding attitudes and beliefs, and the complexities of cultural and social traditions (Bryman, 2004; Gilgun & Abrams, 2002; Graungaard & Skov, 2006; Navalkar, 2004). Merchant and Dupuy (1996) state that "qualitative research involves

personal contacts and interpersonal relationships with participants, which is highly valued in many cultures; thus, enhancing the richness and credibility of the data" (p. 538).

Since the intent of this study is to learn about the lived experiences of African American parents of children with severe cerebral palsy, how they are impacted by caring for a child with severe cerebral palsy, and what support systems they utilize, the principles of phenomenology were followed in designing the process of this research. Understanding the essence of human experiences about a phenomenon, as described by the participants, is the objective of phenomenological research. Phenomenology, also referred to as the 'natural attitude', has its roots in philosophy. Edmund Husserl, a 19th century German philosopher was the principal founder of phenomenology. He began with the problem of how objects, actions, and events appear in the consciousness of the individual (Daly, 2007).

There are two main characteristics of phenomenology. First, it does not predict human behavior. As noted by Kvale (1996), "direct description of the experience, rather than analysis or explanation, is key to gaining access to the lived, everyday life" (p. 166). Secondly, it is person-centered and consists mainly of in-depth conversations. When using phenomenology the particular phenomenon of interest is accessed through establishing a dialogue with the study participants (Kerr & McIntosh, 1999). This dialogue occurs through conversation (interview) and/or participant observation. The researcher and the informants are often considered as co-participants (Chesla, 1995).

The validity of phenomenology as a theoretical framework in disability studies is well supported by the literature (Albrecht, Seelman, & Bury, 2001; Deegan, 2000; Glasscock, 2000; Kermanshahi, Vanaki, Ahmadi, Kazemnejad, & Azadfalah, 2008; Paterson & Hughes, 1999). And although phenomenological analysis is viewed as a popular method to study lived

experience, this researcher chose a separate approach for data analysis. Thematic analysis based on grounded theory was a better approach for this study. It focuses on generating comprehensive explanations of phenomena that are grounded in reality (Corbin & Strauss, 1990). Grounded theory has its roots in sociology. It was developed by Glaser and Strauss (1967) when studying the experience of dying patients. Like phenomenology, grounded theory is a method of social inquiry associated with a qualitative approach to research. The main purpose of using a grounded theory approach is to develop theory through understanding concepts that are related by means of statements of relationships (Corbin & Strauss, 2008). It is essentially discovering theory from data. It is based on the assumption that people develop meanings to an event through experience and social interaction (Daly, 2007). The phenomenological analysis method is used when searching for the central underlying meaning of the lived experience (Creswell, 2006). Since the intent of this study was to understand the phenomenon and situation of African American parents of children with severe cerebral palsy rather than give meaning to these experiences, thematic analysis was selected.

Sample

The sample for this study was nonrandom and purposive. African American parents of children between the ages of five and eighteen with severe cerebral palsy were selected to participate. The sample was comprised of 15 parents. Research has shown saturation, the point at which no new information or themes are observed in the data, is reached in phenomenological research anywhere between five and twenty-five participants (Creswell, 2006; McCracken, 1988; Morse, 2000; Ritchie, Lewis, & Elam, 2003). Guest, Bunce, and Johnson (2006) suggest that "for research studies that aim to understand common perceptions and experiences among a group of relatively homogeneous individuals, twelve interviews should suffice" (p. 79). Although the

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sample for this study was rather homogenous in the sense that all participants were African American parents of children with severe cerebral palsy between the ages of five and eighteen, the size of the sample allowed for some level of diversity in family size, education, income, and marital status, all factors which can directly influence adjustment and coping in caring for a child with severe cerebral palsy.

Non-probability sampling techniques are commonly used in studies that aim to explore the nature and impact of a problem (Bryman, 2004). For this study, it was necessary to invoke an element of judgment in the selection process of study participants. Accordingly, purposive and snowball sampling techniques were used to construct the sampling frame. Purposive sampling is a technique where individuals with particular characteristics are purposefully selected for inclusion in the sample. In snowball sampling, individuals selected for inclusion in the sample are asked to refer other potential participants for the study. Given that non-probability sampling techniques do not use random selection procedures, the sample of this study is not representative of the population. The sole focus of this study is to explore the lived experience of this sample of African American parents of children with severe cerebral palsy. Therefore, purposive and snowball techniques are well-suited for this study since the research questions are limited to African American parents of children with severe cerebral palsy.

Recruitment

The researcher sent letters announcing the study and requesting volunteer participation to school principals and directors of six center-based schools in Central Michigan. See Appendix A for copy of invitation letter. Center-based schools offer comprehensive programs, therapeutic services (physical, occupational, and speech), and psychological and nursing services to students with moderate, severe, and severe multiple cognitive impairments. Special education programs

within mainstream schools were not considered as potential recruitment sites as it was not likely that children with severe cerebral palsy would be enrolled in mainstream schools.

The six schools contacted were specifically targeted for three reasons. Geographical location was considered to balance having students represented from rural and urban communities. Research has noted that families of children with disabilities in rural, isolated communities have limited access to specialized health-care professionals and auxiliary services (Ceglowski, Logue, Ullrich & Gilbert, 2000; Comer & Mueller, 1995; van Dis et al, 2002). Second, it was critical to recruit from schools where African Americans represented at least fifty percent of the student population. Contacting schools with a large African American student population increased the likelihood of identifying eligible participants for the study. The third factor considered for recruitment was the existence of severely multiply impaired (SXI) classrooms within the schools. As was the case for selecting schools with a large African American student population, schools providing services to students with severe cerebral palsy were also an optimum choice in identifying eligible participants.

Of the six schools contacted, three administrators requested this researcher attend a Parent Teacher Organization (PTO) meeting at their individual schools to share information about the study directly with parents and teachers. The researcher accepted the invitations and gave a brief presentation of the study at PTO meetings at three different schools. During the PTO meetings, parents seemed rather intrigued by the study. But most seemed to be curious about the researcher's motivation to conduct the study and to what extent the researcher was familiar with children with severe cerebral palsy. The researcher was forthcoming in sharing her personal background as a parent of a child with severe cerebral palsy and her professional background as an advocate for persons with disabilities. Further discussion is given to interview

disclosure later in this chapter in the section titled, *Position of the Researcher*. Presentations at the three PTO meetings resulted in the recruitment of four study participants. It should be noted that three other parents attending the meetings expressed an interest to participate in the study, but were determined ineligible as their children were either not diagnosed with severe cerebral palsy or did not meet the age requirement.

In addition to the six schools contacted, notification of the study was sent to four organizations in Central Michigan that offer services to individuals and families affected by cerebral palsy. All of the organizations contacted posted an announcement of the study on their respective websites and/or within their newsletter. This effort resulted in the enrollment of two study participants. A total of six participants were enrolled directly from the contacted schools and organizations. The remaining nine participants were secured from efforts using the snowball technique, recruiting directly from interviewees' recommendations of potential participants.

Demographic Profile

Initial recruitment efforts were limited to the Central Michigan area. However, as a result of the snowball technique, five participants were from other states. Four lived in Illinois and one participant resided in Wisconsin. The sample was comprised of 11 biological mothers, two biological fathers, a grandmother and a legal guardian. The ages of the participants ranged from 28 to 63. Seven of the participants were married, five reported never being married, and three were divorced. Regarding religion, all but three participants reported a religious affiliation. Twelve of the fifteen participants were employed at the time of the interview on a full-time or part-time basis. Fourteen of the participants had completed some college, with two of them earning master degrees. See Table 3 for demographic characteristics of the parent participants.

Table 3: Demographic Characteristics of Parent Participants

Characteristics	Number of Participants (n=15)	
Mean Age	40.07	
Range	28 – 63	
Standard Deviation	9.505	
	#	%
Relationship to child		
Biological Mother	11	73.3
Biological Father	2	13.3
Grandmother	1	6.7
Legal Guardian	1	6.7
Marital Status		
Married	7	46.7
Never Married	5	33.3
Divorced	3	20.0
Education Background		
High School Completion of GED	2	13.3
Some College	8	53.3
Bachelor's Degree	3	20.0
Master's Degree	2	13.3
Annual Income		
$ 10,000 or less	2	13.3
$10,001 - $30,000	4	26.7
$30,001 - $50,000	3	20.0
$50,001 - $70,000	3	20.0
$70,001 - $90,000	1	6.7
$90,001 or higher	2	13.3
Number of Children 18 and younger		
1	4	26.7
2	9	60.0
3	2	13.3

There were slightly more male children with severe cerebral palsy than females. The

average age of the children was 12.9 years. All but three of the children were enrolled in a

school setting; ten attended full-time and two part-time. The remaining children were home-schooled. Most parents, 10 total, ranked their child's health as fair, four ranked as poor, and one reported their child's health as good. Of the 14 healthcare specialists listed, most children utilized eight or more of the services. A neurologist, physical therapist, and speech/language therapist were used by every child. Feeding tubes and mobility equipment were the two most frequently used devices. Table 4 below provides an overview of the demographics of the children with severe cerebral palsy being cared for by the parent participants.

Table 4: Demographic Characteristics of Children with Severe Cerebral Palsy

Characteristics	Number of Participants (n=15)	
Mean Age		12.93 years
Range		5-18
Standard Deviation		4.131
	#	%
Gender		
Male	9	60
Female	6	40
Education Setting		
Center-Based (full-time)	9	60
Center-Based (part-time)	2	13.3
Home-School	2	13.3
Secondary	2	13.3
Health Status		
Good	9	60
Fair	3	20
Poor	3	20

Data Collection

Data collection began only after Michigan State University's Committee on Research Involving Human Subjects reviewed the methodology, measures, procedures and consent form of the study and granted approval. A copy of the approval letter can be found in Appendix B. Potential participants informed by the schools or organizations, initiated contact with the researcher to express interest in the study. During this conversation, the researcher explained the purpose of the study, what will be asked of the participant the day of the interview, and that the interview would be audio-taped, yet confidential. After the discussion and upon agreeing to participate in the study, an interview date and time was scheduled to be held in the participant's home or a location of their choosing where confidentiality would not be compromised. Participants were asked to reserve 90 minutes for the interview and to consider a time frame that would ensure their maximum participation and not gravely interfere with their family's daily routine. The day prior to the scheduled interview, the participant was contacted to confirm the scheduled interview. Due to weather, illness or other obligations, it was necessary for three of the participants to reschedule their initial interview date. Recognizing the severity of the child's disability and the demands placed upon parents, the researcher anticipated the probability of cancelled interviews and planned accordingly.

Interviews were conducted over a four month period. Two of the interviews were conducted in a public setting (school and coffee shop) at the participants' request. The remaining 13 interviews were conducted in the participants' home. Interviews ranged from 60 to 220 minutes. The average length of the 15 interviews was about 120 minutes. The total amount of interview time was 28 hours and 20 minutes. Completion of the two surveys with each

participant varied from between 15 to 30 minutes. With this additional time, the researcher spent an approximate average of two and half hours with each participant.

When meeting participants for the interview, they were given the opportunity to review the Michigan State University Committee on Research Involving Human Subjects approval letter for the study, as well as ask questions. The consent form was read and discussed in detail (see form in Appendix C). Participants were informed of potential discomfort they might experience while sharing their stories. They were assured that their participation would remain confidential, and of their right to withdraw from the study at any given time without consequence. The expectations of participation were discussed. Participants were asked to complete two brief surveys, have the interview audio recorded, and to permit the researcher to take notes and, if necessary, contact them for a follow-up interview. They were also informed that upon completion of the interview they would receive a $25.00 gift card as a form of appreciation for their participation. Once they indicated they understood what was expected of them as a study participant and expressed a willingness to participate, the consent form was signed and dated by the participant and researcher.

The measurement tools used for this study were developed after feedback and directives were provided by the researcher's dissertation committee and an initial piloting with five African Americans - three parents of children with disabilities, a center-based school social worker, and an African American and African Studies doctoral student. These key informants played a critical role not only in assisting with the development of the measurement tools but also in identifying most suitable sites for participant recruitment. In addition, the group strongly recommended that the researcher prepare a list of resources for parents as a means of treating the interview as "an exchange of information". When asked what would be ideal information to

share with parents, the group suggested resources that provided financial support. The researcher provided parents with contact information (website, phone number and address) for Children Special Health Care Services (CSHCS). CSHCS is a program that offers medical care and treatment assistance for children with chronic, severe, disabling health problems, and provides service coordination to meet the child and family needs. Interestingly however, all of the study participants from Michigan were well aware of CSHCS and several were currently enrolled in the program. The participants from Illinois and Wisconsin were also familiar with their respective state's CSHCS program.

Survey Measures

Two surveys were used to create demographic profiles of the study participants – the Family Demographic Survey (FDS) and Child Demographic Survey (CDS). FDS is a 14-item measure designed to gather information on the primary caregiver of the child with severe cerebral palsy specific to age, education, marital and employment status, health, and religion (see Appendix D). CDS is a 12-item measure that inquires about the child's education, healthcare, childcare, social activities, and support services (see Appendix E). For both surveys the researcher read the questions and recorded the participants' responses. Every page of the survey was labeled with an assigned number ranging from one to fifteen. The list of assigned numbers will serve as the only evidence of which participant corresponded to the survey. This process ensures confidentiality of the study participants.

