CAREGIVER STRAIN AMONG AFRICAN AMERICAN AND CAUCASIAN FAMILY MEMBERS CARING FOR CHILDREN WITH EMOTIONAL AND BEHAVIORAL PROBLEMS: THE ROLE OF RACE

By

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LIST OF SELECTED ABBREVIATIONS

CBCL	Child Behavior Checklist
CGSQ	Caregiver Strain Questionnaire
CHQ	Child Health Questionnaire
CIS	Columbia Impairment Scale
DSM	Diagnostic and Statistical Manual of Mental Disorders
EM	Expectation Maximization
FBEP	Fort Bragg Evaluation Project
FFS	Fee-for-Service
IOM	Institute of Medicine
MAR	Missing at random
MBHCPS	Managed Behavioral Health Care in the Public Sector
MC	Managed care
MCAR	Missing completely at random
MCMC	Markov chain Monte Carlo
ML	Maximum likelihood
NASB	National Survey of Black Americans
OLS	Ordinary least squares
PS	Propensity score
SAMHSA	Substance Abuse and Mental Health Services Administration

SED	Serious Emotional Disturbance
SSDI	Social Security Disability Income
SSI	Social Security Income
TANF	Temporary Assistance to Needy Families
WIC	Women Infants and Children

CHAPTER I

INTRODUCTION

Caregiver strain--“the demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs” (Brannan, Heflinger, & Bickman, 1997, p. 212)--has seen increasing attention in the research literature over the last several decades. It is postulated that the increase in research is due to factors including deinstitutionalization moving the mentally ill and disabled back into the community and improvements in medicine allowing people to live longer with congenital and chronic illnesses (Sales, 2003). Additionally, the family movement in mental health and developmental disabilities and the system of care in mental health has focused on keeping children successfully in communities (Brannan, et al., 1997; Stroul & Friedman, 1986). For medically fragile children, there was a widely held assumption that in-home care versus hospital or institutional care would be more “normal” and less costly (Burr, Guyer, Todres, Abrahams, & Chiodo, 1983; Frates, Splaingard, Smith, & Harrison, 1985; Goldberg, Faure, Vaughn, Snarski, & Seleny, 1984).

These social and medical advances have increased family responsibility for care. Unfortunately, these advances have not been on par with addressing the needs of families in caring for persons with health, mental health and developmental problems. In the area of children’s mental health services, there has been a growing focus over the past two decades

(Stroul & Friedman, 1986) on the important and central role of the family in service delivery, and that family members should have their needs related to the care of their children incorporated into the treatment process (Friesen & Koroloff, 1990; Koroloff & Friesen, 1997). As a result, attention to the strain imposed on caregivers has been a burgeoning topic of research (Fadden, Bebbington, & Kuipers, 1987; Grad & Sainsbury, 1963; Loukissa, 1995).

Issues related to caregiver strain are important and impactful at all societal levels. Government is interested because the cost savings are high for informal caregiving (e.g. informal caregivers of elderly in the United States contribute approximately $194 billion annually to America's healthcare system with their time and services (Arno, Levine, & Memmott, 1999). Individuals and families are interested because it is a current or imminent concern. Researchers are interested in finding evidence and interventions for bio-psycho-social phenomena (e.g. strain and stress).

It can even be said that this is a global concern. The published literature to date related to caregiver strain is out of Africa, Asia, Australia, Europe, North America, and South America. Across the spectrum the research is largely seeking to substantiate the association between caregiver strain and negative consequences and particularly health and mental health consequences for the caregiver and recipient. Unfortunately most of what we know has been informed by the adult literature. Important reasons for improving our of understanding the influences on strain for different caregivers of youth with disabilities are 1) the health impact of strain on caregivers and 2) the increasing numbers of minority youth with disabilities in the care of parents and other caregivers (Children's Defense Fund, 2001).

The caregivers of children with emotional/behavioral problems and/or disabilities are a diverse group with varying limitations and needs. The health and social disparities, and the changing face of the U.S., make a stronger case for the need for more research. Additionally, it is imperative that diversity is taken into account when addressing the needs of families of youth with serious emotional disturbance (SED) so the interventions are accurate, fair and meaningful. Current estimates project that by the year 2050 half of the U.S. population will be composed of minority group members of African American, Asian/Pacific Islander, Latin American and Native American decent (Cartledge, Kea, & Simmons-Reed, 2002). Yet there is a paucity of research that focuses on minorities and caregiver strain. At the time of this review, searches in the frequently used databases PsycINFO, Sociological Abstracts, and PubMed for the terms "caregiver burden," "caregiver distress," "caregiver strain," and "caregiver stress" and a combination of terms for underrepresented minority groups yielded interesting results. Table 1 shows that there is a very small literature examining caregiver burden, distress, strain or stress for adults or youth from underrepresented minorities.

Table 1. *Count of Search Results for Underrepresented Minority Children/Adolescents (aged 0-18) and Adults with Caregiver Burden, Caregiver Distress, Caregiver Strain and Caregiver Stress by Age Group and Bibliographic Source*[1]

	PsycINFO		PubMed	
	Child/Adolescent	Adult	Child/Adolescent	Adult
Caregiver Burden	18	127	2	28
Caregiver Distress	0	4	0	5
Caregiver Strain	5	10	3	5
Caregiver Stress	3	21	0	9

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[1] Searches conducted January 19, 2008. Underrepresented minority = African American/Black and Hispanic/Latino

What research findings on minorities have demonstrated is that more frequently African Americans report less caregiver strain when caring for an individual with illnesses and/or disabilities. Studies of caregivers of children have found that being older, poor, Caucasian, and isolated from family and friends are factors associated with increased caregiver strain (Raina, O'Donnell, Schwellnus, 2004). Conversely, being African-American, having higher numbers of people in the household and social networks can buffer the effects (Heflinger & Taylor-Richardson, 2004; McCabe, Yeh, Lau, Garland, & Hough, 2003; Raina et al., 2004). What is unknown about the racial/ethnic differences that are reported in response to the level of caregiver strain is why. Are the differences related to race, culture, methodology, measurement artifacts or something else?

The purpose of this study is to shed light on the racial differences and measurement-related issues regarding caregiver strain. This study examines three research questions to accomplish this goal:

1. When compared to Caucasian family caregivers of children with SED, do African Americans report differing levels of caregiver strain?

2. When compared to Caucasian family caregivers of children with SED with similar risk profiles, do African Americans report lesser caregiver strain?

3. Does caregiver mental health and substance abuse affect the relationship between race and caregiver strain?

The following section, Chapter II, reviews the theoretical model that guides this study and also reviews the caregiver strain literature. Chapter III presents the methods that are used to evaluate the research questions examined in this study. Chapter IV presents the results. Chapter V discusses the findings and implications for further research.

CHAPTER II

LITERATURE REVIEW AND CONCEPTUAL MODEL

Overview

This chapter briefly describes a well known stress and coping theory that illuminates the ways in which caregiver strain can be studied. Conceptual models are often compilations of several theories. The theory discussed in this chapter provides the foundation for the conceptual model that is used in this study. The conceptual model that guides this study is presented. The literature review on caregiver strain that concludes this chapter is then organized according to the framework of the conceptual model.

Stress and Coping Theory

Early Models of Stress and Coping

Richard Lazarus is credited with being one of the most influential scholars on stress research in the twentieth century (Daniels, 2001). Lazarus' (1968) work demonstrated that individuals' beliefs, attitudes, expectations and motives influenced perceptions of their environment. This was referred to as the transactional phenomenon dependent on the meaning of stimulus to the individual (Lazarus, 1966). The *Transactional Model of Stress and Coping* became a framework for evaluating the processes of coping with stressful events. These events are interpreted as person-environment transactions and are dependent on the impact of an external stressor. This is mediated by the person’s appraisal of the stressor and the social and cultural resources at his or her disposal (Lazarus & Cohen, 1977; Antonovsky & Kats, 1967; Cohen 1984).

Lazarus’ (1966, 1968) seminal studies of coping processes demonstrated that efforts to manage stress change over time and are shaped by the adaptation context out of which the stress is generated. Since his original work, measures of coping have evolved such that researchers can now examine inconsistencies in the ways individuals cope over time and across stressful encounters (Lazarus, 1993). The studies by Lazarus and Folkman (1988) have served as the blueprint for mapping how people cope with stress.

In Lazarus and Folkman’s model, variables that would influence caregiver strain would depend upon the caregiver’s appraisal of their environment. Consistent with their transactional model factors such as age, race, and social support appear to significantly influence the experience of caregiver strain (Dunkin & Anderson-Hanley, 1998). These stress and coping theories have limitations in that it addresses individual level and/or dyadic levels of analysis (e.g. child-caregiver). There are a much broader level of factors that address the influence on strain. The criticism of stress-coping research and the ubiquitous problem of caregiver strain is that transactional models such as the work of Lazarus and Folkman only account for individual’s appraisal of stress or subjective experience even when they have adapted models to include the individual’s interaction with the environment (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984). It has been recognized that caregiver strain is a societal problem requiring family-level and system level-interventions. A model that incorporates the work of Lazarus and Folkman yet broadens the scope to account for a more ecological perspective is the ABCX model.

ABCX and Double ABCX Models

Family stress theory proposes that the accumulation of acute stressors can lead to family crisis (e.g. child abuse, illness, substance abuse). Hill (1949) first proposed the ABCX model to explain how families adapt to stress. The studies generating this model were based on comparisons of post-Great Depression families that survived versus those that did not. The model includes four variables, A, B, C, and X, thus its name. Broadly, variable A represents the family stressors, and X represents the family crisis that follows. The impact of the stress can be buffered by the two protective factors, B and C, which constitute B internal family resources, and C family perception, appraisal, or meaning. These two protective factors are interrelated with the acute stressors and ongoing social context of chronic stressors, to predict family crises. When the outcome is adaptive, then caregivers experience manageable levels of strain and the resultant outcome may not be negative. However, if the resultant outcome is maladaptive caregivers may experience high levels of caregiver strain (Xu, 2007).

Many studies of families coping with a child with a disability have used variations of this framework (McCubbin & Patterson, 1983) to explain how families deal with stress. Expanded and adapted models have been used to examine children's mental health outcomes, developmental disabilities, traumatic brain injury, intellectual disabilities, cancer and dementia-related disorders (e.g. Brannan & Heflinger, 2001; Bristol, 1987; Hastings, Daley, Burns & Beck, 2006; Jones & Passey, 2004; Saloviita, Italinna, & Leinonen, 2003; Xu, 2007).

The subsequent research in this area has supported Hill and McCubbin's theoretical framework of family stress. For example, family stress in concert with social isolation (the "B" variable) has been highly correlated with variations of family problems and poor family outcomes (Crnic, Greenberg, Robinson & Ragozin, 1984; Modricin & Robinson, 1991; Schwartz & Liddle, 2001).

The expansion of the Hill's framework to the *Double ABCX Model of Family Adaptation and Adjustment* (McCubbin & Patterson, 1983) offers a more encompassing framework to guide theory and interventions for families coping with a child with illnesses and disabilities. The Double ABCX model identifies factors internal and external to the family that affect how well the family adapts to a chronic stressor and extends Hills work by demonstrating that a family's adaption to stress is mediated by new and existing resources and is temporal, as measured by a pile-up of stressors.

The five major concepts of this Double ABCX model are: family demands (stressors) (aA), family adaptive assets (resources) (bB), family definition (perception) (cC), coping (cognitive/behavioral processes used to deal with the chronic condition), and outcome (adaptation) (xX) (Austin, 1993). The additional lowercase a, b, c, and x represent changes over time. In this model, family demands act together with family resources and family definition to create coping behaviors. The coping behaviors lead to adaptation. Figure 1 is an adapted model of the Double ABCX used in caregiver strain research related to children's mental health (McCubbin & Patterson, 1983; Heflinger, Northrup, Sonnichsen, & Brannan, 1998; Brannan & Heflinger, 2001).