In-Depth Interviewing

Once the surveys were completed, data were gathered using an in-depth semi-structured interview with flexible probing questions. The most common types of qualitative methods in research with children with disabilities and their families have been in-depth interviewing and

observation (Daly, 2007; O'Day & Killeen, 2002). In-depth interviewing is favored when the researcher is looking for rich and detailed information shared in narratives and stories (Rubin & Rubin, 2012). Brinchmann (1999) demonstrate in-depth interviewing in his descriptive study based on 30 hours of field observations and seven interviews with parents of children with severe disabilities. The parents in Brinchmann's (1999) study reported having extremely stressful lives. They reported that too little rest and sleep and feeding problems were the most tiring. Through in-depth interviewing, it was conveyed that the parents lacked relief from their situation and characterize their circumstance as "having a baby that never grows up" (p. 137). It is conceivable that as a result of in-depth interviewing, such graphic portrayal of these parents' experiences could be realized. Taking notes of observations of nonverbal communication and the environment during the interviews provided this researcher with a greater depth of understanding of the sample participants' experiences and perceptions.

The interview for this dissertation study was initiated with the researcher reminding the participants that this part of the study would be recorded using a digital audio-recorder. The recording began with the researcher vocally labeling the interview with the assigned participant number. The same number was also recorded on each page of notes taken of the researcher's observation about the interview content and the participant's verbal and nonverbal behavior. The interview questions focused on three key domains: health, cultural values and beliefs, and social support. In addition to the primary questions, probing questions were asked. Many of the probing questions were anticipated and prepared in advance, while others emerged on a spontaneous basis. See *Interview Guide* in Appendix F for list of interview questions.

The overarching research questions for this study are (a) What types of health problems do African American parents experience as a result of caring for a child with severe cerebral

palsy?, (b) What kind of positive and negative statements do African American parents make about caring for a child with severe cerebral palsy that are influenced by cultural and religious values; and (c) What types of informal and formal community resources do African American parents caring for a child with severe cerebral palsy utilize? Using Rogers-Dulan and Blacher (1995) *African Americans, Religion, and Disability* model as the conceptual framework for this study, the identified research questions for this study are directly related to the constructs of the model with each question linking the social contexts (culture, religion, and support) to how parents care for their children with severe cerebral palsy. Additionally, the health of the primary caregivers is also measured as it impacts their ability to care for their child, as well as is impacted by the child's disability. An extensive review of the literature acknowledges that the health of the primary caregiver of a child with a disability, as well as the severity of the child's disability has a direct impact on quality of life for both the child and caregiver (Albrecht, 1995; Farber, 1959; Howe, 2006; Lavin, 2001; Reichman, Corman, & Noonan, 2008; Singer & Farkas, 1989).

The first group of interview questions explored was related to health. They gathered information on the child's diagnosis, family's daily routines, and perceived health problems of the caregiver that currently interfere with, or with progression could potentially interfere with caring for the child with severe cerebral palsy. These questions seek to address the first research question, "*What types of health problems do African American parents experience as a result of caring for a child with severe cerebral palsy?*" Parents were also encouraged to share what happened when they learned of their child's diagnosis, activities relative to caring for their child, and their most pressing concerns for their child.

The second focus area is cultural values and religious beliefs. This category of questions seeks to address the second overarching research question, *"What kind of positive and negative statements do African American parents make about caring for a child with severe cerebral palsy that are influenced by their cultural and religious values?"* Through this line of questioning, parents were asked to share their views of raising a child with severe cerebral palsy, how their cultural and religious values influence them in their role and if they believe caring for a child with severe cerebral palsy was rewarding, challenging, a burden or hardship. Additionally, parents were encouraged to share their opinions of the cultural competence and cultural sensitivity of their child's professional service providers. Gathering information about experiences beyond the home environment and relationship with others gave insight to the parents' opinion of how they are perceived by others. Questions in this category allowed parents to reflect on experiences not only as a parent, but also as a person of color caring for a child with severe cerebral palsy.

The last set of interview questions focused on support systems. Inquiry was made into informal and formal resources utilized and those underutilized. This category of questions seek to address the third research question, *"What types of informal and formal community resources do African American parents caring for a child with severe cerebral palsy utilize?"* Query was used not only to identify formal and informal resources utilized by the family, but also to determine frequency of usage and barriers to utilizing community-based resources. It was imperative to understand if accessibility was limited due to cultural, physical or economic barriers.

The interview concluded with the researcher asking the participant why he or she elected to participate in the study. Literature has repeatedly shown that African Americans continue to

be a seriously underrepresented population in research, more specifically disability research (Balcazar et al, 2009; Corbie-Smith, Moody-Ayers, & Thrasher, 2004; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Huang & Coker, 2010). Based on this lack of representation, the researcher believed it was useful to gain insight into what factors motivate African Americans to participate in research studies.

After the final question regarding participation in the study was asked, the audio recorder was turned off. At this time participants were told they may be contacted for a follow-up interview if any part of their response was inaudible in the recording. It should be noted that it was not necessary to contact any of the families for a follow-up interview. All of the participants answered all the questions posed to them and reported that they were pleased with their decision to participate in the study. As it will be further discussed in the *Findings* section of this dissertation, participants seemed to welcome the opportunity to share their story. Most stated they hoped it would help other African American parents of children with cerebral palsy to be encouraged.

Data Analysis

Responses from the two surveys were analyzed using the computer program, IBM SPSS Statistics 20. The program performed descriptive statistics and the measures of central tendency (mean, median, and mode) of the data entered. Data from each survey was entered using the assigned participant number. A research assistant was used to verify that all variables were correctly entered. This occurred once the research assistant successfully completed the Michigan State University Institutional Review Board tutorial and three hours of training on SPSS data entry. Once accuracy of the entered data was verified, the surveys were secured in a locked cabinet for storage.

An experienced transcriber was contracted to transcribe the 15 digitally recorded interviews. The transcriber also successfully completed the Michigan State University Institutional Review Board tutorial. The internet file storage, Dropbox, was used to securely download all audio recordings. Since recordings were only identified with the assigned participant number, confidentiality was not jeopardized. Once the researcher created a file in Dropbox, authorization was given for the transcriber to access the file via a username and password. Completed transcripts were sent to the researcher via email.

After transcripts of the 15 interviews were received, the qualitative data analysis software NVivo 9 was used to assist in the analysis of the collected data. Before entering data into the analysis software, it was beneficial to identify themes that may come up during the coding. This process of data organization is critical in the three levels of coding stipulated by the thematic analysis and coding used for this phase of the research. As Strauss and Corbin (1990) explain, the three levels of thematic coding allows for developing categories of the phenomena (open coding), interconnection of the categories (axial coding), and building a story that connects the categories (selective coding).

Transcripts of the 15 interviews and the hand written notes taken during and after each interview were reviewed as part of the first step in open coding. The value of reviewing the handwritten notes became even more evident when it was realized that all but two of the interviews were briefly interrupted as a result of the parent needing to address an urgent need of the child with severe cerebral palsy. This was significant to note as it gave insight to the demands placed on the parents. A second common occurrence revealed from the handwritten notes was that six of the participants cried when discussing the health status of their child or prognosis of their child's condition. Both of these observations will be discussed in greater

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detail in the *Findings* chapter. The purpose of reviewing the handwritten notes and transcripts was to identify patterns from direct quotes or common ideas expressed in the interview. This process was performed independently by the researcher, research assistant, and a doctoral student. Having multiple reviewers can allow for reduction in researcher bias, as well as reliability in the understanding of the data (Creswell & Miller, 2000).

Once patterns were identified they were labeled with a code name (theme). Sorting through multiple sources, in this case interview transcripts and handwritten notes, to find common themes is a form of data triangulation which helps establish validity in the study (Denzin, 1978; Johnson, 1997). In an effort to remain true to the data, labels for the themes reflected the words and phrases used by the participants. After several patterns were identified and labeled, they were compared for similarities and differences. This process was repeated several times until uniformity was reached. Then after specific coding categories were developed, the qualitative data analysis software NVivo 9 was used to assist in the final analysis of the data collected from the interviews. Also within this final step of data analysis the literature was reviewed to support selected themes. Aronson (1994) states that when the literature is interwoven with the findings, the story that the interviewer constructs is one that stands with merit. The steps described in the data analysis phase of this study involved check points for accuracy and understanding. This is a critical issue when discussing the integrity and trustworthiness of qualitative data.

Trustworthiness

Trustworthiness in qualitative research is the equivalent of credibility in quantitative research. It exists when the study's findings are authentic enough to allow practitioners to act upon them with confidence. Lincoln and Guba (2000) propose the central question of trust in

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qualitative research is "How can an inquirer persuade his or her audiences (including self) the findings of the inquiry are worth paying attention to, worth taking account of?" (p. 290). Their model of trustworthiness describes four criteria for evaluation of research – credibility, transferability, dependability, and confirmability.

Credibility addresses truth of the findings. Grinnell and Unrau (2008) indicate several measures to enhance credibility including *referential adequacy*, keeping an accurate account of all interviews, tapes, transcriptions, and field notes. This was achieved by the labeling of all survey pages, handwritten notes, audio-recordings, and transcripts with the assigned participant number. Additionally, all study related documents are stored by the researcher in a locked cabinet. The measure, *consulting with colleagues*, was achieved in conjunction with the measure, *triangulation of analysts,* when this researcher, a trained research assistant, and doctoral student were used to achieve a satisfactory level of intercoder reliability.

The degree to which the findings can be applied or generalized to other contexts, settings, or groups is the second aspect of trustworthiness. Grinnell and Unrau (2008) offer two examples of good transferability. One, the researcher cautiously applies the results to parts of the population that share similar contexts and characteristics of the sample. And two, the researcher cautiously applies the results to parts of the population while making note of contradictory data or alternative hypotheses. Since the sample of this study will represent a rather homogenous group and is limited in size, it is imperative that caution is taken to not generalize study findings. However, it is hopeful that these findings could pave the way for similar studies with other ethnic minority parents of children with severe cerebral palsy.

Dependability is the aspect of trustworthiness that addresses the consistency or congruency of the results. Strategies to increase dependability include comprehensive

description of research methods, method triangulation, peer examination, and inquiry audit (Padgett, 2008). Dependability was achieved for this study by providing extensive descriptions of the context and characteristics of the sample; accurately recording the questions asked of the participant and their answers; and describing how the data and conclusions drawn were checked by colleagues.

The last criterion in the model of trustworthiness is confirmability, in which the researchers strive to acknowledge and supplement their own subjectivity and bias. An audit trail of meticulously kept records was intended to reduce the likelihood of biases and preconceptions. As an African American parent of a child with severe cerebral palsy, the researcher's personal experiences influenced the design and implementation of this study. Therefore, the position of the researcher is discussed to offer explanation of how biases were controlled and the integrity of the study was not compromised.

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Position of the Researcher

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The position of the researcher should be discussed because of the potential influence the researcher could have on the research. Many researchers study and write about topics that are important to them due to their personal experience with the selected topic. The influence of those experiences could result in positive and/or negative biases in the research. Several scholars have asserted that it is imperative for researchers to be aware of their own understandings, beliefs, biases and assumptions when conducting qualitative research (Grinnell & Unrau, 2008; Iversen, Graue, & Clare, 2009; Miles & Huberman, 1994; Rubin & Rubin, 2006). Chenail (2011) emphasizes that potential researcher biases should be assessed "especially if the investigator has a strong affinity for the participants being studied or is a member of the population itself" (p. 255).

As an African American parent of a child with severe cerebral palsy, it was imperative for this researcher to be cognizant of potential biases at every stage of the study's development and implementation. In the initial phases of the study's design and through personal reflection, the researcher asked and answered two important questions: 1) what is my opinion of African American parents of children with severe cerebral palsy? and 2) what has influenced this opinion? What was realized from this exercise was a combination of perceptions and opinions based on personal interactions, as well as what was learned from reviewing the literature. As an example, one of the assumptions made by the researcher was that African American parents of children with disabilities do not engage in advocacy. This assumption was largely based on the researcher's personal experiences of not witnessing activism among African American parents. And yet, a third of the participants in this study were engaged in advocacy activities at the time of the interview. One parent proudly shared an article from a major newspaper reporting on one of her most recent advocacy activities.   In retrospect, the study may have been enriched by including questions relative to advocacy in the interview.

Not only was it imperative that the researcher identify potential biases, a "course of action" was also necessary in order to limit influence. Consulting with key informants to include in a pilot testing of the study's measurement tools, particularly the Interview Guide was one of the action steps taken. The cooperation and feedback from the informants, as well as members of the dissertation committee was most helpful in developing a culturally sensitive study.

The influence of a researcher can certainly be an advantage as well as a disadvantage in qualitative research. Having similar characteristics as the population being studied was one advantage that allowed for the building of trust and sense of credibility. Participants viewed the researcher as "one of them", someone who understood first-hand what they were experiencing.

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There was a belief that the researcher could relate to their stories personally and not as "an outsider looking in". Several scholars have recommended "racial matching" as an important strategy for successful recruitment of African Americans as research participants (Brown, 2004; Carter-Edwards, Fisher, Vaughn, & Svetkey, 2002; Gil & Bob, 1999; Gillis et al, 2001; Taylor-Ritzler et al, 2008).

The significance of the researchers' race was argued during the 1960s Civil Rights Movement when Black, Latino, and white scholars alike accused white researchers of systematically exploiting minorities (Schaffer, 1980). The distrust of Caucasian researchers was further realized after the exposure of the infamous Tuskegee Syphilis Experiment. Conducted between 1932 and 1972 by the U.S. Public Health Service, the Tuskegee Syphilis Experiment studied the natural progression of untreated syphilis in rural Black men who thought they were receiving free health care from the U.S. government. However, researchers knowingly failed to treat patients appropriately, refusing to administer an effective cure for the syphilis (Jones, 1993; Katz et al, 2006). This incident and other mistreatment of minorities influenced a response from Black scholars demanding that Black social scientists guide research and writings focused on the Black experiences, which was previously argued by Black scholars such as Edward F. Frazier and W. E. B. Dubois (Twine, 2000).

Hurtado (1994) states, "similarity between researchers and respondents on important social characteristics enhances validity of information obtained" (p. 77). However, in contrast, there are disadvantages of having the same characteristics of the population studied. One challenge for this researcher was hearing about the profound health challenges of the children. This was particularly difficult when the children's condition was very similar to that of the researcher's child with severe cerebral palsy. The researcher was certainly prepared for and

anticipated stories describing serious health challenges for the children; but realized an

awakening of her own pain and fears as she absorbed the stories. Journaling and debriefing with

members of the dissertation committee immediately after the interview was one way to

acknowledge the emotional connection. And although one could argue that the feelings brought

about by the participants' stories could have negatively impacted the research, journaling and

consulting with peers helped to ensure that professional boundaries were not crossed during the

study. Despite the noted challenge, the personal experiences as an African American parent of a

child with severe cerebral palsy, coupled with professional experiences afforded the researcher

comprehensive knowledge about the population studied which greatly contributed to a research

design that was culturally sensitive and achieved trustworthiness.

CHAPTER 4

FINDINGS

The results of data analysis for the study are presented in two sections. Section one provides a description of the sample using data collected with the two demographic surveys. The second section presents the themes and sub-themes that emerged from the results of qualitative data analysis of the in-depth interviews and field notes and links to the three research questions. Tables and pie charts are included to enhance the clarity of the findings. To ensure confidentiality of the participants, their names have been changed.

Family Demographic Survey

Thirteen females and two males participated in this study. Parent participants ranged in age from 28-63 years (SD = 9.505). The average age of sample participants was 40 years old. As shown previously in Table 3, the majority of the participants were biological mothers (n=11). The other four participants were two biological fathers, a grandmother, and a legal guardian. Seven of the participants reported their marital status as married, five as never married, and three as divorced. All the divorced participants reported that the divorce occurred after their child was diagnosed with severe cerebral palsy.

Of the 15 participants, 8 (53.3%) had achieved some college or two-year degree, 3 (20%) had earned a Bachelor's degree, 2 (13.3%) had a Master's degree, and 2 had completed high school or earned a General Education Diploma (GED). A majority of the participants (60%, n=9) reported that their education was interrupted due to demands of caring for their children with severe cerebral palsy.

The average household size for the sample was 3.26 people. Slightly more than half of the households (53%, n=8) were headed by single-mothers. The annual income levels for the

sample varied from very low incomes of $10,000 or less to high incomes of $90,001 or higher.

40% of parents (n=6) reported an annual income of $30,000 or less. Six other parents reported

their income to be between $30,001 and $70,000. The remaining three parents reported an

annual income $70,001 or higher.

At the time of collecting data, 46.7% (n=7) of the participants were employed part-time,

two of which worked from home. Five participants (33.3%) were employed full-time and the

remaining three (20%) were unemployed.   As demonstrated in Table 5 below, a comparative

analysis of participants' employment status before and after their child's cerebral palsy diagnosis

reveals a significant change.

Table 5: Demographic Characteristics of Parent Participants: Employment

Characteristics	Number of Participants (n=15)	
	#	%
Employment - Before Birth of Child		
Full-time Student	1	6.7
Employed Part-time	1	6.7
Employed Full-time	12	80
Unemployed	1	6.7
Employment – After Birth of Child		
Full-time Student	0	0
Employed Part-time	7	46.7
Employed Full-time	5	33.3
Unemployed	3	20

80% (n=12) of the parents were employed on a full-time basis prior to the birth of the

child with severe cerebral palsy, whereas, after the birth only 33.3% were employed full-time.

The part-time employment status changed dramatically as well before and after the birth. The

percentage of the participants working on a part-time basis went from 6.7% before birth to

46.7% after the birth of the child with severe cerebral palsy. A third interesting point noted

regarding employment status change was that both of the biological fathers who participated in the study remained employed full-time after the birth of the child, whereas only two of the 13 biological mothers remained employed full-time.

About two-thirds of the participants (66.7%, n=10) reported their health as very good. One participant reported excellent health. The remaining four participants (26.7%) reported their health as good. None of the participants reported their health as poor. Participants described several health problems that impacted their ability to care for their child with severe cerebral palsy. Back pain, knee pain, and headaches were the most frequently reported. One participant suffers from Type 2 diabetes and two participants reported having shoulder injuries that limit their ability to lift and carry their child with severe cerebral palsy. In regard to health insurance coverage, an overwhelming majority of the participants (73.3%, n=11) reported they were enrolled in a private insurance plan. Twenty percent (n=3) of the participants were enrolled in a public insurance plan and one of the participants reported no insurance coverage.

Relative to religion, the vast majority of participants (80%) reported a formal religious affiliation. Identified religions included Non-denominational (26.7%), Baptist (26.7%), Catholic (13.3%), Methodist (6.7%), and Christian (6.7%). Three participants (20%) reported no religious affiliation. This sample's reported membership of a religious organization is slightly lower than the national statistics of religious affiliation for African Americans. According to the 2007 U.S. Religious Landscape Survey, 87% of African Americans describe themselves as belonging to one religious group or another (Pew Research Center, 2009).

Table 6 shows the reported support resources identified by the sample. An overwhelming majority of the sample (80%, n=12) reported immediate family and friends as the two most utilized support resources. Extended family provided support to 40% (n=6) of the participants.

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A third of the participants (33.3%) listed neighbors as a support. Three participants (20%) reported the church as a support. Only one participant reported seeking support from self-help groups or on-line chat groups.

Table 6: Demographic Characteristics of Parent Participants: Support Resources

Support Resources	Number of Participants (n=15)	
	#	%
Friends	13	86.7
Immediate Family	12	80
Extended Family	6	40
Neighbors	5	33.3
Church	3	20
Self-Help Support Groups	1	6.7
Online Chat Rooms	1	6.7

Child Demographic Survey

The study sample's children with severe cerebral palsy were comprised of nine (60%) males and six (40%) females. Their ages ranged from five to eighteen-years-old. The majority of parent participants (n=9) reported their child with severe cerebral palsy as their first child. Three participants (20%) reported their child as their only child. The children were enrolled in one of three identified programs. Most children (60%, n=9) were enrolled full-time in a center-based school. The remaining six children were equally divided into full-time secondary, part-time center-based and home-based education settings.

Relative to the health status of the children, most participants (60%, n=9) reported their child's health as fair. Three participants reported their child's health as good, and the same number of participants reported their child's health as poor. None of the children with severe cerebral palsy were hospitalized at the time of data collection. However, 11 of the parent

participants (73%) reported that their child had either been admitted to a hospital for a surgical

procedure or taken to the hospital for emergency medical treatment at least once within the past

six months.   All the parent participants reported that their children with severe cerebral palsy

were enrolled in a health insurance coverage plan. Seven of the children (46.6%) were enrolled

in public health insurance plans, three of the children (20%) were enrolled in private plans, and

five (33.3%) were enrolled in both private and public health insurance plans.

Parent participants also reported on the specialists providing medical care or therapeutic

services to their children. Of the 14 specialists listed on the Child Demographic Survey, most of

the participants' children (73.3%, n=11) utilized eight or more of the services. All of the parents

reported that their children were being treated by a pediatrician, neurologist, physical therapist,

and speech therapist. In regard to supportive equipment, feeding tubes and mobility equipment

such as wheelchairs were the two most frequently used devices.

In-Depth Interviews

Research Question 1: Health

The first research question of this study ask, *What types of health problems do African*

American parents experience as a result of caring for a child with severe cerebral palsy? As is

noted in the literature, caring for a child with cerebral palsy can impose rigorous stress on

parents, which can impact their mental and physical health. Several of the study participants

characterized their health as being negatively impacted by their child's disability. The

participants identified three experiences in their role as caregiver of a child with severe cerebral

palsy that has had the most impact on their health, (a) diagnosis and prognosis of their child's

disability, (b) limited support from informal and formal support systems, and (c) barriers to

seeking medical attention for their own health care needs. These experiences were translated into

three themes during the analysis process: (a) a sense of loss, (b) relationship with significant other, and (c) self-care.

Theme 1.1 Sense of Loss

Participants unanimously identified the diagnosis and subsequent prognosis of their child's condition as critical influences on their physical and mental well-being. Most of the study participants were very vocal in expressing a sense of loss and grief for the healthy child they were expecting. Parents expressed that they were not prepared for their child's disability. All the children with severe cerebral palsy discussed in this study suffered a traumatic injury immediately before or during birth. Parent participants reported that there were no indications of a potential birth trauma and none of the pregnancies were categorized as high risk.

Parents go through a process of grieving when their child is diagnosed with a disability (Davidson & Dosser, 1982; Longdo & Bond, 1984; Roper & Jackson, 2007; Sen & Yurtsever, 2007). The study participants described varying reactions to ir child's diagnosis as well as different levels of understanding the diagnosis. Their reactions to the child's diagnosis included feelings of shock, confusion, disbelief, sadness, being overwhelmed, and anger. Several parents indicated they were "frozen" upon hearing the news, unable to express any feelings.

Hilary described the evening of her daughter's birth. "It was like everything went blank. I can't even describe what the person looked like who told me my daughter had suffered a stroke and would probably not survive." Irene, mother of a 17-year-old son stated that when she was told her son would have serious developmental delays, she sat there, "lifeless, just staring at the person". She remembers someone handing her a tissue and her husband grabbing her hand.

Parent participants described several emotional reactions and feelings of sadness to their child's diagnosis. Kiara described feeling "heart-broken". She stated, "I couldn't understand it

because I had did all the right things and didn't think my baby would be born with problems".

Josephine, mother of a 13-year-old son tearfully described the realization of her son's disability:

> They said he wasn't growing, failure to thrive. So he had surgery. They put a
> shunt in his head and a feeding tube. I think that was the hardest time for me to
> see my baby lay in that hospital bed with tubes coming out of him and knowing
> they would be permanent. I'm sorry. I still think about it. It feels like it was
> yesterday.

Laura also expressed sadness after learning of her son's diagnosis:

> The man came in the room and looked at him, touched his legs and told me he'll
> never walk or talk and that was pretty much it, and walked out. So I stayed there
> for about maybe a hour, crying, until somebody came in there to console me and I
> left.

Most participants expressed feelings of anger and being overwhelmed with medical terminology. For the majority of participants (80%, n=12), this was their first birth, they had no prior experience with child-birth. Parents reported that it was not their trusted doctor (i.e. OB/GYN) who gave them the news of their child's traumatic birth and subsequent birth injury, but rather a neonatologist or other specialist whom they had never encountered. This issue added to the complexity of the situation as the parents did not know the physician nor were they aware of the physician's specialized field of medicine. Olivia recalled being overwhelmed with the information of her son's traumatic birth.

> They told me his Apgar scores were one and one and that he was on a ventilator
> in the NICU. I had no idea what they were talking about. I thought what in the
> hell is a Apgar score. I kept asking to see my baby. It didn't dawn on me how

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sick he was until when I went to see him and saw all the machines he was hooked

up to. He was four days old the first time I held him in my arms.

Claudia, mother of a 14-year-old described her experience as:

It was like a bad dream. When he came out, he was really blue. They sent all

these specialists. My room was surrounded. They told me and my husband we

had to do what is called the genome, genealogy test and find out if we were

related. It felt unreal.

Parents also reported feeling angry when realizing the extent of their child's disability. Flora

stated,

When he finally came home I thought he was normal. He was on a lot of

medication. They had us in Early On. They came out to the house every week. I

was so mad at them at the time. It felt like they were always telling me something

was wrong with him. I guess I didn't want to face the facts back then.

Many of the participants expressed that they were angry with the absence of explanation

as to what exactly caused their child's disability. Cerebral palsy is caused by damage to one or

more specific areas of the brain, usually occurring during fetal development before, during, or

shortly after birth. There are four types of brain damage (a) genetic and environmental factors

disturb brain cell migration; (b) brain function is impeded when poor myelin provides an

inadequate protective covering over nerve cells; (c) events in the birthing process that rupture

blood vessels or starve oxygen to the brain; and (d) trauma, infections, and asphyxia that damage

connections developed in the brain (National Institute of Neurological Disorders and Stroke,

2006). Although medical professionals provided parents with these explanations, parents were

still left asking, why did the damage occur? Maria, mother of a 12-year-old daughter shared,

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They never could explain what really happened. I kept asking, why did the cord

wrap around her neck? But all they would say is that it could have been a number

of reasons. So to this day, I have no idea what really happened. I thought for a

long time that I did something wrong. Then I thought they did something wrong.