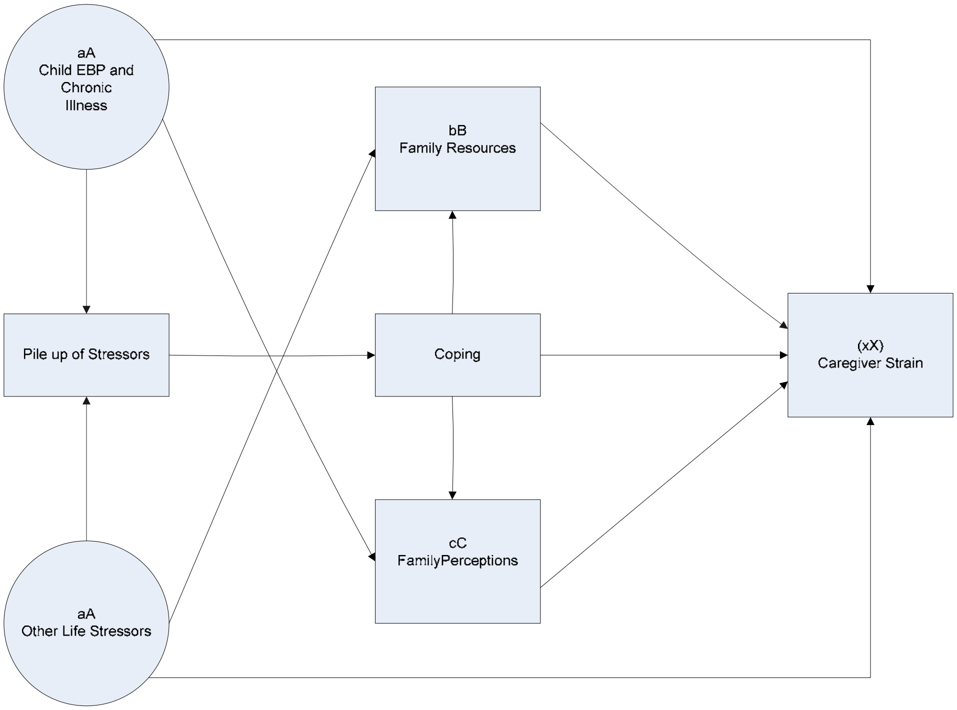

Figure1. Framework for Understanding Influences on Caregiver Strain[2]

The Double ABCX model provides a way of conceptualizing the multifaceted considerations families face when dealing with caregiver strain. The xX factor represents family adaptation which is caregiver strain in this study. This model integrates individual level to macro level factors resulting in a more ecological framework with which to evaluate strain. It provides a useful model for examining the predictors of caregiver strain and, therefore, is used to guide the selection of explanatory variables for this study. The explanatory variables of interest are stressors, resources, perceptions, coping and adaptation.

Stressors (aA). Families often deal with multiple stressors. They can include current or previous events that affect the family or caregiver. Lazarus and Cohen's (1977)

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[2] Adapted from McCubbin & Patterson (1983), Heflinger, Northrup, Sonnichsen, & Brannan (1998), and Brannan & Heflinger (2001)

transactional model of stress and coping defined stressors as demands by the internal or external environment that upset the balance of physical or psychological well-being. Stressors are defined as those life events or occurrences of sufficient magnitude to bring about change in the family system (Hill, 1949). “Stress is not seen as inherent in the event itself, but rather conceptualized as a function of the response of the distressed and refers to the residue of tensions generated by the stressor which remain unmanaged” (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980, p. 857). A stressor is a situation for which a family has had little or no prior preparation and crisis can result from any sharp or decisive change from which old patterns are inadequate.

Resources (bB factor). McCubbin and Patterson (1983) identified resources as tangible supports a family may bring to the management of a crisis situation i.e. existing and potential concrete aid and skills that families use to meet their needs. The authors identified three types of resources: personal resources of the individual family (e.g. financial, physical and emotional health), the internal resources of the family system (e.g. open communication and mutual support), and external resources available to the family (e.g. social support and services). McCubbin et al. (1980) noted physical and emotional health to be among the most significant internal resources.

Perceptions (cC factor). Perceptions refer to the meanings families attribute to the individual and accumulating stressors, available resources, and the crisis. Perception is a critical factor in determining the severity of an event and whether the family experiences it as a crisis (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980). The way in which caregivers perceive or appraise their circumstances and the resources available to them to address the situation influences how they cope (Xu, 2007).

Micro and macro-level factors contribute to perception. It has been suggested that variables such as race (Kerckhoff & Campbell, 1977) affect the perception of normative versus non-normative events and in turn that affects the degree of family stress (Harkins, 1978). Even geographical differences influence perception as they have been shown to impact access to care and community beliefs (Taylor, Repetti, & Seeman, 1997).

Additionally, research has demonstrated that appraisal of the degree of control one has over the stressor as well as the judgments about the potential impact and quality of the stressor varies among individuals (Sapolsky, 2004). Lazarus and Folkman (1984) discuss this appraisal of stressors as benign, threat, harm/loss, and challenge. According to Patterson and McCubbin (1983), assignment of meaning to the stressor helps clarify the situation, helps families to come up with potential solutions, makes the crisis more manageable and allows for restoration of equilibrium (Xu, 2007).

Coping. Coping has been defined as a process through which families manage excessive demands and depleted resources, while realizing that changes are necessary to restore functional stability and family well-being (Tak & McCubbin, 2002). It involves actions and emotions. It is a bridging concept in the model (Saloviita et al., 2003). Coping is a key concept in the handling of stress and can be predictive of adaptive health and mental health as it involves cognitive and behavioral responses (Heflinger et al., 1998). Studies have demonstrated that emotions, cognitive attributions, and coping responses have a direct correlation with physical and psychological health (Coelho, Hamburg, & Adams, 1974). Coping is viewed as dynamic process influenced by environmental and personal factors (Aldwin & Yancura, 2004). Aldwin and Yancura listed five general types of coping strategies that are not mutually exclusive: problem-focused (directed at dealing with the issue), emotion-focused (involve strategies directed at regulating the caregiver's emotional response to the problem), social support, religious, and making meaning. Aldwin and Yancura note that the way individuals interpret situations impacts how they cope. Interestingly it has been shown that women are more emotion-focused in their ways of coping while men are more problem-focused (Folkman & Lazarus, 1980). It has also been shown that coping styles relate to caregivers perception of objective and subjective burden (Olin, 1995).

Adaptation (xX factor). Adaptation is the outcome of the model. Adaption to the crisis is shaped by the other factors in the model and leads to positive or negative adaptation termed by McCubbin and Patterson (1983) as "bonadaptation" or "maladaptation". Family adaptation using effective coping strategies is considered a positive response to stressors (Glanz, Rimer, & Lewis, 2002; Yu, 2007). Adaptation has been measured in multiple ways, but most commonly as a construct related to the caregiver's psychological well-being (e.g. caregiver strain) (Saloviita et al., 2003). Research has demonstrated that the demands for families of a child with disabilities are greater than that for a child that is typically developing and as a result may have unique needs, but these demands do not necessarily translate into increased strain (Glidden, 1993; Nachshen & Minnes, 2005). Caregivers' perception or appraisal particularly as it relates to the caregiving role differentiates caregivers that exhibit adaptive versus maladaptive coping.

All factors of the Double ABCX can be interpreted as positive or negative. Illness related issues and psychological stress of the child and family affect the adaptation of the family to the child's illness or disability (Katz, 2002). Not all caregivers of children with disabilities report their caregiving duties as negative. Researchers in the child intellectual and developmental disabilities literature are increasingly beginning to study the positive aspects as well as the stressors of caregiving (Greer, Gray, & McClean, 2006; Hastings & Taut, 2002). However, the bulk of the literature supports the view that caregiver strain is a more common experience for caregivers of children with disabilities than typically developing children (Friedrich & Friedrich, 1981; Singer & Irvin, 1991; Scott, Atkinson, Minton, & Bowman, 1997). In a study of children with Asperger Syndrome it was found that parents reported higher strain than parents of normally developing children (Sivberg, 2002). Mother's of autistic children reported greater stress than mother's of children with Down Syndrome (Holroyd & McArthur, 1976), mental retardation (Bouma & Schweitzer, 1990; Kasari & Sigman, 1997), and other disabilities, (Dumas, Wolf, Fisman, & Culligan, 1991).

Several studies have used the Double ABCX model to explore family-level and individual-level responses to stressful events. Within the disabilities literature (Hastings & Taunt, 2002) researchers have found that there are different variables associated with negative and positive perceptions, and thus, each dimension should be explicitly measured. Ultimately, Hastings and Taunt (2002) asserted that positive perceptions may moderate the coping process.

Although the measurement of family adaptation has been varied, most studies have supported that all elements of the Double ABCX model significantly predict the construct (Bristol, 1987). Yet, most studies have included individual level versus family-level measures as dependent variables (Saloviita et al., 2003). The Double ABCX model has been used in several studies to explore the influence of child behavior problems and disabilities on family and caregiver outcomes (Brannan & Heflinger, 2001; Pakenham, Sofronoff, & Samios, 2004; Jones & Passey, 2004; Saloviita et al., 2003; Shin & Crittenden, 2003). Jones et al. (2004) found that family coping style and parental internal locus of control were the strongest predictors of parental stress. Further, believing their child's disability did not control their lives and employing optimism and cooperation as coping strategies lowered their overall stress.

Gender has also been found to influence outcomes using this model. In a study of children with intellectual disabilities, negative definition of the situation increased stress with fathers reacting to social acceptance of the child and mothers to the child's behavior problems (Saloviita et al., 2003). In a sample of children with chronic illness Katz (2002) found that father's perception of social support, negative impact on the family and his ability to function within the family affected appraisal whereas mothers were concerned with emotional issues and physical care of the child.

Researchers in various topic areas have found the Double ABCX model useful for conceptualizing families' adaptation to stress because the model can be so broadly applied. Many researchers have used the model to support findings that parents of children with disabilities report higher levels of stress (Hastings & Johnson, 2001; Heflinger et al., 1998; Nachshen & Minnes, 2005). Even so, some findings using the model are equivocal. The construct validity of the model (Heflinger et al. 1998), ordering of variables, and the direction of effects has come under question. For example, researchers in mental retardation have found a linear model best fits with progression from stressor (aA) to adaptation (xX) (Orr, Cameron, & Day, 1991). In other studies of children with developmental disabilities Herman and Marcenko (1997) and Shin and Crittenden (2003) did not find a direct effect of the stressor (aA) on the families resources (bB) and subsequent researches have questioned if these relationships exist (Nachshen & Minnes, 2005).

Four mechanisms that may account for the relationship among the components of the Double ABCX model have been noted by Aldwin and Yancura (2004) in studies of coping and health outcomes. The effects they identify are direct (simple correlations between model components and caregiver strain), mediated (model components buffer the effect of strain), moderated (model components vary as a result of the degree of strain), and contextual (model components vary as a function of context or appraisal of individuals in the context). For example, Lavee, McCubbin, and Patterson (1985) found that social support has a direct effect on family adaptation to pile-up of stressors. For parents of children with developmental disabilities, behavior problems and chronic illness resources such as social support as well as coping have been shown to mediate negative outcomes (Hastings & Johnson, 2001; Jones & Passey, 2004; Katz, 2002). Marital research using the Double ABCX found that couples experiencing more stressful events should be more vulnerable to negative marital outcomes, and this effect is moderated by the couple's levels of resources and the couple's definitions of events (Karney and Bradbury, 1995). However, most researchers do not fully describe the relationships among the model’s variables even though they rely on the model and its constructs (Nixon, 2006).