But I learned to just accept it for what it is.

Parents reported suffering from depression as a result of the unexpected diagnosis. As it

was not the scope of this study, postpartum depression, mood changes which occur after birth,

was not a measured variable. However, according to a recent study, one out of every seven

mothers will experience postpartum depression (Wisner et al, 2013). It is therefore conceivable

that at least one of the 11 biological mothers of this study's sample experienced postpartum

depression. Gladys described some ambivalence about being diagnosed with depression.

I had been having some bad dreams about Miracle and I get these bad headaches.

My doctor told me they were stressed induced and that I should possibly consider

talking to a therapist to better understand why I have the dreams. He also

prescribed me Prozac but I don't take it. I don't think I'm depressed. I have

been, but I don't think I need it.

Laura shared that she feels tired a lot and was taking an antidepressant. Josephine, mother of a

13-year-old son shared that she didn't want to deal with anybody after her son was born. She

didn't accept phone calls or visits. She stated, "I just wanted to be left alone to make sense of

everything that was happening".

Most participants of the study expressed a variety of feelings upon learning of their

child's diagnosis. Such feelings included shock, confusion, disbelief, sadness, depressed, being

overwhelmed, and anger. Parents linked these feelings, and others, to how they were able to

process the diagnosis, understand the potential impact, and adjust to and cope with the demands of caring for a child with severe cerebral palsy; all of which directly impacted their health. Additionally, the level of support from others would also affect the caregiver's health.

Theme 1.2 Relationship with Significant Other

There are many research studies that have examined marital relationships of parents of children with disabilities (Risdal & Singer, 2004). Findings from these studies show that having a child with a disability may influence marital relationships, or have no effect at all. Friedrich and Friedrich (1981) argued that having children with disabilities would adversely impact marital relationships and increase divorce rates due to the stress of caring for a child with a disability. However, in contrast other studies have found positive influences on marital relationships when having children with disabilities (Abbott & Meredith, 1986; Chang & Hsu, 2007).

This study's sample of participants reported both positive and adverse influences on relationships when caring for a child with severe cerebral palsy. Seven of the participants (46.6%) reported their marital status as married. Three of the participants (20%) reported their marital status as divorced. The remaining five (33.3%) reported their status as single or never married. And of this single or never married group, two of the participants were currently living with a significant other. The total 15 participants seem to be equally split on the impact of caring for a child with severe cerebral palsy on relationships. Many of the parents described having to do it on their own, without the assistance of the child's second parent. In this sample, the discussed "absent" parent was identified as the biological father.

Gladys, who reported her marital status as never married expressed that her daughter's diagnosis had an adverse impact on her relationship with her daughter's father. "He didn't want to go to doctor's appointments or watch her while I was at work." The relationship ended two

years after their daughter's birth. Gladys also shared that her boyfriend who lived with her at the time of the interview was very supportive and always there to help in caring for her daughter with severe cerebral palsy.

The three divorced parents reported that their dissolution of marriage occurred after the birth of their child with severe cerebral palsy. Laura, who divorced a year before participating in the study, spoke about how her husband of five years left after not being able to cope with their son's severe cerebral palsy. She stated,

> It was rough. When he got the diagnosis he couldn't deal with it and it was pretty hard. I don't even really know how I was able to cope. He left when he got the tracheostomy and hasn't seen him since.

Irene described a problematic marriage that was further complicated after the birth of her son.

> We were already having problems before he was born. And then it was so frustrating that I was doing all the work by myself, going to doctor appointments, getting up throughout the night, and taking care of our other son who was not even two yet.

Kiara, the last divorced participant expressed that in the seven years since her divorce, "I can count on my hands how many times he's been here to see his kids".

The married participants of the study presented contrasting opinions about the influence of their child's severe cerebral palsy on their marital relationships. Aaron, father of an 18-year-old daughter described how he and his wife cope with the challenges of caring for a child with severe cerebral palsy.

> Communication is the number one factor, then we understand the stress factor.
> Prime example, just like when me and [my daughter] went on a little road trip to

give [my wife] time to herself, everybody need their me time. And when they

went out of town, then I had my me time.

Barbara emphasized the importance of sharing responsibilities in the care of her daughter. She

works during the day and her husband works during the evening hours. Although she admitted

that she is mostly responsible for her daughter's daily hygiene care, she also stated that there is a

balance of responsibility since her husband takes on more household chores such as cooking,

cleaning, and running errands. Daniel described the impact of caring for a child with severe

cerebral palsy on his marriage as follow:

Well my marriage has been affected where we have to make time for our

daughter, put her needs at the forefront of our marriage and work around that

because we both have demanding work schedules. So we have to come together

to have a plan to make sure that our family's taken care of. And so we basically

plan around our daughter.

A second similarity among study participants who identified a significant other helping

with the care of their child with severe cerebral palsy in comparison to study participants who

were without the support of a co-parent was fewer reports of health related problems. They

expressed more relief from the physical demands of caring for their child with severe cerebral

palsy.

Theme 1.3 Self-Care

From the data, back pain, knee pain, and headaches were the most frequently reported

health problems. One participant, Josephine, reported that she suffers from Type II diabetes but

rated her health as good. She does however feel that there are times when her diabetes interferes

with her ability to care for her 13-year-old son.

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Some days I am so tired that it takes all I have to muster the strength to lift him. He is about 85 pounds so it is not easy. They gave me a brace and it helps but when my sugar is up and I'm feeling tired I just don't have the energy.

Laura reported that she was recently scheduled for an MRI because of complaints of lower back, hip and leg pain. She described the struggles of lifting and carrying her seven-year-old son. Maria described the back pain she was experiencing as a result of carrying her 12-year-old daughter. "It is a strain on my back because she is on the heavier side, she takes a steroid. It really is hard, a struggle." Natalie, the oldest caregiver in the sample and only grandparent reported that she suffers from leg and knee problems which she attributes to the many years of lifting and carrying her 18-year-old grandson.

I carried him on my hip till he was almost long enough for his feet to touch the floor. My husband used to tell me to wait for him to come home to help with washing him and changing him, but he could have me waiting for hours. But now that my daughter and her son, he's 16, is here, they do all the lifting for me.

One parent shared an injury unrelated to caring for her son with severe cerebral palsy. Flora broke her collar bone and dislocated her shoulder a few years ago and as a result struggles with lifting her 12-year-old son. She stated that her live-in boyfriend mostly helps with the lifting and carrying. But that she is able to meet all her son's other needs.

Many of the parent participants who reported health problems also acknowledged that they are reluctant in seeking medical attention for themselves. Hilary stated that she has hip and knee problems, but has yet to see a doctor. She stated that she bought a knee brace from a local drug store to give her better support, but realized it wasn't doing much to offer her any relief.

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Kiara shared that she has been experiencing shoulder and knee pain. She is worried it may be the early stages of arthritis, but had yet to see a doctor.

The third health problem most frequently reported was headaches. Participants attributed the headaches to stress, lack of sleep or both. Daniel described waking several times throughout the night to the alarm of his daughter's feeding machine, indicating that it is empty or if she wakes through the night and need a diaper change or to be repositioned. Josephine also described headaches that were due to waking several times throughout the night. She stated,

> I get these bad headaches cause I don't sleep good at night. I'm up five or six times during the night to change him, give him medicine or suction him. I probably only get about four hours of sleep a night.

The responses for the theme, "Self-Care," showed that health problems are seen more frequently among single-parents. The sharing of caregiving responsibilities afforded the married participants' time for self-care. There are clearly other factors, such as dietary habits and other stressors which could have also contributed to the participants reported health problems. However this sample of participants expressed that their health problems were caused or exacerbated by the demands of caring for a child with severe cerebral palsy.

In summary, findings from the data relative to health problems show that caregivers of children with severe cerebral palsy report feelings of grief and loss, as well as physical health problems such as back pain, knee pain, and headaches. Although 66.7% of the participants reported their health status as 'very good', most participants also reported physical health problems they believe were the direct result of, or exacerbated by caring for their child with severe cerebral palsy. Parents described the rigorous task of lifting and carrying as the most physically demanding in caring for their child. This was greatly stressed among single parents

and the 11 parents of teenage children. They also reported daily dressing, bathing, and diaper changes as other physically demanding responsibilities. Many parents reported that their nightly sleep is often interrupted because of the need to change a diaper, give medication, or respond to an equipment alarm (i.e. feeding machine). Some parents expressed that they may only get four to six hours of sleep a night.

There were reported differences among parents who identified a significant other who assisted with the care of the child and those who were single parents. Single parents reported that caring for a child with severe cerebral palsy had adverse influences on marital relationships. Married parents or those who identified a significant other however, expressed that caring for a child with severe cerebral palsy had a positive influence on their marital relationship.

Research Question 2: Positive and Negative Statements

The second research question of this study ask, *What kind of positive and negative statements do African American parents make about caring for a child with severe cerebral palsy that are influenced by cultural and religious values?* The process of data triangulation yielded sub-themes and themes from the individual interviews and field notes. Eleven sub-themes emerged from the data relative to positive statements. After grouping the 11 sub-themes, 3 main themes were developed - *Pride in Child's Achievements, Self-Confidence, and Life has Purpose/Meaning*. Table 7 lists the eleven sub-themes that were grouped to form the three main themes.

Table 7: Positive Statements from Interviews

Main Themes	Sub-Themes
Pride in Child's Achievements	School performance
	Developmental milestones
	Family activities
Self-Confidence	Balance work and family/flexibility
	Gather information
	Advocate for child
	Coping with child's disability
Life has Purpose/Meaning	Advocate for child
	Value self-worth
	Help other families
	Rewards of caregiving

The positive statements recorded are discussed to give greater depth to the understanding of how this sample of study participants adjust to and cope with caring for a child with severe cerebral palsy. As noted earlier in Chapter 2, dependability is the aspect of trustworthiness that addresses the consistency or congruency of the results. By presenting the participants' statements verbatim, the researcher is able to maintain trustworthiness in the study.

Theme 2.1   Pride in Child's Achievements

Cerebral palsy is a condition which affects muscle control and tone. The symptoms of the condition become apparent with the course of child development when children do not achieve expected milestones such as seating unsupported, standing and walking independently. Several of the parent participants expressed how they were impacted and encouraged when their children made progress and achieved a particular milestone.

Barbara shared that one of the most memorable experiences for her was when her daughter was about three-years-old and held her bottle for the first time. She stated she was so

excited that she called her mother to share the news. Two other parents also reported an act of independence such as drinking from a cup or sucking from a straw as memorable experiences. These reported oral motor activities occurred beyond the infancy stage, which is the typical period for such developmental milestones.

Speech and language milestones were also noted as memorable moments. Eight of the parents expressed that when their child spontaneously said "mama" or a variation of it such as "ma" for the very first time it was one of their most unforgettable experiences. Josephine's account of her experience of hearing her son say "ma" was as follow:

> I'll never forget it. I hear it like it was yesterday. It was bedtime and I kissed him goodnight. As I turned to leave the room I heard it. It was as clear as a bell. I didn't scream or get excited cause I didn't want to scare him. I just hugged him with tears rolling down my face. Makes me want to cry just reminiscing about it.

Positive statements were also reflected in discussions relative to relationships between the children with severe cerebral palsy and their siblings. Flora described how her children include their brother in family activities. She stated,

> The kids love their Wii game. They even put a remote in Michael's hand so he can play too or at least it's like he's playing. And we like to eat. So we cook a lot. The kids make their own pizzas; bake cookies, make homemade ice cream. And Michael's right there with them helping too.

Parents expressed that they were not only elated in their children's achievements, but were also encouraged for their children's future potential. Because of those initial milestones, parents were optimistic their children would achieve more. This sense of optimism was also

realized in the parents' confidence in their own abilities to care for a child with severe cerebral palsy.

Theme 2.2   Self-Confidence

Responses that were coupled together and labeled with the sub-theme, *Self-Confidence*, were not limited in any regard. Parents described their abilities to navigate bureaucratic systems in order to address their children's needs. They shared how they spent countless hours researching books, the internet, and human resources in order to learn as much as possible about cerebral palsy. One parent described how he and his wife traveled out of state to an acclaimed cerebral palsy center to have their daughter evaluated by a world renowned pediatric neurosurgeon. Most parents also reported how they were able to manage the demanding schedule of care for their children. Maria stated,

> Taking care of her let me know how strong of a person I am, with being able to handle the stares, the questions, the juggling [of] her life of medications and appointments. It felt like a calendar in my head.

Josephine shared that although she had to go from working full-time to part-time in order to care for her son, she appreciated having the opportunities to observe his physical and occupational therapy sessions at school so she would be able to repeat the exercises with her son in his home environment.