Although many studies of caregiver strain have incorporated a broad range of measures and child and family characteristics, researchers have typically addressed the main effects of predicator variables on caregiver strain. Hastings and Brown (2002) noted that relevant psychological theory suggests that interrelationships between variables are likely to be crucial in understanding the impact of caring for a child with significant disabilities on caregiver outcomes (Lazarus & Folkman, 1984; McCubbin & Patterson, 1983).

Literature Review on Caregiver Strain

Caregiver strain research has its foundation in the stress and coping literature with the early works of researchers such as Selye and his stress research of the 1930s, Hill's family stress and crisis research of the late 1940s, the family stress and coping research of Lazarus and colleagues of the 1960s and 1970s, and Pearlin's (e.g. 1978, 1981) research of the 1970s and 1980s. Early approaches to the specific study of caregivers' adaptation to having an adult family member with mental illness and the associated burdens were conducted by Clausen and Yarrow (1955), Grad and Sainsbury (1968), Hoenig and Hamilton (1966) and Hoenig (1974). Grad and Sainsbury (1963) have been credited with being the first researchers to study the impact of burden for those caring for mentally ill relatives (Vitaliano, Young, & Russo, 1991). Later Hoenig and Hamilton (1966) distinguished between subjective and objective dimensions of burden. The initial and ongoing work from these researchers from various disciplines has contributed tremendously to our understanding of the underlying mechanisms associated with the phenomenon of caregiver strain. More recently, in the child literature there has been important work in caregiver strain research regarding chronic illness and developmental disabilities generating new findings and expanding on and modifying existing theory.

Terminology and Definitions of Strain (xX)

Before the literature on caregiver strain is reviewed, however, it is important to identify definitional issues and the significance of this topic. Next, the ABCX factors are used to organize the existing literature on caregiver strain. Caregiver strain is defined as "the demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs" (Brannan, Heflinger, & Bickman, 1997, p. 212) in this study. Unfortunately, there is a lack of uniformity in the literature regarding the terminology used to define caregiver strain. The construct is frequently labeled as caregiver burden, caregiver distress, or caregiver stress. All of these terms are intertwined and generally synonymous although researchers have found that, for example, caregiver strain and caregiver distress are distinctly different constructs (Brannan & Heflinger, 2001). That stated, no attempt will be made to disentangle them here. The term caregiver burden is more frequently used in the literature. At the time of this review, searches in the frequently used databases PsycINFO, Sociological Abstracts, and PubMed for the terms "caregiver burden," "caregiver distress," "caregiver strain," and "caregiver stress" yielded dramatically different results (see Table 2) with the term "caregiver burden" clearly being most popular. Based on the results of these searches, it appears the psychological literature has been responsible for the majority of the published work in this area. Although less frequently used, this paper will use the term "caregiver strain" as it conveys a less negative connotation than the term "caregiver burden" (Brannan, et al., 1997).

Table 2. *Count of Search Results for Caregiver Burden, Caregiver Distress, Caregiver Strain and Caregiver Stress by Bibliographic Source*[3]

	PsycINFO	Sociological Abstracts	PubMed
Caregiver Burden	2904	473	665
Caregiver Distress	141	19	125
Caregiver Strain	138	36	110
Caregiver Stress	301	70	192

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[3] Searches conducted January, 2008

Early research measuring strain described it as a one-dimensional global construct (Zarit, Reever, & Bach-Peterson, 1980). Current research identifies at least 2 domains of strain irrespective of the field. These dimensions are universally termed objective and subjective dimensions of caregiver strain (Hoenig & Hamilton, 1966; Montgomery, Gonyea, & Hooyman, 1985; Platt, 1985; Schene, 1990). Objective strain refers to onerous observable events and occurrences experienced by the family and caregiver as a result of the relative’s problems, such as financial strain, disrupted relationships, interruptions at work, reduced personal time and social contact, among others. Subjective strain captures caregivers' feelings about caring for relatives, such as anxiety and worry, or anger and resentment. Discovery of these two dimensions was an important step for caregiving research in recognizing the complex multidimensional experience of strain.

Limitations in the Study of Caregiver Strain

Many factors contribute to caregiver strain and there is no one set of factors for predicting caregiver strain. This section describes the common factors in the literature that have been found to contribute to, influence or protect against caregiver strain. The majority of the published studies measure strain quantitatively. Yet, due to the fact that the study of caregiver strain for a variety of chronic health and mental health issues is relatively new many studies of sub-populations (e.g. racial and ethnic minorities) are qualitative in nature. These studies aim to build theory rather than test existing knowledge. Although these studies are informative about the experience of the impact of strain on small selective groups of caregivers, they are not generalizable to other populations.

Additionally the majority of qualitative and quantitative studies focus on the impact of strain and not the influences on strain, leaving significant gaps in knowledge. Still much of the caregiver strain research is descriptive focusing on factors correlated with strain and the amount of strain experienced (e.g. Hoare, Harris, Jackson, & Kerley, 1998) with simple descriptive studies that examine bivariate relations among a few variables which are not likely to advance the field further (Zarit, 1989, p. 147).

Other gaps include risk factors being more frequently studied than protective factors and the failure of research to catalog the range of factors that contribute to or protect against strain.

Sociodemographics

Early research found that sociodemographic factors did not contribute much to caregiver strain (Pai &Kapur; 1982; Thompson & Doll, 1982). More recent research found that sociodemographic characteristics such as age, race, income level, and the number of other caregivers to help with caregiving duties play a role in adaptation to caregiver strain (Stone, Cafferata, G., & Sangl, 1987). In most studies of the influences on caregiver strain, sociodemographic characteristics are discussed descriptively and/or controlled (Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). Few studies explore how these characteristics may act as risk or protective factors. Indeed it is important to be cognizant of findings such as those from Schulz and Beach (1999) that after adjusting for sociodemographic factors participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than those whose spouse was not disabled, but it is also important to look at the particular contributions of sociodemographic factors to the experience of strain. These factors may provide insight into how different caregivers cope and provide opportunities for tailored interventions.

Research on stress has found that what defines an event as stressful is dependent upon the appraiser. Certain groups therefore, with similar characteristics may interpret strain similarly. This has been the foundation for stating that, for example, African American caregivers have been found to experience less strain, regardless of illness, than their Caucasian counterpart. Despite these findings, other research has found that African Americans do experience stress and that being female, unemployed and low education were significantly related to poorer mental health (Neighbors, Jackson, Bowman & Gurin, 1983).

Factors influencing caregiver strain may act as risk for strain or as a buffer, or neither depending on the context and group for which they are studied. For example, African Americans have been found to rely more than Caucasians on informal social networks (e.g., family, friends, church and neighbors) versus formal networks (therapeutic support groups, hospitals) to cope with stress (Gibson, 1982; Logan, 1996; Neighbors et al., 1983; Taylor, Chatters, Tucker, & Lewis, 1990). Race is an important demographic variable in these studies but it is considered as a family perception variable discussed below.

Stressors(aA)

The literature on stressors is diverse and encompasses many factors that are relevant to caregiver strain. The factors that are targeted in the present study are the characteristics of the child, child’s illness and the caregiver.

Child type and severity of illness/problem. There is a large literature that exists on the variety of stressors including but not limited to need for extra services, extra time and money, trauma, accidents, level of symptoms, severity and level of impairment or disability, death, life transitions, and legal issues. In the child literature, research regarding the level of influence on strain differs depending on the type and severity of the child's problems.

The types of childhood illnesses may vary from chronic relapsing physical diseases such as cancer and rheumatoid arthritis and emotional and behavioral disorders to developmental delays. There is a small body of research that has even attempted to make comparisons of what types of disorders result in more strain for caregivers. One possible explanation for the lack of research in this area may be the reticence of researchers to appear that they are placing a value on an already difficult experience for caregivers. Earlier in the chapter when the ABCX model was presented it was noted some illnesses result in more strain for caregivers than others. Looking across studies high levels of distress were found among caregivers of children with severe neurological handicapping (Breslau, Staruch, & Mortimer, 1982) conditions while little to no distress was found among those caregivers of diabetics (e.g. Kovacs, Finkelstein, Feinberg, Crouse-Novak, Paulauskas, & Pollock, 1985) which is less functionally disabling.

Severity can be measured by burden on family or society in terms of cost, high service utilization, time caring for the child/demand, etc. (Stein, Gortmaker, Perrin, Perrin, Pless, Walker et al., 1987). Severity includes clinical severity of the illness, impact on child development, school performance, and family functioning (Perrin & MacLean, 1988). It has been established that severity of child illness is hard to determine, yet research has shown that child chronic illness impacts caregiver strain. Hobbs, Perrin, & Ireys (1985) noted the complexity of establishing the severity of childhood chronic illness. The nuances and degrees of illness within specific diseases add to the difficulty of comparison across diseases or illnesses. In the adult literature severity is rarely discussed with the exception of dementia which has a progressive deteriorating trajectory.

Despite the difficulty in measuring severity, it remains an important clinical variable in the picture of caregiver strain. In the case of child emotional and behavioral problems severity is generally discussed in terms of the level of the child's problems as assessed and measured by a clinician and/or psychiatrist. As stated throughout this review higher levels of problems are a predictor of higher levels of caregiver strain.

For some illnesses there has been considerable research and attention in the literature, while others have received very little or no attention. Two areas that have received considerable attention, and from which most of our current understanding of caregiver strain is based, are families caring for severely mentally ill adults (e.g. schizophrenia) (Greenberg, Greenley, McKee, Brown, & Griffin-Francell, 1993) and persons with memory impairment (e.g. Alzheimer's and dementia) (George & Gwyther, 1986; Poulschock & Diemling, 1984; Zarit, et al., 1980). For caregivers of children, researchers in mental retardation and developmental disabilities have made the most strides in discussing the impacts of caring for a child with problems (Cahill & Glidden, 1996; Glidden & Floyd, 1997; Glidden & Schoolcraft, 2003; Gray, 2003; Hastings & Brown, 2002; Kolomer, McCallion, & Janicki-Matthew, 2002).

A few researchers have investigated illnesses comparatively to determine what types of illnesses create greater levels of strain (e.g. ADHD and oppositional defiant disorder (Ross, Blanc, McNeil, Eyberg, & Hembree-Kigin, 1988); Down Syndrome vs. other developmental disabilities). The findings are mixed, but the common factor regardless of whether the person being cared for is a child or adult is caregiver appraisal of the impact of the illness on the caregiver.

Illnesses that manifest with more behavior problems are overwhelmingly cited as the source of the highest levels of caregiver strain, regardless of whether it is dementia, schizophrenia or child emotional/behavioral problems (Greenberg, Greenley, McKee, Brown, & Griffin-Francell, 1993; McCabe, Yeh, Lau, Garland, & Hough, 2003; Poulschock & Diemling, 1984).

Emotional/behavioral status. Research has shown that a child’s emotional/behavioral status is predictive of caregiver strain (Brannan, Heflinger, & Foster, 2003). Floyd and Gallagher (1997) also noted that stress experienced by parents is associated with a child’s behavior problems. Naturally, parents cope better when they do not have to contend with difficult behaviors. Emotional/behavioral problems are wrought with episodic peaks and valleys affecting the parental expectations for the child’s future as well as strain experienced by parents and caregivers (Lefley, 1997). “The stresses and difficulties of caring for a child with a disability are reflected in the ways in which parents [or caregivers] of children with emotional disabilities report that their lives are affected by their children’s problems” (McDonald, Gregoire, Poertner & Early, 1997, p. 138). Caring for a child with emotional and behavioral problems has been shown to be one of the most powerful predictors of caregiver strain (Angold, Messer, Stangl, Farmer, Costello, & Burns, 1998; Brannan & Heflinger, 2001). It is estimated that serious emotional disturbance affects between 9 and 13 percent of youth in the United States (Mark & Buck, 2006). Additionally, data from the 2003 National Survey of Children’s Health reports parental concern about emotional and behavioral problems to be quite high; for example, 36% were concerned about anxiety and depression (Blanchard, Gurka, & Blackman, 2006). Families of children with behavior problems report financial strain, disrupted family and social life, interruptions of personal time, and negative effects as a result of the challenges associated with caring for a child with emotional and behavioral problems (Baker & McCal, 1995; Brannan, et al., 1997; Farmer, Burns, Angold, & Costello, 1997; Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998).

Researchers from the Great Smoky Mountain Study (GSMS; Angold, et al., 1998) found that not only did parents associate burden with their child's emotional behavioral problems, but burden was associated with mental health service use. In this same study, Farmer, et al. (1997) found that parents of the youth in the GSMS receiving psychiatric services reported more worries, depression and feelings of incompetence as a result of the child's problems than parents of youth not using psychiatric services. Heflinger and Brannan (2006) also found that caregivers of youth with emotional behavioral problems and substance use problems report high levels of subjective internalized strain (worry and sadness) having significant implications for addressing this type of strain in treatment and further.

Chronic illness and other disabilities. Chronic illness such as developmental and intellectual disabilities and long-term sicknesses like asthma and cerebral palsy are the most widely studied childhood problems in the caregiver strain literature. Even so, strain is often not the outcome variable in these studies. Blanchard, et al. (2006) noted that the number of children with developmental delay being severed in schools under the federal Individuals with Disabilities Act has increased 633% between 1997-1998 and 2000-2001. Their study found that families of children with developmental problems experience more problems with issues of childcare, employment, parent-child relationships and caregiver burden.

Long-term care in particular can be a negatively charged situation for caregivers because of the depletion of physical, emotional, and financial resources (Townsend, Noelker, Deimling, & Bass, 1989). When someone with a chronic illness is cared for in the home caregivers become responsible for highly skilled nursing care tasks which often are an additional burden.

More than any other disability, researchers in physical and developmental disabilities are beginning to explore the positive aspects of caregiving. The shift from the negative focus has been in part due to the growing evidence finding positive benefits can improve mental and physical health (Ebersole & Flores, 1989; Saloviita, Itaelinna & Leinonen, 2003).

Caregiver stressors. Several other salient factors have the potential to influence caregiver strain including caregiver health status, substance abuse status, mental health status, and relationship to child. Any number of these in combination or alone are potential contributions to caregiver strain. Issues like health status, psychological status and substance abuse status are generally discussed as impact on the caregiver after the fact or as a result of caregiving (i.e. the outcome of caregiving). Little attention is given to the pre-existing status of the caregiver and its influence on the already stressful endeavor of caregiving.

Caregiver's health status. Caregiver's health status refers to the mental health, substance use and physical health of the caregiver. Research has found that caregivers with poorer mental health reported more stress, more family problems and more pessimism about their family members and perceived that they had less social support (Finnegan, Dooley, & Walsh, 2004).

In an ideal setting, pre-appraisal of health, mental health, and substance status would be incorporated into all studies of caregiver strain. Due to the cross-sectional nature of most studies, little research has looked at the pre-appraisal of caregiver health prior to their caregiving role. To understand fully the impact of caregiver strain, it would be helpful to know the overall health status of caregivers prior to the start of their caregiving role. However, it is difficult to determine who may become a caregiver of a child with disabilities or emotional/behavioral problems. Although it is difficult to determine the direction of causality, research on the link between caregiver health, strain and child problems is important. Wear-and-tear models of caregiving suggest that the longer care is provided the more the psychological strain on the caregiver (Lawton, Moss, Hoffman, & Perkinson., 2000; Townsend, Noelker, Deimling, & Bass, 1989). If caregivers start out with compromised health the effect of caregiver strain could significantly increase mortality and morbidity of these caregivers.

There is a legitimate rationale to attempt to elucidate the influence of caregiver mental health and substance abuse problems in particular. First of all, caregiver's mental health and substance abuse status can result in perception of caregiver strain or their ability to accurately rate their strain. On the other hand, these statuses can result in a real difference in the caregiver's strain. Research has examined the influence of illicit drug abuse of the caregiver recipient (Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003). Minimal research has been devoted to examining the influence of substance abuse as an influence on caregiver strain. The research to date has resulted in equivocal findings. Caregiver substance abuse was not a significant predictor of caregiver strain among youth entering mental health or substance abuse treatment (Heflinger & Brannan, 2006) but was among caregivers of HIV infected family members (Pirraglia, Bishop, Herman, Trisvan, Lopez, Torgersen et al., 2005). More research has explored the influence of caregiver mental health status finding lower ratings of caregiver mental health resulting in higher levels of caregiver strain (Brannan & Heflinger, 2001; Heflinger & Taylor-Richardson, 2004; Noh & Turner, 1987).

The picture is not completely bleak for those caring for an individual with a disability. There is an emerging literature that discusses the positive aspects of caregiving (Fulton-Picot, Youngblut, & Zeller, 1997). This said the reality is that many caregivers experience increased strains in their caregiving role. Most literature has focused on the outcome of caregiver strain on health. There is a paucity of research on the impact of the existing health status of the caregiver on strain. Concurrent burdens on caregivers' time and negative impact on health behaviors such as smoking, drinking, exercise, sleep, and weight management have the potential to influence caregiver strain (Gallant & Connell, 1998).

Resources (bB)

Formal and informal resources available to meet caregiver demands and needs have been shown to make an important contribution to caregiver adaption. Resources targeted in this study include social support and financial resources.

Social support. Dictionary definitions of social support describe it as the physical and emotional comfort given to us by our family, friends, co-workers and others; knowing that we are part of a community of people who love and care for us, and value and think well of us. Social support has been defined several ways in the literature. Some define it as formal or informal services by organizations such as churches or the Salvation Army or friends and neighbors. Cobb (1976) defines it as information exchanged at the interpersonal level which provides, (1) emotional support, leading the individual to believe that he or she is cared for and loved; (2) esteem support, leading the individual to believe he or she esteemed and valued; and (3) network support, leading an individual to believe he or she belongs to a network of communication involving mutual obligation and mutual understanding. All references to social support have some element of emotional support, tangible help and practical services, and exchange of viewpoints.

Research on the effect of social support is mixed. It has been found that perceived social support is negatively correlated with psychological and physical symptoms (Billings & Moos, 1981). Path analytic studies by Dean and Ensel (1982) and Lin and Ensel (1984) demonstrate that perceived social support is negatively correlated with depressive symptoms. Results are equivocal regarding the buffering effect of social support for different groups. Studies have found that social support offered by extended kin is beneficial as a buffer for African Americans but not as often for Caucasians (Lawton, Rajagopol, Brody, & Kleban, 1992; Morycz, Malloy, Bozich, & Martz, 1987; Smerglia, Deimling, & Barresi, 1988). Other studies in the adult dementia literature have found either no race difference in social support or that Caucasians report receiving slightly more support (Hofferth, 1984; Roschelle, 1997). However, in a study of caregivers of children with ADHD, although African Americans reported having smaller social networks than their Caucasian counterparts, they reported more frequent contacts within those networks and higher levels of emotional and instrumental support (Bussing, Zima, Gary, Mason, Leon, Sinha et al., 2003. In a study of caregivers of youth with emotional and behavioral problems African American caregivers reported lower perceived social support but still reported lower levels of caregiver strain thus social support did not explain lower levels of strain in this sample (McCabe, Yeh, Lau, Garland and Hough, 2003).

Financial Resources. Others have found that financial resources of the caregiver predict amount of strain. For example, low-income grandparent caregivers experienced more strain than those who were not low-income (Williams, Forbes, Mitchell, Essar, & Corbett, 2003). In a study of children with serious emotional disturbance, SES was a significant predictor of caregiver stress (McDonald, Gregoire, Poertner, & Early, 1997). In a study of caregivers of children with chronic medical conditions, Canning, Harris and Kellerher (1996) also found that families with lower income report more caregiver distress. These studies point up an important finding that economic resources are an important factor in psychological well-being and warrant further exploration in future caregiver strain research.

Perceptions (cC)

Caregiver perception is a key variable in normative and non-normative stress studies (McCubbin et al, 1980). Caregiver perception functions as a gauge of a caregiver's ability to meet demands and is a critical factor in how the caregiver determines the severity of an event.

Review of perception research. Studies using the ABCX model have employed a variety of different constructs and instruments to measure perceptions of caregivers. In caregiving studies, perception is frequently measured as the caregiver's expectation about how they will manage in relation to the child's illness. Perception is conceptualized as: appraisal or definition of the situation; sense making; self-efficacy; and sense of coherence (Lavee, McCubbin, & Patterson, 1985; Lustig & Akey, 1999; Pakenham, Sofronoff, & Samios, 2004; Saloviita, Italinna, & Leinonen, 2003).

In terms of caregiver perception instruments, most are specifically geared to one particular childhood disease. For example, Diabetes and Asperger Syndrome, (Appraisal of Diabetes Scale—Carey, Jorgensen, Weinstock, Sprofkin, Lantinga, Carnike et al., 1991; two Asperger instruments—Pakenham, Sofronoff, and Samios, 2004; and Parental Stress in Management of Asperger's Syndrome scale—Sofronoff, 2002; and the Parental Self-efficacy scale—Sofronoff & Farbotko, 2002). Sofronoff's Parental Self-efficacy in the management of Asperger syndrome scale contains a list of behaviors the parent rates his/her confidence in managing (e.g. when the child is unable to follow routines or lacks empathy). There are exceptions to the use of disease-specific instruments. Studies of children with developmental disabilities have used more global instruments such as the Parent Stress Index (PSI; Abidin, 1995) (Nashchen & Minnes, 2005) and the Parental Locus of Control scale (PLOC; Campis, Lyman & Prentice-Dunn, 1986) (Jones & Passey, 2004).

In most cases it is reported that the caregiver's perceptions are influenced more often by caregiver characteristics (e.g. constitution) than by the gravity or type of illness or disability of the child, and that caregiver gender, whether the family is Asian or American, and race also affect perceptions. Caregivers of children with Asperger syndrome that reported higher levels of meaning regarding the situation also reported higher levels of self-efficacy (Sivberg, 2002). Parenting stress and, specifically, internal locus of control influenced the caregiver perception of the situation as stressful (Jones et al., 2004). Saloviita, Italinna, and Leinonen (2003) used the Social Readjustment Rating scale (Holmes & Rahe, 1967) in a study of parents of children with intellectual disabilities and found that the way in which parents define their situation is more important in the prediction of parental stress than properties of the child. Zarit, Todd, and Zarit (1986) emphasize the importance of appraisal in their findings stating that caregivers' appraisals of the stressfulness resulting from patients' problems were more important than the severity of the patients’ problems in determining caregivers' perceived stress. Female and male caregivers appear to experience different etiologies and outcomes of caregiver strain. In a study of intellectual disabilities (Saloviita & Leinonen, 2003), defining the situation as negative was the most important predictor of parental stress although mothers focused on the child’s behavior problems and fathers on social acceptance. Katz (2002) demonstrated that a negative perception of a child with a chronic illness differed for mothers versus fathers with negative perception resulting in less martial satisfaction for fathers and poorer coping for mothers.

In a study of American and Korean mothers of children with mental retardation, the cause of stress for the American mothers was specific to the individual variables and for Korean mothers cultural values were more strongly associated with their attitudes towards the child and their experience of stress (Shin & Crittenden, 2003). Xu (2007) used a qualitative approach to explore cultural differences in an Asian and American family with a child with disabilities. The perceptions were different for both families and, initially, the American family perceived resource issues as more concerning where the Asian family’s cultural frame of reference resulted in a perception that the child’s illness was a form of punishment. However, these views were also dynamic as circumstances changed.