Exercise and being physically fit were also described as ways of being able to manage the physical demands of caring for a child with severe cerebral palsy. Irene reported,

> I never used to work out that much until I realized he was getting too big for me to carry around. And even though I don't go to a gym or one of those workout

places like *Curves*, I run on my treadmill every day. I also have eight pound hand

weights that I use two or three times a day.

Maria was also motivated to develop a regular exercise routine when it became more difficult for

her to lift and carry her daughter. She stated, "I didn't really exercise that much other than going

for walks. But when she started getting bigger I knew I had to keep my strength up so I bought a

few workout videos for the Wii and do that as often as I can." Parents also reported other

healthy lifestyle choices such as avoiding stress, eating healthy, and not smoking.

Self-confidence was also evident in responses of the two parent participants who were

not the biological parents of the child with cerebral palsy. They both described the process of

becoming their child's primary caregiver as a natural occurrence. Natalie, grandmother of an 18-

year-old male stated,

Me and my husband didn't have to think twice about taking him. We knew his

mom couldn't handle it and we wanted her to go back to college so she could get

her degree and have more to offer him. So we did it and had him ever since. I

had never taken care of a child with CP or no other disability. But I was his

grandmother and I knew God would take care of us.

Olivia, legal guardian of her 14-year-old brother shared, "It was so hard on my mom. She was

so depressed, couldn't handle it. I was always there and was willing to do whatever I had to do.

I quit school and been taking care of him ever since."

Confidence in oneself and in one's powers and abilities can certainly be considered a

strength or attribute. For this study's sample of participants, self-confidence not only influences

their views and beliefs about raising a child with cerebral palsy, it is also influenced by those

beliefs as well. Parents recognize that seeing their child positively and their role as caregiver rewarding, presented them with a different perspective on life.

Theme 2.3   Life has Purpose/Meaning

When asked if they believe raising a child with a disability is rewarding and a challenge, or a burden and a hardship, parents responded unanimously that it is rewarding and a challenge. From these responses, the sub-theme, *Life has Purpose/Meaning,* emerged. Most parents expressed opinions that their role as caregiver to a child with severe cerebral palsy was a blessing, gift from God. One parent stated the following:

> Oh it is definitely a reward. I see that now. [He] is my blessing. I hate it when I hear people complain about having to care for their child. The child didn't ask to come into this world with a disability. I do admit that it is a lot of work and some days I don't feel like I can take it. But you just gotta pull it together and be there.

A second example is a response from Gladys. She stated that,

> Being a mother is rewarding within itself, but being the mother of a miracle child is even more of a blessing. There are definitely times when it's a challenge or you go through hardships trying to provide. But it doesn't make me angry or bitter. If anything I'm a better person because of it.

Daniel also expressed a similar viewpoint by stating,

> It's a reward and a challenge because, you know, that love is unconditional and caring for someone and taking care of someone is always the most precious gift that was given by God. And it's also a challenge, trying to meet her needs and to make sure that she's well taken care of. And has a full and productive, prolonged life.

Parents also believe that taking care of their child with severe cerebral palsy had influenced a positive change in them. Laura stated, "I think it's rewarding because I think I've learned a lot from my son. I mean I've learned patience. I've learned how to not take things for granted." Kiara also shared how she's been influenced by her child. She stated,

> I don't know how to explain it but I believe I am a better person because I am his
> mother. I used to be the one that cared about stuff that really didn't matter, like
> clothes and stuff. But now I really understand what should matter most in life.

In addition to the opinion that raising a child with severe cerebral palsy is rewarding, parent participants also acknowledged that it is challenging. Parents mostly related the challenges to financial hardships and the overwhelming physical demands involved in caring for their children with severe cerebral palsy. Access to resources and services was also reported as a challenge. Six of the parent participants expressed that their home environment (i.e. limited space, stairs, rural settings) created challenges for them in caring for their child with severe cerebral palsy. One parent described the constraints of her home as,

> I wish I had the finances to afford a bigger house. Giving him baths and just even
> being able to have him move around in his wheelchair is hard in this small space.
> We moved here after my divorce. At the time it felt like it was gonna work out,
> but now with him being so big we need more space.

A second parent stated, "I had to get a hospital bed for him and they put in the living room because it wouldn't fit in the bedroom. So that is where he sleeps."

Parents' descriptions of the challenges of caring for a child with severe cerebral palsy revealed some negative statements. For the purpose of this dissertation, negative statements are defined as statements that are discouraging or pessimistic. The following three sub-themes

emerged from the grouping of negative statements: *Single Parenting, Anticipatory Grief, and Financial Challenges.* These three sub-themes produced one main theme – *Caregiver Burden.* The following table highlights interview responses that generated the sub-themes which were later consolidated into the one main theme.

Table 8: Negative Statements from Interviews

Sub-Themes	Interview Responses
Single-Parenting	Marital disruption Carrying the full load of responsibilities Changes in life plans/long-term goals Interrupted education
Anticipatory Grief	Sense of loss Prognosis Unpredictable health problems
Financial Challenges	Unexpected medical expenses Loss of employment/income

Theme 2.4 Single-Parenting

Several statements from parent participants emphasizing the challenges of caring for a child with severe cerebral palsy were directly related to their status as a single-parent. Parents expressed that they are often overwhelmed in their caregiver duties, which led to feelings of frustration, grief, anger and disappointment.

Several parents shared their reluctance to trust others and questioned the genuine intentions of others. Flora stated, "They seem to care, but sometimes I feel like they are just nosey. Want to know more about why he is the way he is, not really wanting to get to know him or build a relationship with him". Another parent participant expressed her frustration with not being able to socialize outside the home in the following statement,

I definitely don't want to sit around a lot of folks answering question after

question about what's wrong with her. And since she has a shunt I am very

careful taking her out in bad weather. And that's half the year in Michigan. And

she wears a diaper so I have to think about where I can change her when we go to

somebody's house or bolus feed her. So we don't go nowhere, just stay in the

house. And I don't like always being cramped up inside the house but what else

can I do?

Balancing the demands of caring for a child with severe cerebral palsy and attending

college was overwhelming for a few parents. Irene shared that it was necessary for her to quit

college after two semesters. She stated,

It just got to be too much. I was turning in papers late and missing a lot of

classes. Some of my professors understood my situation and tried to work with

me, but even then I couldn't keep up. So I came to realize that I wasn't gonna be

able to do it.

Olivia, the legal guardian of her younger brother with severe cerebral palsy shared that after

becoming her brother's primary caregiver, it was necessary for her to withdraw from college.

She stated,

I was only in my first semester when we went to court. So I didn't have a lot

invested in school. But gotta admit I was disappointed that I wasn't gonna get a

college degree. I keep thinking I might be able to go back one day, but I know it

probably won't happen because [he] needs so much attention.

Parent participants discussed sacrifices, role changes, and deferred goals with a sense of

grief. Statements describing concerns for their children's well-being reflected feelings of

sadness and fear. Fear was often linked to discussions of long-term care for the child.

Recognizing the severity and vulnerability of the child's condition, parents struggled emotionally

with the limited options that would be considered for long-term care of their child. These

statements were grouped under the label, *Anticipatory Grief*.

Theme 2.5 Anticipatory Grief

Parents expressed fear and sadness when sharing their reactions to the probability for

difficult problems related to caring for their child long-term in the home environment. Most

parents shared that these reactions occurred when learning of potential health problems for their

child. Although the majority of parents rated their child's health as fair, parents also expressed

concerns of possible complicated, life-threatening health problems for their child with severe

cerebral palsy. Edana expressed her biggest concern is her son dying. She stated, "Just don't

know what could happen. Don't know if that cold is gonna be what takes him". Daniel made

the following statement:

> Her hip, body twists and so I'm concerned that it may get worse, sliding out of
>
> socket. Any type of pressure on her hips. I don't want her to be in pain. Will she
>
> live a long life without that affecting her, hurting her in any way?

Gladys stated,

> Since she has a shunt and will need it all her life that scares me. I've heard some
>
> horror stories about the shunt not working properly, leaking, causing infections so
>
> it does make me a little paranoid. Of course there are no guarantees in life. I
>
> don't know how long she will be here with me or even how long I will be here for
>
> her.

Barbara also described her concerns regarding long-term care. She has considered out-of-home care for her 18-year-old daughter in the event she and her husband were no longer able to care for her. She stated,

> With me in my 40s and he's in his 50's we worry about where she would go. I wish there was a place, a group home just for children and young adults with CP and focused on Black children. We don't have anything like that. And that is important when you think of something as simple as taking care of our hair. I want her to be cared for by people who look like her, like us.

Through further elaboration, Barbara explained the ideal group home should serve only children with cerebral palsy because "they are always overlooked" and she believes they would not get the specialized attention they deserve if grouped with children and young adults with other disabilities, particularly less severe disabilities.

Like many other parent participants, Barbara's concern regarding long-term care options for her daughter was tied to financial security, as well as other circumstances. Finances were the focus of many negative statements from the parent participants. Parents linked their financial struggles to expenses such as unexpected medical costs, as well as to the loss of income/employment.

Theme 2.6 Financial Challenges

Negative statements from parent participants relative to financial challenges focused on two issues, unexpected medical expenses and loss of income. As noted earlier in this chapter, the employment status for most participants changed dramatically after the birth of their child with severe cerebral palsy. The full-time employment status of sample participants went from 80% before birth to approximately 33% after the child's birth. Although there were no reports of

regret in their decision to reduce employment for the sake of meeting their children needs, many parents however expressed the impact of their loss of employment. Flora was one of the parents who described leaving her job. She stated,

> I used to work for the sheriff's department as a dispatcher. They were supportive of me at first. You know giving me a different shift to work, understanding when I had to call off because my daughter was sick. But after a while they basically told me I couldn't keep missing days. And I know it was a problem because they would have to find someone to come in at the last minute. So I knew then I had no other choice but to quit. I hated it. I missed my job, still do. But I did what I had to do.

Hilary described the transition of going from full-time employment to part-time employment. She shared,

> My husband and I realized that both of us couldn't keep working full-time and be there for her like we needed to be. So we decided that I would go to part-time. I love the flexibility to be home with my daughter, but it has put a strain on us financially. So we don't do the things we used to do like eating out, or traveling.

Like Hilary, other parents shared how the loss of income negatively impacted their ability to engage in leisure activities. Irene shard, "I used to get my hair done every other week. A manicure and pedicure every month, faithfully. It was my treat to myself. But I couldn't afford it anymore. I miss pampering myself. It made me feel good".

Parent participants also reported that in addition to the loss of income, they also suffered a loss of personal healthcare insurance. Olivia shared that prior to her son's birth she worked full-time with an employer who provided medical, dental and vision employee benefits.

However, after her son's birth, she transitioned to part-time employment and became uninsured. Of the sample participants, Hilary was the only parent without healthcare insurance.

Despite these noted challenges and negative statements, there were no reports of resentment toward the child with severe cerebral palsy. This sample group of parents displayed confidence in their abilities to care for their child with severe cerebral palsy. They described necessary changes made in their budget to accommodate income loss, as well as sacrifices of personal care needs. Although parent participants reported many challenges in their role as caregiver of a child with severe cerebral, they also reported numerous strengths they've applied to help them positively adjust to and cope with their child's severe cerebral palsy.

Research Question 3: Informal and Formal Support Resources

The third and final research question of this study asks, *What types of informal and formal community resources do African American parents caring for a child with severe cerebral palsy utilize?* Parent participants reported on support resources utilized and underutilized. Data analysis of the 15 interviews identified four categories of informal support resources – *Immediate Family, Extended Family, Friends, and Neighbors.* Parents in this sample described immediate family support as support from members of their household, which mostly referred to parents and siblings of the child with severe cerebral palsy. Live-in partners were also included in the immediate family category. Extended family referred to family members outside of the home who were a blood relative of the child with severe cerebral palsy.

Theme 3.1 Informal Support Resources

As was shown earlier in this chapter in Table 6, a majority of parent participants (80%) identified immediate family as an informal support resource. Parents described support from spouses, children, live-in partners and other relatives residing in the home. Both of the

biological fathers in the sample identified their wives as most supportive. Charles described his

support as follow:

> My wife is it. She is always there taking care of our daughter, of me. We take
>
> care of each other. It's basically just a small support channel. I have friends and
>
> family that I could call on but that's a last ditch.

Four parents identified an older sibling of the child with severe cerebral palsy as their support.

Claudia described support from her daughter. She stated,

> She was only ten when he was born and has been a big help. Whatever I need,
>
> she's right there. Even when she don't want [to]. I can see it in her eyes. I can
>
> see tired, frustration in her eyes, [but] she never complains.

Flora identified the support of her mother by stating,

> My mother is great. When I feel discouraged or scared she knows what to say to
>
> help me understand. Her health is getting bad, she is a diabetic so I try not to
>
> bother her but she loves him and always there for us.

While discussing support, several parents also shared struggles in seeking assistance from

family and friends. Barbara stated,

> Most of our neighbors are getting older and they're getting close to retirement age
>
> and stuff, whereas in the past, they were able to help us. The people who have
>
> supported us, they're getting older. They're older than us. And then our friends
>
> that we do have, they don't live close by. Their kids are growing up. They're
>
> getting older.