Race as perception. There is mounting evidence that race is more of a social construct than a biological one. Race is not captured by variations in genetic phenotype; furthermore, race categorizations have changed throughout history and have been used as a tool to create social classes (Jones, 2001; Muntaner, 1999; Muntaner, Hadden, & Kravets, 2004; Williams, 2008). According to Critical Race Theory, race is a fluid construct that is deconstructed and reconstructed by societal perceptions and context, as well as sociopolitical forces (Parker, & Lynn, 2002). Zuberi (2000), states that race is not an attribute, but a dynamic construct that is dependent on social circumstances and that race should be treated as an event that affects the acquisition of attributes over time.

There is increasing controversy about race measures in health and social science research. Race is a term without generally agreed upon definitions carrying complex connotations and reflecting a variety of factors. Here race is understood as a social category (Laveist, 1994) with no biological foundations (Kaufman & Cooper, 2008). LaVeist (1994) contends that we must acknowledge that what is measured by the race dummy variable is not culture, biology, values, or behavior. However, race is frequently used as an imperfect proxy for social class, culture, genes, political status, socioeconomic status, and ancestral origin (Collins, 2004; Jones, 2001).

Because the construct of race has changed over time, and is variable across societies, it is not always clear what each researcher is measuring when using race.

There is a growing debate that the current measures of race are imprecise for researchers along with the argument that the changing face of America may make current race categories deficient (Mays, Ponce, Washington, & Cochran, 2003). In fact, the growing use of multiple categories for race in the Census as dictated by the Office of Management and Budgets (OMB) will no doubt further complicate the issue of race in research. The OMB observed problems with data collected from Census prior to 1990; these data were not capturing adequately how people thought of themselves and as a result individuals are now permitted to choose more than one race category (Mays et al., 2003). Although society may impose constraints on opportunities due to race, clearly, individuals' ideas about what race means to them can be variable.

Race is a social fact and as stated by Muntaner (1999), as such "blackness" or "whiteness" is not an unalterable feature of an organism but contingent on changing social relations. Thus, "blackness" or exposure to "whiteness" can be an appropriate counterfactual. This has been effectively applied in a study of employment where the counterfactual is interpreted as the proportion of African Americans that would have been employed if they were Caucasian (Sundstrom, 1997) and a study of birth outcomes with the counterfactual, what would have the outcomes of African American infants been if they were Caucasian (Ma, 2007).

There has been some discussion in public health and government to discontinue to collection of race information. But the idea was dismissed with the notion that scientific advances would be lost in understanding the role of race as a risk and protective indicator in disease patterns and responses to treatment (Mays et al., 2003). In support of this view, The Institute of Medicine's (IOM) report on *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* documented numerous studies showing the independent effect of race as a significant explanatory predictor after controlling for various social, environmental, and cultural variables (Mays et al., 2003). This seesaw regarding how to conceptualize, measure, and interpret race in research elucidates the complexity of the construct.

Although we are assigned race early, and this assignment may result in differences in opportunities and life chances (Jones, 2001), it does not mean it is not a mutable characteristic. Because of the social fact of race, appraisal based upon it is contextual and therefore mutable. Consequently, here race becomes a proxy for a constellation of social and demographic factors that may or may not be different between African Americans and Caucasians that would account for caregiver strain.

For purposes of this study, the race data is self-reported as African American or Caucasian by the respondents. This study aims to capture race as a measure of acquired attributes and perceptions related to self-identity as a caregiver. Research has found many health and illness behavior risks are determined by a respondent's self-identity (Mays et al., 2003). Early research leading to this idea of racialized appraisal, as it will be called here, came from the work of Kessler (1979) which found differences in response to stressors that were attributed to the individual’s race.

However complicated, researchers have concluded that measures of race can be useful, nonetheless, and what is most critical is to clearly indicate the factor for which race is serving as a proxy, along with any policy or practice implications to be derived from the research (Laveist, 1994). With these caveats in mind, what follows is a review of current literature on caregiver strain comparing African Americans to Caucasians.

Race and strain. It has been suggested that race affects the perception of normative versus non-normative events (Kerckhoff and Campbell, 1977) and in turn affects the degree of family stress (Harkins, 1978). The results of caregiving studies that compare African Americans and Caucasians are mixed, but overall African American caregivers consistently report lower levels of strain after controlling for SES (Hinrichsen & Ramirez, 1992; Young & Kahana; 1995), health status (Gibson & Jackson, 1987; Mui, 1992), available formal and informal support, and care for relatives with greater levels of impairment (Mui, 1992). In addition, Kessler (1979) found that comparable stressors had greater impact on whites versus non-whites, although non-whites were more socially disadvantaged. Lawton et al. (1992) has been noted as a pioneer in investigating racial appraisal in adult caregiving research. In a study of racial differences of 629 caregivers, Lawton, Rajagopal, Brody, and Kleban (1992) found that African American caregivers reported a greater sense of mastery, less subjective burden, and less sense of intrusion on their lives from caregiving responsibilities than Caucasian caregivers. As stated earlier, it is currently reported that the caregivers of children with emotional behavioral problems not being raised by parents are largely African American and they are reporting lower levels of strain than their Caucasian middle-income counterparts (McCabe, Yeh, Lau, Garland, & Hough, 2003).

Despite these findings, other research has found that African Americans do experience caregiver strain and that being female, unemployed and having little education were significantly related to poorer caregiver mental health (Neighbors, et al., 1983). In a review of factors associated with caregiver burden in mental illness (Baronet, 1999), six studies were evaluated and found that being Caucasian was associated with increased overall burden (Horowitz & Reinhard, 1995; Stueve, Vine, Struening, 1997). However, in this same review, no associations were found between race and subjective burden (Solomon & Draine, 1995; Song, Biegel, & Milligan, 1997).

One reason for these different levels of measured caregiver strain may be methodological in that many studies of African Americans have small sample sizes compared to Caucasian studies (Martin, 2000). It is also not clear whether African Americans are really less burdened by the care of children with chronic illness, or if the current measures and measurement techniques (i.e., survey research) are not adequately capturing their caregiving experiences. In addition, research has not adequately accounted or controlled for other strengths and vulnerabilities these caregivers are facing. Lawton et al., noted that the inability to find a cultural mechanism for supporting ideas about African American's attitudes about caregiving was perhaps the result of having no items that uniquely captured the "black experience" (Lawton et al., 1992). Finally, much of the stress and coping literature has treated racial groups as monolithic.

Epidemiological studies like the National Survey of Black Americans (NSBA) (Neighbors, Jackson, Bowman, & Gurin, 1983) were designed to address the limitations of minority stress and coping research by looking at intra-racial comparisons of African American mental and physical health, religion, interaction with family and friends and other understudied concepts, with the goal of providing theoretical and empirical approaches to methods and measurement of the study of African Americans. Research has shown that supportive social and familial networks seem to be more extensive for African Americans compared to their Caucasian counterparts (Kasper, Shore, & Pennix, 2000), and may be an important coping tool for African American women.

These findings have been contradicted in studies of homogenous African American grandparent caregivers who are poor, and living in inner-city communities (Burton, 1992; Minkler, Roe, & Price, 1992). Other studies have found that African Americans more than whites rely on informal social networks (e.g., family, friends, church, and neighbors) versus formal networks (therapeutic support groups, hospitals) to cope with stress (Gibson, 1982; Logan, 1996; Neighbors, et al., 1983; Taylor, Chatters, Tucker, & Lewis, 1990).

Therefore, exactly why African American caregivers report lower strain than Caucasians has largely eluded researchers. Researchers from the adult caregiving literature have attempted to explain these differences by postulating that: 1) more fit and homogeneous samples of African American caregivers are being compared to heterogeneous samples of

Caucasians (Jackson, Chatters, & Neighbors, 1982); 2) African Americans are more resilient due to lifetime experiences of adversity (Neighbors, Jackson, Bowman, & Gurin, 1983); 3) African American caregivers derive unique benefits from their caregiving role (Dilworth-Anderson & Anderson, 1999; Lawton et al, 1992); 4) initial lower income makes them less likely to drop from middle class as a result of caregiving responsibilities than Caucasian counterparts (Hartung, 1993); and 5) African Americans in general have greater support networks (Bussing et al., 2003) and better coping strategies (Bowman, Landefeld, Quinn, Palmer, Kowal, & Fortinsky, 1998) via cultural traditions such as active religious affiliations (Taylor, 1993).

As discussed in earlier sections, cross-cultural studies using the ABCX model have demonstrated differences in perceptions for different groups. Studies such as these demonstrate the relevance of race and culture as it relates to the Double ABCX model. This model has the capacity to evaluate the needs of diverse caregivers as it emphasizes caregiver functioning as dynamic versus static and can evaluate caregiver and family system functioning.

The review of race differences in caregiver strain research, as well as criticisms, highlighted several issues, two of which are addressed in this study: 1) adequate comparison groups and 2) small sample sizes of African American caregivers, particularly. To address these two issues, the current study aims to create comparison groups that are matched on characteristics that are common to other caregiving studies and uses a large sample size from Medicaid data from a multi-site study. Researchers have noted that observational studies should take into consideration that study samples should match subjects on personal characteristics, including risks to reduce issues of selection bias (Rosenbaum, 2002; Little &

Rubin, 2000). This approach has not been used previously in examining racial differences in caregiver strain.

CHAPTER III

METHODS

Research Questions

The purpose of the present study is to shed light on the relationship between caregiver strain and race. As discussed in the previous section, the caregiver strain literature suggests that race is an important construct and the results of the extant literature are inconclusive. The present study examines the role of race in caregiver strain among a Medicaid sample of African American and Caucasian caregivers using the ABCX model. Specifically,

1. When compared to Caucasian family caregivers of children with SED, do African Americans report differing levels of caregiver strain?

2. When compared to Caucasian family caregivers of children with SED with similar risk profiles, do African Americans report lesser caregiver strain?

3. Does caregiver mental health and substance abuse affect the relationship between race and caregiver strain?

Data Source

The present study involves secondary analysis of existing data; therefore, a brief description of the project that yielded the data is provided. More detailed descriptions of the data can be found in Cook, Heflinger, Hoven, Kelleher, Paulson, Stein-Seroussi et al., (2005), Cook, Fitzgibbon, Burke-Miller, Mulkern, Grey et al. (2004), and Cook, Heflinger, Hoven, Kelleher, Mulkern, Paulson et al. (2004). These data are from the Children and Adolescents with Serious Emotional Disturbance (SED) Substudy. The data were collected through funding by the Substance Abuse and Mental Health Services Administration (SAMHSA) as a part of the Managed Behavioral Health Care in the Public Sector (MBHCPS). The steering committee consisted of principle investigators (PI) from five sites, Pennsylvania, New York, Ohio, Oregon, and Tennessee/Mississippi[4]. Additionally, a PI from the University of Chicago at Illinois and a consumer representative also participated.

The goal of the original study was to improve knowledge about the effects of managed behavioral health care and its impact on costs, service utilization and outcomes on Medicaid funded children with mental health and substance abuse problems (Cook, Heflinger, Hoven, Kelleher, Paulson, Stein-Seroussi et al., 2005). The data from the original study included baseline interviews from caregivers regarding service and outcomes of children and families enrolled in managed care or fee-for-service Medicaid.

Study Population and Sample

At each of the five sites, Medicaid-enrolled youth with SED and Managed Care (MC) or fee-for-service (FFS) behavioral health plans were enrolled in the study. Children and youth with SED were defined as being age 4 through 17 at the time of study enrollment; being enrolled in Medicaid at the baseline interview; having a *Diagnostic and Statistical Manual Mental Disorders-Fourth Edition* (DSM-IV; American Psychiatric Association,

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[4] The Tennessee and Mississippi data were combined as one site so that there would be a MC and FFS condition as Tennessee only had MC.

1994) diagnosis of mental disorder; and using in the past year at least one type of intensive mental health service, including inpatient, residential, intensive outpatient, partial hospitalization, in-home support, special school, foster care, crisis services, or intensive case management. Each site used a different method of recruitment based on that state's method of determining Medicaid enrollment in MC versus FFS plans. Sites varied on other characteristics such as types of children with SED, types of caregivers, funding of services, and the political and social climate at the service location.

Inclusion criteria for the adult caregiver interviews were presence of a knowledgeable caregiver willing and able to give informed consent. Respondents were either family members or professional caregivers. Caregiver interviews were conducted at baseline study enrollment and at six-month follow-up. (Note: this study uses only baseline data). Exclusion criteria for the SED sample included having a *DSM-IV* mental disorder diagnosis consisting solely of adjustment disorder, having a diagnosis of mental retardation or developmental disorder and being served primarily through the mental retardation or developmental disability system.

In the baseline data set, 1,724 caregivers participated in the interviews across all five sites. The data for this study, however, were restricted to a subset of adult African American and Caucasian family caregivers pooled from four sites[5]. The Oregon site was excluded from

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[5] Previous research using these data has found site differences between racial groups. Techniques such as hierarchical linear modeling (HLM) or generalized estimating equations (GEE) have been suggested to handle these types of problems. However, given that the goal is to control for the effects of site as opposed to make inference regarding the effect of site on caregiver strain, I instead include site in the propensity score model. Propensity scoring models allow us to better estimate treatment effect when treatment assignment is not random. By including site in the propensity score model, I have taken into account the effect of site on our exposure of interest (race). Diagnostics will be run to examine correlated errors, and addressed if necessary, and will be presented in the Results.

analysis as it only had one African American family caregiver, resulting in an *n* = 1089. It is this subset of adult respondents that were included in this study. No other caregiver characteristics were used to determine eligibility.

Measures

Measures used in this investigation were collected from the child's primary family caregiver in the form of self-report questionnaires. Table 3 presents the participant demographic and background characteristics of the sample. Tables 7 and 8 present the demographics and characteristics of the sample by race, additional instruments, and variables that were used in the analyses, organized by the ABCX model components. Although coping is a component of the Double ABCX model, it is not a variable of interest in the present study. Variables that relate to service utilization such as amount of service and family involvement in service have been interpreted as coping in one study (Heflinger, 1998). Here informal and formal services are interpreted as measures of social support. Other adequate measures of coping are not available in this data set. Because the current study is concerned with the net result of the effect of these measures on strain and not the path by which they operate, classification is less of a concern. The model used for this study (Figure 2) serves as a guide to the selection of variables. The figure illustrates the variables that represent each of the components of the model.

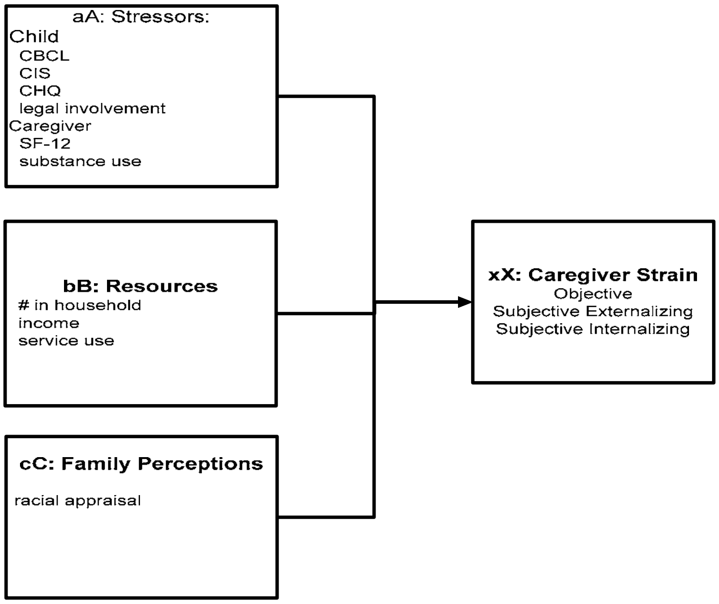

Figure 2. ABCX Measurement Model of Caregiver Strain

Table 3 describes the participant demographics and background characteristics of the family caregivers and the children. Participants came from four sites, New York, Ohio, Pennsylvania and Tennessee/Mississippi. Half of the youth were 12-17 years old with an average age of 11.7. Over thirty two percent of youth were female and almost 34% were African American. Caregiver's average age was 39 with 95% being female and 38% African American. Over 80% of youth were being cared for by a biological parent. Over 33% of the sample was married or living as married and over 35% reported having a high school diploma or GED.

Table 3. *Participant Demographic and Background Characteristics of Total Sample*

	N = 1089
Study Site	
New York	300
Ohio	67
Pennsylvania	361
Tennessee/Mississippi	361
Child	
Age	
Percentage ages 4 to 8 years	16.9%
Percentage ages 9 to 11 years	30.3%
Percentage ages 12 to 18 years	52.5%
Mean age in years (SD)	11.7 (3.2)
Gender, female	32.4%
Race	
Percentage African American	33.6%
Percentage Caucasian	61.2%
Caregiver	
Mean age in years (SD)	39.1 (9.8)
Gender (% female)	95.0%
Race	
Percentage African American	38.0%
Percentage Caucasian	62.0%
Caregiver is the biological parent	80.3%
Marital Status, married/living as married	33.2%
Education, HS diploma or GED	35.6%

aA: Stressors. Both child and caregiver-level measures were used to represent the stressors (aA) in the model. Child stressor events were measured by child problems including child behavioral health and health problems and other stressors such as child legal involvement. Caregiver-level stressors such as health and mental health status, and substance use were used.

Internalizing and externalizing scores on the *Child Behavior Checklist* (CBCL: Achenbach & Edelbrock, 1991) were used to measure child behavioral health and the Columbia Impairment Scale (CIS) to represent child psychosocial functioning. The CBCL has been used extensively and has good reliability and validity. The CBCL (Achenbach & Edelbrock, 1991) is designed to assess behavioral problems and social competencies for children ages 4 through 18 years. It is a parent or caregiver self-report measure that should be completed by a caregiver that has known the child at least 3 months. Parents report on a series of 112 problem items that distinguish clinically referred from non-clinically referred children. It has been norm-referenced for large populations (Achenbach & Edelbrock, 1991; Zima, Wells, & Freeman, 1994) and demonstrated adequate test-retest reliability. The CBCL scores are comprised of two broadband syndromes (Internalizing and Externalizing) and eight narrow band syndromes (Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior). The T-score cutoff for the clinical range is ≥ 63 for the Total score, Externalizing and Internalizing scores and is based on T-scores normed on a clinical population (Achenbach & Edelbrock, 1991; Armsden, Percora, & Payne, 1996). Studies have demonstrated the validity of the CBCL; additionally, the relation between the syndrome scores and DSM diagnoses has been supported (Edelbrock & Costello, 1988; Rey, Morris-Yates, & Stanislaw, 1992).

Youth psychosocial functioning was measured with the caregiver report version of the *Columbia Impairment Scale* (CIS; Bird, Shaffer, Fisher, Gould, Staghezza, Chen et al., 1993). The CIS includes 13 items assessing psychosocial functioning at home, school or job, and peers rated from 0 (i.e., no problem) to 4 (i.e., a very big problem). The reliability and validity of the CIS has been supported in previous research (Bird, et al., 1993).

The Child Health Questionnaire Parent Form (CHQ; Landgraf, Abetz, & Ware, 1996) was used as a measure of child physical health. The CHQ is a 50 item, 14-concept health status and well-being scale designed to measure the physical and psychosocial functioning for children ages 5 years of age and older (the measure was used for four year olds in this study). The CHQ assesses a child's physical, emotional, and social well-being from the perspective of a parent or guardian. The CHQ produces standardized scale scores from 0 to 100 with higher scores being indicative of higher levels of functioning and fewer limitations. The three scales of the CHQ are the Global Health Status (parent's assessment of the child's health as excellent, very good, good, fair, or poor); the physical functioning Scale (presence and extent of physical limitations in self-care, mobility, and activities varying in strenuousness); and the General Health Perceptions Scale (parent's assessment of overall health and illness). Studies of the CHQ have reported high internal reliability ($\alpha = .93$) in U.S. samples. For this study, the General Health Perceptions subscale was used to assess the caregiver's perception of the child's health.

Legal involvement was measured by a single item with "yes/no" responses inquiring as to whether the child had ever been arrested.

Caregiver stressor events are measured by physical and behavioral health scales. The *SF-12 Short Form* health survey (SF-12; Ware, Kosinski, & Keller, 1996) was used to measure physical and mental health of the caregiver. The SF-12 is the short version of the SF-36 which has shown good internal reliability in adult outpatient studies with alphas ranging from .76 to .86. For the SF-12, scale scores have been calculated on a 0-100 scale with higher scores indicating better health status and functioning. The test-retest reliability for the SF-12 was excellent ($r = .89$).

Two variables were used to assess the prevalence of *substance abuse* among caregivers. Caregivers reported the average number of alcohol drinks consumed per day over the past 30 days. The responses were coded into four categories: 0 drinks (i.e., indicating no alcohol use in that time period), 1-2 drinks, 3-5 drinks, or more than 5 drinks. Caregivers also reported the number days in the past month that they used illegal drugs (i.e., cannabis, cocaine/ crack, amphetamines, barbiturates, or sedatives, hallucinogens, inhalants, opiates). Also, descriptive statistics about the percent of substance use is reported, measured by two dichotomous (yes/no) variables inquiring about past month use of 1) alcohol and 2) illegal drugs.

bB: Resources. Household-level continuous variables were included to represent family resources (bB) with *income* measuring family material resources. Household-level variables included in these analyses are number of people in the household and family income. Caregivers reported on total monthly income by all family members from a variety of sources including earned income; foster family payments, income support programs (i.e., WIC, food stamps, TANF); federal support for disabled persons (i.e., SSI, SSDI); worker's compensation; unemployment compensation; pensions, retirement, investment, or savings income; Social Security; and unreported or other income. Three questions on service use, with a dichotomous (yes/no) response set, were also be used as a measure of resources. These questions asked in the past 6 months if caregivers or families had: 1) visited a priest or minister, 2) attended a self-help group, and 3) attended a parent support group.

cC: Perceptions. Race of caregiver was used as a measure of perception or appraisal of the situation. Caregivers self-identified their race. The data was restricted to African American and Caucasians in the sample coded as 0 (Caucasian), 1 (African American).

xX: Adaptation. Caregiver strain is the measure of caregiver adaptation to the crisis and is measured by the *Caregiver Strain Questionnaire (CGSQ)*. The CGSQ is a 21-item self-report instrument that asks specifically about the impact of caring for children with emotional and behavioral problems in the past six months (Brannan, Heflinger, & Bickman, 1997). Items were rated on a five-point Likert scale with 1 equivalent to “not at all” and 5 equivalent to “very much” in reference to the amount of burden felt by the caregiver in relationship to the child. The questionnaire consists of three subscales: (1) Objective Strain (negative, observable occurrences resulting from caring for the child; question 1-11), (2) Subjective- Internalized Strain (feelings internalized by the caregiver regarding caring for the child; 12, 16-18, 20, and 21), and (3) Subjective- Externalized Strain (negative feelings directed at the child; questions 13-15, and 19) (Brannan, Heflinger, & Bickman, 1997). The items in the CGSQ are negatively worded (“How much of a problem was…”) with the exception of question 14 (“How well do you relate to your child?”). This question was reverse coded so that it would score in the same direction as the other items. Reliability analysis was done on the CGSQ with the Tennessee/Mississippi Medicaid sample as a part of this study (Cronbach’s alpha = .93). Previous reliability analysis was done on the CGSQ with the FBEP sample (Brannan et al., 1997). The CGSQ demonstrated adequate reliability and validity and was found to be internally consistent in both samples (Cronbach’s alpha = .93). Caregiver age, race, and gender were also included.