Linda's comments were as follow:

I have my girlfriends that I get together with for a girls night out but I ain't did

that for about three months now. But they do call and ask how things are going. I

think they want to help out more but they have jobs and families too and just can't

be there for everybody.

Although several parents reported on limitations of their informal support resources, they

also expressed appreciation for the level of support they did receive. Edana stated,

I kinda know people's limitations and I'm fine with their limitations because what

they're comfortable doing, it helps me out. Like going to a drug store to pick up

prescriptions. One less trip I have to make, one less line I've gotta stand in. So I

think that's like one of the biggest reliefs. So I'm very happy for just even those

little things.

Three of the parent participants reported self-help groups or online chat rooms as a

support resource. However, at the time of data collection, all reported they were not currently

participating in the support groups, but they had participated within the past six months. Gladys

described her experience with a self-support group. She stated,

I attended these Family-to-Family events. They were once a month. You meet

parents of children with disabilities. Share your stories. Learn how they're

handling situations. It's a nice outlet. Nice to be with other people experiencing

some of the same things I'm going through. But I haven't been in a while. The

summer gets busy with activities and then school just started.

Like Gladys, the other two parents also stated that demanding schedules were the reasons for

their inactivity with the identified support groups. It was also reported that parents did not incur

expenses as a result of participating in the support groups.

Theme 3.2 Formal Support Resources

When identifying utilized formal support resources, only one resource was identified among the sample. A majority of the sample (80%, n=12) reported a religious affiliation. However, when describing support relative to their religious affiliation, only three of the 12 parents expressed that their church was supportive. The remaining nine reported that their church provided very little, if any support. Gladys stated, "I don't find that they give me any support. I mean when I go, they ask about my daughter and offer prayers. But that's the extent of their support." Several parents stated that they sought support or comfort in their spiritual beliefs and not necessary in their church. These beliefs were described as "faith in God", "power of prayer", and "God's healing power".

Parents further distinguished between their religious affiliation and spiritual belief when discussing their level of attendance at worship service or other church related activities. One such example is a statement from Flora. She stated, "Yes, I belong to a church. My family go to Church of God in Christ, but I don't go to church. I know there's a God and I pray, but I just ain't into the church thing". Aaron explained that he believes in God and lives a "Christ-like" life, but due to his work schedule and demands of caring for his daughter, he and his wife do not attend church services. He stated, "I believe in getting proper rest from work and getting rest so I can go to work and take care of my family". Two parents reported that their churches were not easily accessible due to the fact that the only way to enter the building is by way of steps, and unfortunately neither of the churches had a wheelchair entrance ramp.

Parent participants also described feelings of rejection from their church.   Irene shared the following:

I don't go to church anymore because of the way they treat us. I feel so

uncomfortable. You get the stares. He drools a lot and sometimes he has loud

outburst. And they seemed annoyed by it. Then some of them come right out and

tell me I should stay home. They say something like, I'm surprised you came out.

I thought you would have kept him out of the cold. Stuff like that. I know what

they really mean. So I stay home.

Similar feelings were expressed when discussing other formal support resources such as

community-based resources. Parents were asked to share any resources they would like to use

but had not and the reasons for not utilizing the resources. Although parents acknowledged that

some services were not utilized due to financial barriers, many parent participants reported that

experiences with rejection and discrimination influenced their decision to not access formal

support resources. Edana shared an experience when visiting a doctor's office. She reported,

Just seeing you and your physical presence, they make assumptions that you are

uneducated. It's like they think they doing you a favor. I don't like that. And I

hate that they make us wait for so long. It don't make no sense. They should

make it so that you don't have to wait more than 15 minutes. Sometimes it takes

me a hour just to get to the appointment and he gets fussy. It's very tiring.

Flora also shared an experience at a physician's office. She stated, "I feel like white people get

more sympathy than Black people. When I'm in the waiting room they look at you like

something wrong with you. It's like they think you ain't a good mother".

Parents also shared their opinions of the cultural competence and sensitivity of

professionals. Parent participants reported instances where professionals exercised less than

acceptable demeanor when they encountered them. Gladys described an incident that led to her filing a formal complaint against a professional. She stated,

> When we were at the developmental assessment clinic, a social worker came to talk to me. I didn't know her and wasn't expecting to talk to a social worker. We were waiting for the therapist. So she introduced herself and went right into telling me about special programs for low-income families. I interrupted her and informed her that I didn't qualify for those programs. But she just kept telling me that organizations can help poor minority families with services and I shouldn't feel ashamed asking for help. I was shocked. I asked her what made her think I was low-income. She said the majority of Black families seen at the clinic are low-income. I was so upset. I asked for a supervisor and filed a complaint.

It is important to note that Gladys was one of the five parents who remained employed full-time after the birth of her child with severe cerebral palsy.

Hilary reported that when she met the principal of her daughter's school for the first time, the principal was surprised to learn that she had a master's degree. The principal remarked, "You have a master's degree. Where did you go to school?" As a result of the principle's insulting remarks, Hilary considered withdrawing her daughter from the school, but her husband convinced her otherwise.

These reports of culturally insensitive care from professional service providers led to parents expressing much frustration and reluctance to seek services. This is consistent with prior research that also noted the consequence of cultural incompetence and insensitivity (Freedman & Boyer, 2000; Thornton, 2002). Beyond formal support resources, parent participants also

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expressed frustration with the limited information about African American families caring for children with severe cerebral palsy currently available.

Motivation to Participate in the Study

The interview concluded with the researcher asking parent participants why they choose to participate in the study. Eight of the parents responded that they wanted to share their stories with other African American parents of children with cerebral palsy in hopes that it will encourage them, give them hope, and let them know they're not alone. Laura stated,

> I actually read your paperwork and it was like for African Americans, that kinda got me because I feel like a lot of African Americans are left out in the dark with a whole lot of things that they don't know about and that's been like one of the biggest things. I'm always trying to pass information along to the next person.

Charles expressed that he, "just want to get the word out there and let them know that they're not alone because I'm sure there's probably a lot of Black kids out there with [cerebral palsy] and people are not aware of it." Josephine responded, "I think as Black people we just don't know enough about [cerebral palsy] and so we don't know what to do or how to help our family."

Four participants shared their motivation to participate in the study was in part due to the fact that the researcher was an African American parent of a child with severe cerebral palsy. Kiara stated, "Well, when you came to talk to our group it was nice to know someone understood what other Black families were going through so I didn't mind talking to you for the study." Flora expressed a similar sentiment in her response. She stated,

> I wanted to do it because when [the principle] told me about it, she said it would help Black families. But I was like why do white folks always want to know how

we raise our kids. I didn't realize you were Black. And I'm glad cause I don't

think I would have said as much if it was a white person.

The researcher's background also influenced Gladys' decision to participate in the study. She

stated,

When I read the flyer, it looked really interesting. But what really convinced me

to do this was our telephone conversation. I was happy that you were Black and

the parent of a child with CP. I knew you were genuine and what you were trying

to do would only help us.

In conclusion this chapter describes several characteristics of the sample of parent

participants and their children with severe cerebral palsy. Interesting findings relative to the

parents' role as caregiver to their children with severe cerebral palsy are also presented. The

findings from the data describe the lived experiences of these parents and how such experiences

have influenced them in their caregiving role.

Parents are self-reliant in meeting their children's needs. They rely upon and exercise

their own judgment in addressing problems relative to their child's daily needs, medical care, and

education. Parents are able to identify the challenges they face in their caregiver role. They

present multiple strengths in recognizing and addressing these challenges. Parents limit seeking

support beyond informal support resources.

Parents have experienced discrimination, dismissive attitudes, and rejection, all of which

have led to mistrust of many formal support resources. And lastly, parents were motivated to

participate in this study in order to share their stories in hopes of helping other African American

parents of children with severe cerebral palsy, and because the researcher was also an African

American parent of a child with severe cerebral palsy.

As discussed earlier in the *Methodology* chapter, thematic coding was used for the analysis phase of this research. The process of developing categories or open coding from the interview responses identified main themes. Interconnecting those categories, also referred to as axial coding, established sub-themes. The final step of thematic coding is selective coding which allows for building a story that connects the categories. Table 9 is a flow chart linking the research questions with the emerged themes and sub-themes. These themes and sub-themes characterize the factors which contribute to the adjustment and coping of the fifteen African American parents of children with severe cerebral palsy who participated in the study.

Table 9: Research Questions and Coding

RESEARCH QUESTIONS	OPEN CODING	AXIAL CODING	SELECTIVE CODING
What types of health problems do African American parents experience as a result of caring for a child with severe cerebral palsy?	Parents reported physical and mental health complaints while also stating their health was generally good.	Sense of Loss Relationship with Significant Other Self-Care	Self-Reliance
What kind of positive and negative statements do African American parents make about caring for a child severe cerebral palsy that are influenced by cultural and religious values?	Parents reported meaningful, positive experiences associated with caring for a child with severe cerebral palsy.	Pride in Child's Achievements Self-Confidence Life has Purpose/Meaning	Caregiver Strengths
	Parents reported painful, depleting, and negative experiences associated with caring for a child with severe cerebral palsy.	Single-parenting Grief Financial Challenges	Caregiver Burden
What types of informal and formal community resources do African American parents caring for a child with severe cerebral palsy utilize?	Parents reported some informal support from immediate family and friends and to a lesser extent, neighbors and online groups.

Almost no formal support reported by parents. Religious faith and spirituality was the only consistently identified formal support resource.

Parents reported rejection and poor mannerisms on behalf of church members. And similarly, parents expressed rejection and insensitivity by professional service providers. | Dismissive Attitudes Discrimination Rejection | Mistrust |

CHAPTER 5

DISCUSSION

This study explored the lived experiences of a sample of 15 African American parents of children with severe cerebral palsy. The study was initiated to better understand how these parents adjust to and cope with their child's severe cerebral palsy. The results chapter demonstrated the many factors that influence parents' adjustment and coping. The four themes that developed as a result of responses from most of the sample participants were *Self-Reliance*, *Caregiver Burden, Caregiver Strength, and Mistrust.* All of the themes have a relation to caregiver health, cultural and religious beliefs, and formal and informal support resources.

The findings of this study were consistent with other studies (Breuhat et al, 2004; Krigger, 2006) that found parents of children with severe cerebral palsy experience health problems as a result of caring for a child with severe cerebral palsy. Although the incidence was higher among single parent participants than the married parent participants, collectively, study participants reported back and hip pain and headaches as the most frequently experienced health problems. Parents expressed that these health issues resulted from the physical demands of lifting and carrying the child with severe cerebral palsy and because of the frequent disruption of sleep, which was largely due to meeting the child's immediate needs such as diaper changes, feedings, dispensing of medication, or to soothe and comfort the child.

Relative to the discussion of parents getting medical attention for their health issues, an overwhelming majority of parents reported that they did not seek medical attention and relied on over-the-counter medications and products for relief. Parents explained their reluctance to seek medical attention was mainly due to time constraints and expenses. Although all but one of the parent participants were covered under a health insurance plan, the reality of expenses for doctor

visit co-pays and medications have the potential to be a financial burden for some families.

Parent participants experienced loss of employment and income, interruption in education, marital separation, and limited social activities outside the home environment, which are consistent with findings from previous studies (McDaniel, Hepworth, & Doherty, 1992; Singer & Farkas, 1989; Seligman & Darling, 2007). The loss of employment and income has gravely impacted parents in their ability to best meet the needs of their child with severe cerebral palsy. Living conditions were not optimal for the child with severe cerebral palsy and options to acquire a larger home or more easily accessible home was not sustainable for families as they did not have the financial resources to support such an endeavor. Parents also reported that limited income hindered them in securing adaptive equipment such as a lift or accessible vehicle, both of which would address health problems caused by lifting and carrying their child with severe cerebral palsy.

Additional findings showed that parents relied heavily on their own knowledge, capabilities and judgment to address the challenges they faced relative to meeting the needs of their child with severe cerebral palsy. Parents demonstrated resourcefulness and initiative in gathering as much information as possible about cerebral palsy from multiple sources. In this quest to gain knowledge and understanding, parents discovered that information relative to African American children with severe cerebral palsy was extremely limited. Parents did not find educational materials that spoke to the experiences of African American parents of children with cerebral palsy, nor saw such families depicted in any form of mass media. Parents expressed a desire to have a better representation of their experiences in materials designed to educate the general public about cerebral palsy. Although this study did not examine educational materials about cerebral palsy to determine if African Americans were presented and discussed,

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the literature substantiates that African American children with cerebral palsy are grossly underrepresented in research studies (Britner et al, 2003; Copeland, 2005; Ha, Greenberg, & Seltzer, 2001; Huang & Coker, 2010; Patterson & Blum, 1993).

Parents also realized that as a community, African Americans are not informed about cerebral palsy or aware of the resources available to assist families caring for a child with cerebral palsy. This has since motivated parents to take an active role in creating awareness about cerebral palsy in the African American community. Parents hope this knowledge will provide other parents with better support, as well promote a better understanding of cerebral palsy. Parents' motivation to participate in the study was also due to the lack of information available about the experiences of African American parents of children with severe cerebral palsy. They participated with the hope that other African American parents would be inspired by their stories and realize they are not alone.

The conceptual framework used for this study was a model developed by Rogers-Dulan and Blacher (1995). Their model, *African American Families, Religion, and Disability*, suggests that religious connectedness, culture/ethnicity, and family structure and functions influence the interpretations, coping resources, and adjustment of African American families with children with disabilities. Findings of this study showed that the presence of a child with severe cerebral palsy did not negatively impact the fundamental values of the parents, which is the essence of the Rogers-Dulan and Blacher (1995) model. However, there was some ambiguity of the influences of the model's three social contexts – religion, culture, and family.

The significance of religion was strongly demonstrated by parents. They relied on their religious beliefs to make sense of their experiences and seek understanding of their child's condition. Religious faith gave them comfort in their grief and provided support in their overall

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coping. Parents distinguished that support was central to their belief in God and not as a result of

their religious affiliation. Since the birth of their child with severe cerebral palsy, parents were

no longer participating in church related activities. Parents did not believe their lack of religious

activity as prescribed by their church, was incongruent with their religious values. They found

the church to not be a supportive resource, but found solace in their belief in God.

Differentiating between support from the church and support from religious beliefs can be rather

taxing as many theologians would argue they are one in the same (Krause et al, 2001). Parent

participants desired to get positive support from their church and were disappointed and

saddened when support was not provided, which influenced parents' decisions to no longer

actively participate in church activities.

Parents depend on immediate family within the household and friends for assistance.

Parents struggled with securing support from other informal support resources such as extended

family. This was due to multiple reasons such as individuals lived far away, had demanding

lives, or were limited in their abilities to provide care. This finding is not consistent with

findings from other studies. McAdoo (2007) and Hill (2003) along with other researchers

asserted that African Americans value and utilize extended family as an informal support system,

particularly for vulnerable and fragile families. For the participants of this study, their child's

condition played a role in the extent of support provided by extended family members. This

issue is relative to an earlier discussion on the need to better inform and educate the African

American community on cerebral palsy. Bringing about awareness and educating the African

American community could increase comfort levels and promote greater support within African

American families and the community at large.

Older siblings of the children with severe cerebral palsy also played a critical role in

family adjustment. There was a sense of unity, connectedness, and acceptance of necessary role changes. Of the 15 children in the study, all but three had siblings, most of which were younger. Research studies have noted that siblings are also affected by the child's disability (Kaminsky & Dewey, 2001; Longo & Bond, 1984; Vadasy et al, 1984). Although this study did not inquire into the relationship of siblings, parent participants did not report any incidents of problems with sibling relationships.

Overall formal support resources were not utilized by parents. These findings are consistent with prior research that indicated that African Americans are less likely to utilize formal support systems and more likely to depend on family for support (McAdoo, 2007; Uttal, 1999). Parents reported they did not seek out formal support for themselves directly, but mainly utilized services that directly benefit their child with severe cerebral palsy. Of the formal services utilized, some parents reported negative experiences. Parents encountered cultural incompetence and insensitivity from professional service providers. Parents believed racial stereotypes influenced assumptions which professionals made about their circumstances and level of need. When asked what formal support services parents would like to utilize, most replied they were in need of services that would provide financial support, equipment, or medical supplies. Parents expressed they are not sure where to reach out to as they believe they are misguided by professionals.

Parents were not resentful of the challenges they faced or the limited support available to them. Parents had an appreciation for their child's life and believed that as a result of caring for a child with a severe disability they were a better person. They expressed that they understood the true meaning of life and their purpose in life. And although parents expressed sadness for the loss of the life they had planned to live, they were hopeful for the life they were living. Based on

these findings, Figure 2 was developed to identify all the factors parents reported as contributing

to their adjustment and coping with their child's severe cerebral palsy.

Figure 2: Factors Contributing to Adjustment and Coping
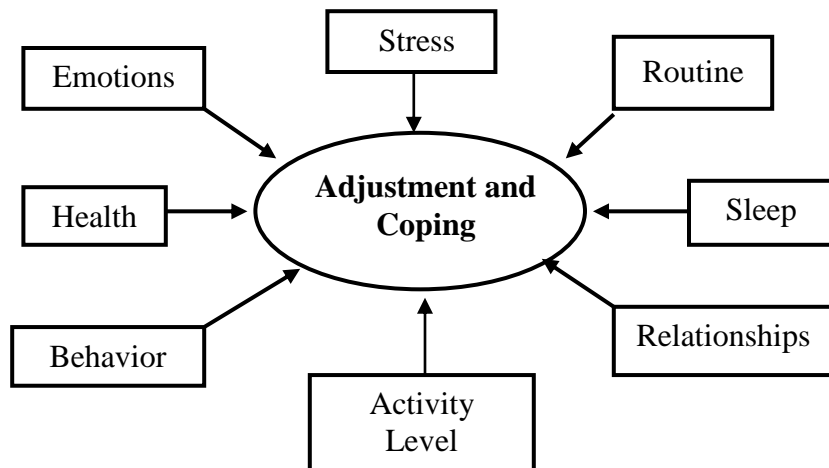
Implications

Social Work Practice and Research

This study has implications for social work practice and research. The social work profession plays a vital role in addressing the needs of African American children with severe cerebral palsy and their families. Social workers provide services in medical, education, private and public social service settings. Social workers not only provide children with disabilities and their families resources to help meet their needs, they are also advocates and influential in policy development. The role of social work in meeting the multiple needs of these families is even more critical when considering that life expectancy is improving for children with severe disabilities, and they are likely to remain in their home environment throughout their lifetime.

African American parents of children with severe cerebral palsy face financial hardships, physical and emotional challenges, and because support is limited, they often make great sacrifices in their personal goals and ambitions. As the profession of social work strives to promote self-determination among the populations they serve, social workers could be instrumental in developing policies and implementing programs that help alleviate some of these hardships.

Parents in the study who earned an income above the poverty rate, but still experienced financial challenges due to health care related expenses for the child with severe cerebral palsy, expressed they were often denied services which provided financial support. Although their child's medical condition met the criteria for services; these parents were determined ineligible for services because of their annual income. An example of such a program is Medicaid. The income eligibility requirement for Medicaid for children with disabilities who are under the age of 18 and live with their parent(s) is 100% of the poverty rate. So in essence, for a family of

three (which was the average household size for this sample of parent participants), parents' annual income could not exceed $19,090.   Based on this standard, less than a fourth of this study's sample could potentially be eligible for Medicaid.

Findings from this study also suggest that social workers, and other professional service providers, need to improve upon cultural competence and sensitivity skills. When social workers demonstrate awareness for cultural differences and find ways to integrate the cultural values of African American families into their delivery of services, families feel more supported and believe their views and opinions are valued in the decision-making process. Cultural competence and sensitivity can also foster positive working relationships and facilitate more engagement of formal support resources by African American families.

A review of the literature for this study exposed a major gap relative to African American children with severe cerebral palsy and their caregivers. This may in part be due to limited federal funds available for the study of cerebral palsy and its impact on caregivers. According to National Institutes of Health (NIH) funding for cerebral palsy was $29 million dollars in fiscal year 2009. An estimated number of new cases of cerebral palsy diagnosed each year is approximately 12,000, subsequently $2,400 Federal research dollars were spent for every new case of cerebral palsy. In comparison, $93 million Federal dollars were spent on cystic fibrosis research. There is an estimated 4,000 new cases of cystic fibrosis annually. Thus, $23,000 Federal research dollars were spent for every new case of cystic fibrosis, a 10-fold difference over that spent for cerebral palsy research. This is an alarming comparison when considering reports that cerebral palsy in children is higher than childhood cancer, hearing and vision loss, spina bifida, hemophilia, fetal alcohol syndrome, cystic fibrosis - and similar to the prevalence of

Autism in 8-year-old children (American Academy for Cerebral Palsy and Developmental

Medicine, 2012).

The findings of this study recommend more research aimed at understanding the impact

of cerebral palsy on African American families. The presence of African Americans in research

can be increased by a variety of methods, including partnering with key stakeholders in the

African American community. Findings from the study were consistent with results from other

studies (Hurtado, 1994; Taylor, 2009), which show that African American families are more

likely to participate in research studies when the researcher has a similar racial/ethnic

background. Therefore measures should be taken to increase the number of African Americans

conducting research.

Religious Community

This study also has implications in the religious community, particularly among Black

churches. Although there is little research pertaining to the attitudes of members of Black

churches toward children with severe disabilities, they are regarded as having great influence in

the Black community in areas of health, politics, and other societal issues (Aaron, Levine, &

Burstin, 2003; Freedman, 1993; Markens, 2002).

Black churches can play a major role in educating their members and the Black

community about cerebral palsy and the challenges families face when caring for a child with

cerebral palsy. First however, it is critical that leaders within the church have a clear

understanding of cerebral palsy and its impact on families. Once they are confident in their level

of understanding, they could disseminate information through sermons, workshops, and

community outreach events. It would be ideal for the church to identify members with

disabilities who could serve as ambassadors for the church. This strategy not only empowers

individuals with disabilities, it allows for more leadership of individuals who are otherwise often marginalized.

Black churches can also be instrumental as liaisons between the religious community and community agencies serving children with cerebral palsy. They could become knowledgeable about the resources available and procedures to access services. This would certainly require that those identified community agencies value the role of the Black church and assert a desire to engage with the Black church in an effort to create greater awareness about cerebral palsy, as well as address the unique needs of African American parents caring for children with cerebral palsy.

Through these recommended measures the Black church can establish a greater relationship with families of children with severe cerebral palsy. By demonstrating an understanding of cerebral palsy more consideration could be exercised for the needs of the child as well as their family. The church will then be a model for the community in recognizing the frailty and promoting the dignity of children with severe cerebral palsy.

Limitations of the Study

There are several noted limitations in this study. The lack of literature that looks specifically at the experiences of African American parents of children with severe cerebral palsy was a limitation to this study. Additionally, there is very limited research on the cultural values and beliefs of African Americans about childhood disabilities. This was challenging as there was minimal evidence to substantiate findings from this study relative to adjustment and coping of African American parents of children with cerebral palsy. This study will therefore contribute knowledge and close gaps in the literature relative to the studied population. There were several noted studies in the literature that looked at the impact of caring for children with

severe disabilities; however African Americans were not well represented in those samples. Questions from the developed interview guide for this study gathered data specific to the impact of cerebral palsy on caregiver health and family dynamics. Again, providing insightful information and addressing a gap in the literature.

Although the sample size meets the standards for saturation, it poses a limitation for generalizability. Of the fifteen participants, only two were men. And although they greatly contributed to the findings of the study, generalizability of the findings may be problematic with fathers. However, the design of this study was not intended to produce a generalizable model. But because the study is transparent, offering a comprehensive explanation of the steps taken in its design and implementation, it has the potential of being adopted for exploratory research on African American fathers, as well as other minority groups caring for a child with severe cerebral palsy.

The three measurement instruments used were developed for this study. Since they had never been used in any prior research, measurement validity, the extent to which measures indicate what they are intended to measure, poses a limitation for the study. The three instruments were pilot tested with parents of children with disabilities, a center-based school social worker, and an African American and African Studies doctoral student; all of whom were African Americans. Pilot testing instruments used in qualitative research can help to establish content validity (Creswell, 2006). Additionally, members of the researcher's dissertation committee and the Michigan State University Committee on Research Involving Human Subjects reviewed and approved each of the instruments before they were utilized.

There are several inherent limitations in qualitative research. Bias in data interpretation is an often-cited potential problem. Data triangulation or the cross-checking of data with

multiple sources (observations, interviews, and questionnaires) was used in this study to help establish corroboration of data findings.   This popular practice among qualitative inquirers results in a narrative account that is valid because researchers go through this process and rely on multiple forms of evidence rather than a single incident or data point in the study (Creswell & Miller, 2000). Investigator triangulation was a second technique used to address bias in data interpretation. Data from the interviews, questionnaires and notes taken during the interviews were reviewed by the researcher and two other individuals.

Similarly, self-reporting is an often-cited problem in qualitative research. It can create issues relative to over- or underreporting, as well as poor recall. Respondents may provide answers they believe the interviewer prefers rather than providing their own unique answers. This study collected data using in-depth interviewing, which increases the likelihood of honest reporting. According to Grinnell and Unrau (2008), "for most people, it is easier and more natural to respond to questions orally than in writing, and a casual, relaxed setting leads to more spontaneous answers" (p. 240). Interviews for this study were conducted in participants' homes or a location of their choosing.

Assuring confidentiality also motivated accurate reporting from participants. Research has shown that in qualitative research studies, participants may answer differently, with a less valid response, when they think that their privacy may be compromised (Gillis et al, 2001; Grinnell & Unrau, 2008; Ritchie & Lewis, 2003). The researcher took several steps to maintain confidentiality. Identifiable information was separated from data. Surveys, audio recordings, and transcripts for each participant were labeled with an assigned number. The list of assigned numbers was the only evidence of which participant corresponded to the data. Identifying characteristics, such as names were changed when reporting findings.