Missing Data

Patterns of missing values were assessed for each variable. Because the data set is largely complete, imputation techniques were not attempted for most variables. All variables in this study have less than ten percent missing data with most variables having less than five percent, with the exception of income. Income has almost seventeen percent missing data for

Caucasians and eight percent for African Americans. Therefore single imputation techniques were used to impute missing values for this variable. Table 4 shows the missing data for each variable of interest in this study. The imputation technique used to impute the value for income is discussed along with a general discussion of issues for addressing missing data.

There are various solutions for addressing missing data each with it strengths, limitations, and assumptions. There are three general approaches to analysis when data are missing, 1) delete, 2) augment, or 3) impute. Hearst (2007) has detailed many of the issues which will be described here. Guidelines offered in a comprehensive text on missing data by McKnight, McKnight, Sidani, & Figueredo (2007) are also discussed.

Deletion. In the first approach cases are deleted from an analysis if any of the variables used in a given, analysis model have missing values (i.e. listwise or pairwise deletion). For the results to be credible this requires the assumption that all missing data occur completely at random (MCAR) (Rubin 1976; Rothman & Greenland, 1998) if left missing. This means that any cells with missing data are not related to other variables in the data set. Chi-square can be used to test if missing variables are independent of the outcome. However, this is stringent assumption that is rarely met. A more realistic assumption for handling analyses with missing data is missing data at random (MAR). This assumption is more flexible by acknowledging that missing data is systematically related to other variables in the data set and the values of the related variables may be used to account for the missing data and those cases may be included in the analysis model rather than deleted.

Augment. In the second approach parameter estimates based on the observed data are augmented by the extra information provided by an assumed underlying distribution or probability model. The two general categories here are model-based and adjustment. Model-based procedures like maximum likelihood (ML), expectation maximization (EM), and Markov chain Monte Carlo (MCMC), can yield robust estimates, but they must be custom-tailored to each situation and the computations can be quite complex. Empirical adjustment procedures like weighting and dummy code adjustment correct parameter estimates so as to prevent or decrease expected biases. Although adjustment methods are widely used in survey research, they are weak choices that produce biased estimates or are only suitable under highly constrained conditions (McKnight, McKnight, Sidani, & Figueredo, 2007).

Impute. The third approach, imputation, can involve single or multiple varieties. In the hierarchy of methods to handle missing data, multiple imputation is touted as the most desirable approach. Simply, multiple imputation replaces each missing value with multiple imputed values X and generates X completed data sets. Multiple imputation thus not only accounts for the variance within a variable, but also incorporates uncertainty of the model by "displaying the variation in valid inferences across the models" (Little and Rubin 2002). Current statistical software reduces the complexity of multiple imputation, but its application was beyond what was deemed necessary for this study.

Hot deck imputation. Three methods for single imputation involve substituting either a constant or a random value into the cells with missing data. The most familiar type of single imputation is mean substitution. Here a constant, the mean of a variable is substituted into missing cells within that variable. Mean substitution is now generally ill-advised because it reduces the variance of the variable. In regression imputation, another method of single imputation, regression equations are used to predict the value of the missing value. The regression method has the problem that all cases with the same values on the independent variables will be imputed with the same value on the missing variable, causing a portion of the same problems as mean substitution.

A better method of single imputation, *hot-decking*, substitutes a value selected at random from those observed in the current data. The important feature is that the exact value imputed cannot be traced to anything but a random selection procedure. While hot decking is usually thought to be a more suitable approach than mean substitution, it must be used with caution because there is still some concern with reduced standard errors, which can lead to an increase in Type I errors.

Hot deck imputation uses “a respondent’s valid value (donor) for a specific variable and assigns it to another respondent who does not have a valid value for the variable (recipient).” (Kalton & Kish, 1981; Davern, Blewett, Bershadsky, & Arnold, 2004; Titterington, 1985). Simply, by matching respondents based on select characteristics, actual values are used for imputation into the matched respondent’s missing value field. The underlying assumption with this technique is that the value of the variable being estimated is not moderated by the missing data mechanism (Davern et al., 2004). Hot deck imputation may alter summary statistics of the individual variables, but should not alter the relationship between two variables. This method imputes actual values selected at random from the pool of donors, as opposed to imputing a mean. The U.S Census Bureau uses hot decking to correct for item non-response as well as other demographic surveys (Davern et al., 2004). Hot deck imputation was used here for missing data imputation using Stata 10.0. Table 4 presents number and proportion of cases with missing data for each variable including income before hot deck imputation.

Table 4. *Number and Proportion of Cases with Missing Data for Each Variable*

		Cases with missing data	
Variable description	Total *N*	*n*	%
Race	1089	0	0.0
Participant characteristics			
Child age	1083	6	0.6
Child gender	1089	0	0.0
Caregiver age	1079	10	0.9
Caregiver gender	1089	0	0.0
Caregiver (bio parent)	1089	0	0.0
Caregiver marital status	1088	1	0.1
Caregiver education	1087	2	0.2
Stressors			
CBCL Internalizing	1060	29	2.7
CBCL Externalizing	1056	33	3.0
CIS	1087	2	0.2
CHQ	1086	3	0.3
Youth legal involvement	1084	5	0.5
SF-12 physical health	1049	40	3.7
SF-12 mental health	1049	40	3.7
Substance Use (days)	1084	5	0.5
Past month drinking	1084	5	0.5
% illegal drug use	1088	1	0.1
Past month use of drugs	1086	3	0.3
Resources			
Household composition	1008	81	7.4
Household income (before imputation)	960	129	11.8
Priest/minister visited	1086	3	0.3
Self-help group visited	1089	0	0.0
Attended parent support group	1051	38	3.5

Other Studies Using this Data Source

Other studies have used a subset of these data to conduct analysis of caregiver strain. Only one study explored racial differences in caregiver strain. Kang, Brannan and Heflinger (2005) examined racial differences in response to the Caregiver Strain Questionnaire (CGSQ) (Brannan et al., 1997). They used a subset of the Tennessee/Mississippi site data to compare African Americans (*n* = 316) and Caucasians (*n* = 375). Significant item-level and scale differences were found with African Americans consistently reporting lower caregiver strain. To examine for criterion related validity, the authors used the CBCL and several variables found to influence caregiver strain including parenting arrangement, income, number of people in the household, caregiver age and gender, and satisfaction with family life. The results of the study showed that CBCL scores were positively related to objective caregiver strain for African Americans and Caucasians. African Americans experienced less increase in objective strain than Caucasians at a given increase in the child's internalizing problems. Race did not predict either of the two subjective dimensions of strain. The study demonstrated that the CGSQ had good reliability and validity and has been shown good measurement equivalence with African Americans as well as Caucasians.

Heflinger and Brannan (2006) explored differences in families of youth with substance abuse disorders (*n* = 121) and youth with mental health problems (*n* = 185). Only data for the youth with mental health problems is a subset of the data being used in this study. For caregivers in this subset, the authors found that for objective strain, the more depressive symptoms the caregiver reported and the greater the child's problems with psychosocial functioning, the greater the strain. For subjective-externalized strain, the greater the child's externalizing behavior and the lower the internalizing behavior on the CBCL, the greater the strain. Subjective-internalized strain was higher for biological relatives. More problems with youth psycho-social functioning and increased caregiver depressive symptoms were also predictive of subjective-internalized strain.

Taylor-Richardson, Heflinger and Brown (2006) used the Tennessee/Mississippi (*n* = 648) subset of these data along with a military (*n* = 978) sample to examine how parents and other caregivers and different family caregiver populations experience strain. It also examined the reliability of the CGSQ for these groups. It was found that overall, the Medicaid sample reported higher levels of strain than the military sample. Factor analysis results reported in this study supported differences in the way other relative caregivers report strain compared to parents. Overall the factor analysis showed that the CGSQ performed similarly for the Medicaid and military samples.

Heflinger and Taylor-Richardson (2004) used the Tennessee/Mississippi sample to explore caregiver type differences. In a comparison of youth living with parents (*n* = 539) and youth living with other relatives (*n* = 109), parents consistently reported higher levels of strain than other relatives. Caregiver's relationship to the child only significantly predicted strain for the Subjective-Internalizing scale with parents reporting higher levels of strain.

Research has shown that African Americans frequently report lower levels of caregiver strain independent of disease type, social support and other important characteristics such as health status and other instrumental resources. Other studies have looked at the correlational relationship between race and strain for families of youth with emotional and behavioral problems. By using propensity score methodology defined in the following Data Analysis section, this study further advances the knowledge on caregiver strain by specifying causal relations between race and caregiver strain.

Limitations of the Secondary Data

Several limitations regarding these data warrant noting. This data were collected from caregivers of children with Medicaid, the publicly funded insurance program. Therefore, the results may not be generalizable to other groups of caregivers and the children in their care. Second, these data also may not be generalizable to other Medicaid samples as there is variability among Medicaid programs across states (Semansky, Koyanagi, & Vandivort-Warren, 2003). Finally, among the states in the sample there were notable differences in settings, service availability, severity of problems and demographic characteristics.

Data Analysis

This study evaluated caregiver strain using methodological strategies specifically designed to minimize the confounding related to selection bias. Descriptive statistics were used to describe the sample and test item-level differences between African Americans and Caucasians. T-tests and chi-squares were done to look for significant mean differences between African Americans and Caucasians and percents clinical ranges for relevant instruments on all predictor and dependent variables. Remaining analyses were conducted according to the research questions. Tables 5 and 6 outline which variables were used in each analysis.

Question 1: When Compared to Caucasian Family Caregivers of Children with SED, do African Americans Report Differing Levels of Caregiver Strain?

An ordinary least squares (OLS) regression was used to determine the effects of race on the three dimensions of caregiver strain controlling for other child and participant characteristics and demographics, stressors, resources covariates. The rationale for this analysis is to provide a baseline for assessing whether more restrictive comparisons in the analysis of Question two will help minimize bias.

Question 2: When Compared to Caucasian Family Caregivers of Children with SED with Similar Risk Profiles, do African Americans Report Lesser Caregiver Strain?

A propensity score of race was calculated using logistic regression. The propensity score is added to an OLS model of strain. This propensity score adjusted OLS model was compared to the findings from Question one to evaluate whether it provides a better fit over the standard OLS regression. More details on propensity score methodology are presented below.

Question 3: Does Caregiver Mental Health And Substance Abuse Affect the Relationship Between Race and Caregiver Strain?

Similar to the analysis Question two, an OLS regression was run first without the propensity score then using the propensity score. The first model was run with race, parental mental health and substance abuse variables as predictors of caregiver strain. The second model included these variables with the propensity score.