As discussed earlier in this chapter, the researcher is an African American parent of a child with severe cerebral palsy. Therefore the researcher has first-hand knowledge and understanding of the challenges experienced by African American parents caring for children with severe cerebral palsy. This background certainly presents the potential for bias. The researcher recognized the probability of this limitation in the initial stages of the study's development and design. Precautions were taken at all stages of the study that included consulting with key informants, debriefing with dissertation committee members and colleagues not affiliated with the study, taking meticulously detailed notes, and journaling.

Despite all the noted limitations, this exploratory study gives voice to African American parents of children with severe cerebral palsy. It provides useful foundational information about a population that is seriously underrepresented in the research literature. The findings from this study have relevance for current practice and future research. This study identifies with the challenges, strengths, and values of a sample of African American parents caring for a child with severe cerebral palsy and proposes suggestions for which to apply those characteristics in identifying and addressing the needs of this group.

Researcher's Reflections

Meeting the eligibility criteria for participation in this study, as an African American parent of a child with severe cerebral palsy, was a unique challenge for me as the principal investigator of this study. As much as I recognize and appreciate how my personal experiences were a motivator to initiate and complete this project, it also presented complications. While conducting the study I was reminded of my own struggles in caring for my daughter and subsequently experienced feelings of sadness and fear.

I am without regret in conducting this study and believe that the richness of what was gained from the study is in part due to the fact that I have a keen understanding of this exceptional population. However, based on this experience, I would take great caution in conducting similar studies. As much as I prepared for hearing the stories of the participants, it was difficult at times to not allow their emotional responses to affect me. In review of my field notes, I realized that on four separate occasions, I cried after leaving the parent participant's home. I was overwhelmed in sadness for their experience, and also fearful for what I could possibly experience with my daughter. It was a great support for me professionally and personally to express those feelings of sadness and fear with a trusted colleague, not associated with the study. This proved to be invaluable in helping to achieve trustworthiness in the study.

Conclusion

The aim of this study was to gain insight into the lived experiences of fifteen African American parents of children with severe cerebral palsy. Using a phenomenological approach, this study explored the influence of caregiver health, cultural and religious values, and support systems on adjustment and coping of the parent participants. What was realized is that African American parents are self-reliant and resourceful in meeting the needs of their children with severe cerebral palsy. Although African American parents of children with severe cerebral palsy face challenges that at times are overwhelming, they do not respond to their situation with resentment or bitterness. African Americans are positively adjusting to and coping with their children's severe cerebral palsy. Despite the fact they experience sadness for the loss of the life they had planned to live, they are hopeful for the life they are living.

APPENDICES

APPENDIX A

Recruitment Letter to Potential Parent Participants

Dear Parent,

My name is Rita Walters and I am a doctoral candidate at Michigan State University School of Social Work. My dissertation research is titled, *Adjustment and Coping of African American Parents of Children with Severe Cerebral Palsy* and has been approved by the Michigan State University Institutional Review Board. Through this research I hope to better understand the unique needs, cultural values and beliefs of African American parents caring for a child with severe cerebral palsy.

I am recruiting African American parents of children between the ages of 5 and 18 who are diagnosed with severe cerebral palsy. Participation is voluntary and will be kept confidential. It involves completing three brief questionnaires and a one-on-one interview to be conducted in your home. I anticipate that the entire process will take approximately 60 minutes of your time. As an appreciation for completing the study, participants will receive a $25.00 Meijer or Wal-Mart gift card.

If you are willing to participate or would like to learn more about the study, please contact me at 517-256-0091 or via email at walter99@msu.edu.

Sincerely,

Rita Walters, PhD Candidate
Michigan State University
School of Social Work
234 Baker Hall
East Lansing, MI 48824
walter99@msu.edu
517-256-0091

Michigan State University Institutional Review Board Approval Letter

March 1, 2012
To: Ronald Hall
224 Baker Hall

Re: **IRB# x12-162e** Category: EXPEDITED 2-7
Approval Date: February 28, 2012
Title: Adjustment and Coping of African American Parents of Children with Severe Cerebral Palsy

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been deemed as exempt** in accordance with federal regulations. The IRB has found that your research project meets the criteria for exempt status and the criteria for the protection of human subjects in exempt research. **Under our exempt policy the Principal Investigator assumes the responsibilities for the protection of human subjects** in this project as outlined in the assurance letter and exempt educational material. The IRB office has received your signed assurance for exempt research. A copy of this signed agreement is appended for your information and records.

Renewals: Exempt protocols do not need to be renewed. If the project is completed, please submit an *Application for Permanent Closure*.

Revisions: Exempt protocols do not require revisions. However, if changes are made to a protocol that may no longer meet the exempt criteria, a new initial application will be required.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects and change the category of review, notify the IRB office promptly. Any complaints from participants regarding the risk and benefits of the project must be reported to the IRB.

Follow-up: If your exempt project is not completed and closed after three years, the IRB office will contact you regarding the status of the project and to verify that no changes have occurred that may affect exempt status.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Sincerely,
Harry McGee, MPH
SIRB Chair

c: Rita Walters

APPENDIX C

CONSENT FORM

I am requesting your assistance in a research study I am conducting about understanding the unique needs of African American parents of children with severe cerebral palsy. Very little is known about African American parents' perceptions and experiences in caring for a child with a severe disability. This is an opportunity for you to tell your story and contribute to a better understanding of your cultural values and beliefs. This study has been approved by Michigan State University Institutional Review Board, IRB# x12-162e.

Your participation in this research study is voluntary and confidential. You have the right to withdraw from the study at any given time. All of the information collected will be reported as group results and will not contain any identifiable information about you or your child. The results of this study will be disseminated through conferences and academic journals.

If you agree to participate, you will be asked to complete two brief questionnaires and take part in a one-on-one interview to be conducted in your home at a time that is convenient for you. It is anticipated that the questionnaires and interview will take approximately one hour to complete. Although I foresee no risk for participating in the study, you may experience some discomfort or reflect on unpleasant or upsetting experiences while sharing your story. You may refuse to answer any questions during the interview. As an expression of appreciation for your participation, you will receive a $25.00 Meijer or Wal-Mart gift card upon completion of the questionnaires and interview.

If you have questions about this study you may contact me, Rita Walters at (517) 256-0091 or via email, walter99@msu.edu. Dr. Ronald E. Hall, my dissertation committee chairperson and study principal investigator can be reached at Michigan State University School of Social Work, 224 Baker Hall, East Lansing, MI 48824, (517) 432-3729 or hallr@msu.edu.

By signing below you agree to willingly participate in this research study and understand that you can withdraw from participation at any given time. Additionally, you consent to being audio-taped during the one-on-one interview.

_____   _____
Participant's signature   Date

_____   _____
Researcher's signature   Date

FAMILY DEMOGRAPHIC SURVEY

1. What is your relationship to your child?
    ___ Biological mother   ___ Biological father
    ___ Adoptive mother   ___ Adoptive father
    ___ Grandparent   ___ Other relative
    ___ Legal guardian

2. What is your age? _____

3. What is your sex?
    ___ Male
    ___ Female

4. What is your marital status?
    ___ Never married
    ___ Married
    ____ Divorced/separated If divorced, did this occur after your child's diagnosis?
    ___ Widowed If widowed, did this occur after your child's diagnosis? _____

5. What is your employment status?
    ___ employed full-time
    ___ employed part-time
    ___ full-time student
    ___ unemployed

6. What was your employment status before your child's diagnosis?
    ___ employed full-time
    ___ employed part-time
    ___ full-time student
    ___ unemployed

7. In general, how would you rate your overall health?
    ___ Excellent
    ___ Very Good
    ___ Good
    ___ Fair
    ___ Poor

8. What is your health insurance coverage?
    ___ Private Insurance (please describe): _____
    ___ Public Health Plan
    ___ Uninsured

9.　　What is the highest grade or level of school that you have completed?
　　　___ Some high school, but did not complete
　　　___ High school graduate or GED
　　　___ Some college or 2-year degree
　　　___ 4-year college graduate
　　　___ More than 4-year college degree

10.　　Were your education plans interrupted due to your child's needs? _____

11.　　What is your yearly household income?
　　　___ $10,000 or less
　　　___ $10,001 - $30,000
　　　___ $30,001 - $50,000
　　　___ $50,001 - $70,000
　　　___ $70,001 - $90,000
　　　___ $90,001 or higher

12.　　What is your religious affiliation?
　　　___ Baptist
　　　___ Catholic
　　　___ Jehovah's Witness
　　　___ Lutheran
　　　___ Methodist
　　　___ Muslim
　　　___ Seventh Day Adventist
　　　___ Other (please describe): _____
　　　___ None

13.　　Who do you identify as part of your social support system?
　　　___ Immediate family
　　　___ Extended family
　　　___ Friends
　　　___ Neighbors
　　　___ Church
　　　___ Self-support group
　　　___ On-line chat rooms, discussion boards, other internet sources

14.　　How many children, under the age of 18 live in the home? _____

CHILD DEMOGRAPHIC SURVEY

1. What is your child's sex?
    ___ Male
    ___ Female

2. What is your child's age? _____

3. What is the birth rank of your child?
    ___ Only
    ___ First
    ___ Middle
    ___ Last

4. What is your child's education setting?
    ___ full-time elementary   ___ part-time elementary
    ___ full-time secondary   ___ part-time secondary
    ___ full-time center-based   ___ part-time center-based
    ___ home-based

5. Which of the following specialist does your child see regularly? (Check all that apply)
    ___ Audiologist
    ___ Dietician
    ___ Neurologist
    ___ Nurse (in-home care)
    ___ Nutritionist
    ___ Occupational Therapist
    ___ Ophthalmologist/Optometrist/Optician
    ___ Orthopedic Surgeon
    ___ Pediatrician
    ___ Physical Therapist
    ___ Psychologist
    ___ Social Worker
    ___ Speech-language Therapist
    ___ Others (please list): _____

6. Which of the following equipment/devices does your child use? (Check all that apply)
    ___ Adaptive Communication Devices
    ___ AFOs (Ankle Foot Orthosis)
    ___ Electric Wheelchair
    ___ Feeding Tube
    ___ Hearing Aids
    ___ Manual Mobility Equipment (i.e. wheelchair, cruiser, stander)
    ___ Others (please list): _____

7.   What is your child's health insurance coverage?
        ___ Private Insurance
        ___ Public Health Plan
        ___ Uninsured

8.   Child lives in the home with (list all individuals residing in the household, their relationship to the child, and their age).

FIRST NAME	RELATIONSHIP	AGE

9.   List of child's caregivers (list how many hours child spends with caregiver).

CAREGIVER	TOTAL DAYS PER WEEK IN CARE	TOTAL HOURS PER DAY IN CARE
Afterschool Program		
Babysitter		
Daycare Center		
Extended Family		
Nanny		
Neighbor		
School		
Other:		

10.   What types of social activities does your child participate in?

_____

11.   What types of community activities/events does your child regularly attend?

_____

12.   How would you rate your child's overall health?
        ___ Good   ___ Fair   ___ Poor

INTERVIEW GUIDE

HEALTH:

How were you told of your child's diagnosis and what was that experience like for you?

        Probing questions: What did you know about cerebral palsy prior to your child's diagnosis?
                                       What were your immediate needs? Did you get any counseling?

Can you describe a typical day of care for your child?

        Probing question: How often is your daily routine interrupted as a result of the needs of your child?
                                       How are weekends and holiday spent?
                                       What do you do in your leisure time?

Has you health declined since you began caring for your child? If so, please explain.

        Probing question: Do you believe your health will continue to decline, if so why?
                                       How have you maintained being healthy?

Do you have any medical problems that interfere with your ability to care for your child?

        Probing questions: How are you treating your illness/condition? What is the prognosis?
                                       How do you compensate for this limitation in caring for your child?
                                       What techniques do you use to stay healthy?

What are you most concerned about regarding your child's life?

        Probing questions: How are you addressing these concerns?

CULTURAL BELIEFS:

Some families believe raising a child with a disability can be rewarding and a challenge or a burden and hardship. What are your feelings about it?

What are some of the challenges you experience that you think are unique to African American parents caring for a child with a disability?

        Probing Question: How do you address those challenges?

Have you or your child ever been treated differently because of your race? If so, please explain.

       Probing Question: How did you respond to the situation?
                                       How has that experience affected you in your role as a caregiver?

What is your opinion of the professionals providing services to you and your child?

       Probing Question: How are they most helpful to you?
                                       What would you like to see different in your working relationship with them?

SOCIAL SUPPORT:

Can you talk a little about your religious background?

       Probing Question: How often do you attend church?
                                       Are you able to attend as often as you like?
                                       How would you rate their level of support?

Can you describe your informal support circle?

       Probing Question: Who do you identify as most supportive, and why?
                                       Who do you identify as least supportive, and why?

How has your marriage/relationship been affected by your child's disability?

       Probing Question: What is the agreement for who is responsible for childcare?

Can you describe the formal support services you utilize?

       Probing Question: Which would you identify as most supportive?
                                       Which would you identify as least supportive?

Which community resources would you like to utilize but have not been able to?

       Probing Question: What are the barriers to you accessing those resources
                                       How would this resource help you and your child?

CONCLUSION:

Is there anything more that you would like to add to this interview?
Why did you choose to participate in this study?
Do you have any questions?

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