Table 5. *Dependent Variables in OLS and Propensity Score Adjusted Regression Models*

	Model A	Model B	
Dependent variable	OLS	Calculate PS	OLS with PS adjustment
Objective Strain	x		X
Subjective Strain, Externalizing	x		X
Subjective Strain, Internalizing	x		X
Race		X	

Table 6. *Independent Variables in OLS and Propensity Score Adjusted Regression Models*

	Model A	Model B	
Independent variables	OLS	Calculate PS	OLS with PS adjustment
Child			
age	x	X	
gender	x	X	
CHQ	x	X	
CBCL	x	X	
CIS	x	X	
legal involvement	x	X	
Caregiver			
age	x	X	
race	x[3]		x
caregiver (bio parent)	x	X	
gender	x	X	
income	x	X	
education	x	X	
SF-12 physical health	x	X	
SF-12 mental health	x[3]		x
substance use	x[3]		x
Other			
service use	x	X	
study site	x	X	
propensity score			x

[3] Variables also used in OLS regression model for Question 3 without propensity score

Propensity Scores

Propensity score methodology has largely been used in economics and biostatistics to control for confounding in observational studies (Dehejia & Wahba, 2002; Rosenbaum & Rubin, 1984; Rubin & Thomas; 1996; Winship & Morgan, 1999). Caregiver strain is a complex phenomenon that can be confounded by a number of different factors. To date, only two studies were identified that used propensity score techniques to study caregiver strain related issues with both being in adult samples (Christakis & Iwashyna, 2003; Williams, Bakas, Brizendine, Plue, Tu, Hendrie et al., 2006). To minimize possible confounding and to balance African Americans and Caucasians along multiple matching criteria, propensity scores were used (Rosenbaum & Rubin, 1983, 1984; Smith, 1997). Simply, in propensity score analysis, balancing is used to overcome confounding and results in treated and control groups that are comparable in the sense that they have similar distributions of observed covariates. The propensity score corrects for all observed differences. Treated and control groups are also referred to as exposed and unexposed with the exposure being the treatment. This is the language that will be used throughout this study.

Using methods presented by Rosenbaum (2002) and Rubin (1997), this study aimed to create comparison groups that mimic experimental conditions found in randomized comparison groups, creating a counterfactual condition (i.e. what would happen if Caucasians perceived caregiver strain more like African Americans?). Rosenbaum and Rubin (1983) showed that, under certain assumptions, conditioning analyses of the propensity score reduces the confounding between exposure effects and observed covariates when comparing groups in observational studies.

Essentially, the propensity score, $\lambda(x)$, represents the conditional probability that a subject will receive a particular exposure given a set of covariates. The score is calculated by including the covariates in a logistic regression without including the outcome. The set of covariates are grouped into one variable. The calculation of the propensity score requires 1) the estimation of a standard probability model and 2) using the propensity score to control for confounding or as an index for matching cases from a control group.

When propensity score methods are used to control for sample selection bias due to observable differences between exposed and unexposed groups the matching technique involves creating exposed and unexposed groups that are similar in terms of observable characteristics. In the case of this study, race becomes the exposure variable and the propensity score is the predicted probability of group membership. African Americans are the exposed and Caucasians are the unexposed group. To describe the propensity score let the dichotomous (0, 1) variable Z indicate race, and let the X be a matrix of the available covariates. The propensity score $e(\mathrm{X})$ for an individual is defined as the conditional probability of being African American given his or her covariates X: $e(\mathrm{X}) = \Pr(\mathrm{Z} = 1 \mid \mathrm{X})$ (Kurth, Walker, Glynn, Chan, Gaziano, Berger et al., 2005).

Use of propensity scores offer several improvements over standard regression models. Although logistic regression is often used to control for group imbalances when there are many variables, too many variables in a model compared to the number of events can result in model misspecification. The propensity score condenses the entire set of observed covariates to a single composite that provides a summary for the entire set of covariates. Using this single propensity score allows for the straightforward assessment of between group overlap with regard to the observed covariates (Rubin, 1997). Overlap refers to the range of propensity scores where the group distributions of the propensity scores overlap. Second, if the propensity scores are split five balanced strata or quintiles, called stratification, assumptions of the methodology state that 90% of the bias, based on the observed covariates, should be removed (Cochran, 1968). Finally, the problem of data mining is avoided since the procedure does not rely on looking at the outcomes (Dehejia, 2005).

Like any methodology, it has drawbacks that limit its utility. Because it cannot account for and thus balance unobserved covariates, these variables can remain a source of bias (Winkelmayer & Kurth, 2004).

There are several propensity score approaches. Analysis may be conditioned on propensity scores by stratifying cases on the propensity score (Rosenbaum & Rubin, 1985), one to one matching or by weighting cases with the odds associated with their propensity score (Hirano, Imbens, & Ridder, 2003). Stratification was used here.

Stratification. Propensity score methodology can be employed using several difference techniques. Sub-classification or stratification as it will be referred to here is defined as a procedure used to stratify groups based on the probability of receiving treatment (Rubin, 1997; Rosenbaum & Rubin, 1984). When employed correctly, the score results in a design whereby group assignment into treatment and control conditions does not differ with respect to the observed covariates used in calculating the propensity score (Dehejia & Wahba, 1999; Rosenbaum & Rubin, 1984; Winship & Morgan, 1999).

Steps for propensity score analyses. First, the potential risk factors of interest were identified. For a binary exposure, the propensity score is the estimated probability of being exposed conditional on the subject's individual values for the potential risk factors. The propensity score was derived by fitting a logistic regression model relating the exposure (dependent variable) to the potential risk factors (independent variables) for the entire cohort. The propensity score is the fitted values from this model for each subject. The estimated propensity score, ($\hat{e}\,(X)$), was obtained from the fit of a logistic regression model for which observed variables that have been known to influence caregiver strain based on race were considered.

Next, plots were constructed of the distribution of the propensity scores separately for exposed and unexposed subjects and overlap was assessed. If there is not sufficient overlap, the propensity score analysis may produce biased exposure estimates. If there is sufficient overlap, then an assessment was made if the propensity score balanced the distribution of the potential risk factors. Third, to assess the balance of the potential risk factors, a regression model was fitted relating the risk factor (dependent variable) to the exposure and propensity score (independent variables). Propensity scores are often categorized based on quintiles for these models. This was done for each risk factor individually. If the exposure is not related to the risk factors after adjusting for the propensity score, then there are no detectable imbalances in the distributions of the risk factors, and the propensity score is used in regression models relating exposure to outcome. The propensity score is included in the regression model as a categorical variable (i.e., quintiles).

Power Analysis

Using a two-sample comparison of means, power calculations were done for each subscale of the Caregiver Strain Questionnaire based on data from Kang, Brannan and Heflinger's (2005) study of racial differences in the CGSQ (n = 316 for African Americans and n = 375 for Caucasians). The sample size for analyses in this study provides a power of .95 (*ES* = .25), .36 (*ES* = .10) and .50 (*ES* = .13) for the Objective Strain Scale, Subjective Internalizing Scale and, Subjective Externalizing Scale respectively. In Cohen's (1992) classic work, small, medium and large effect sizes are .20, .50, and .80 respectively for α = 05. Cohen cautions that the quantities represent typical effect size estimations for the social sciences and that they should not be applied indiscriminately to specific topic areas.

Because the sample size for the data for this study is larger issues of power should not be a consideration.

CHAPTER IV

RESULTS

Results are presented in 2 sections. Participant demographics and background characteristics and characteristics in the ABCX model are described. This is followed by primary analyses addressing each of the three research questions.

Participant Characteristics and Demographics

Table 7 presents the sample characteristics for the overall sample as well as by race. The focus of this chapter is on the differences between African Americans and Caucasians. For more information on the total sample see the Methods section (Chapter III).

General Characteristics

The majority of caregivers of both racial groups came from the New York, Pennsylvania, and Tennessee/Mississippi sites. However, New York and Tennessee/Mississippi had more equal representation of both groups. There were significant differences in the ages of the children cared for by these caregivers with African Americans having younger children (x = 11.1) than Caucasians (x = 12.1) by one year on average. African American caregivers had a higher percentage of female children than Caucasians, 34.5% vs. 31.1% respectively. The ages of the caregivers were similar with African Americans being slightly younger at an average age of 38.7 and Caucasians 39.4. The caregivers in both groups were largely female with 95.5% being female for African Americans and 94.7% Caucasians. A significantly lower number of African American caregivers reported being the biological parent; 74.6% vs. 83.9% for Caucasians. This is consistent with the literature that higher numbers of minority youth are being cared for by a relative other than a parent; in this sample these caregiver self-identified as grandmothers and grandfathers (Fuller-Thomson, Minkler & Driver, 1997). Significantly more Caucasians reported being married. The samples similarly held high school diplomas or GEDs.

Table 7. *Participant Demographics and Background Characteristics by Race*

	N = 1,089	African American *n* = 414	Caucasian *n* = 675
Study Site			
New York	300	60.0%	40.0%
Ohio	67	64.2%	35.8%
Pennsylvania	361	6.1%	93.1%
Tennessee/Mississippi	361	46.8%	53.2%
Child			
Age			
Percentage ages 4 to 8 years	16.9%	22.0%	13.7%
Percentage ages 9 to 11 years	30.3%	33.2%	28.5%
Percentage ages 12 to 18 years	52.5%	44.8%	57.8%
Mean age in years (SD)	11.7 (3.2)	11.1 (3.2)**	12.1 (3.2)
Gender (% Female)	32.4%	34.5%	31.1%
Caregiver			
Mean age in years (SD)	39.1 (9.8)	38.7 (10.9)	39.4 (8.8)
Gender (% Female)	95.0%	95.5%	94.7%
Race		38.0%	62.0%
Caregiver is biological parent	80.3%	74.6%**	83.9%
Marital Status, married or living as married	33.2%	18.6%***	42.1%
Education, HS diploma or GED	35.6%	33.9%	36.1%

*$p < .05$, **$p < .01$, *** $p < .001$

Caregiver Characteristics Used in the ABCX Model

Table 8 shows descriptive statistics for the model by race (cC). There were fewer self-reported African Americans than Caucasians in this sample. The child and caregiver stressors (aA) used in the analytic model are discussed next. The youth in both groups had high CBCL scores with Caucasians' mean score closer to the clinical cut off of 63. Also noteworthy is that both groups had high percentages of youth at or above the clinical cut point score of 63; African Americans 45.9% and Caucasians 47.4% indicating a high percentage of youth with significant impairment. African Americans had significantly lower mean scores on the Columbia Impairment Scale (CIS) (22.3) compared to Caucasian (24.7) caregivers. These high symptom and functioning impairment scores confirm that these youth have SED. Mean CHQ scores were not significantly different although African Americans had lower mean scores (61.1) than Caucasians (63.0) on a scale where higher scores indicate better health. African Americans reported having a higher percentage of youth being arrested by the police (19.3% compared to 14.6% for Caucasians). This is consistent with literature that African American youth are more likely to be arrested and are overrepresented in the legal system compared to Caucasian youth (Drakeford & Garfinkel, 2000).

Although African Americans had lower mean scores on physical health scale and higher on the mental health scale of the SF-12, there were no significant between group differences on this measure. Caregivers reported their average number of drinks per day of alcohol use in the past 30 days similarly across all levels except African Americans reported a lower percentage of five or more drinks than Caucasians (15.6% vs. 18.8%). African American reported using significantly fewer days of illegal drug (i.e., cannabis, cocaine/crack, amphetamines, barbiturates, sedatives, hallucinogens, inhalants, or opiates) use (5.3 vs. 15.9) than Caucasians in the past thirty days.

In the resources (bB) category, the number of people in the household differed significantly between African Americans and Caucasians with African Americans reporting closer to five people per household and Caucasians four. There were no other significant differences in the resource variables. Average monthly incomes for both groups demonstrated that they were in very depressed income brackets. Both groups also used religious, self-help, and support group services similarly.

There were significant differences on 2 of the 3 subscales of the Caregiver Strain Questionnaire (CGSQ). African American caregivers reported significantly lower levels of strain on the Objective strain and Subjective-Internalizing scales. They also reported lower levels of strain on the Subjective-Externalizing scale but this difference was not significant.

Table 8. *Descriptive Statistics for Model by Race* (cC) (*N* = 1,089)

Model variables	African American (*n* = 414)	Caucasian (*n* = 675)
Stressors (aA)		
Child		
Child Behavior Checklist (CBCL)		
Total	60.2 (33.4)	62.9 (32.2)
Internalizing	14.6 (10.3)	15.5 (10.0)
Externalizing	22.8 (13.0)	23.9 (13.1)
Percentage ≥ 63 (clinical cutoff)	45.9%	47.4%
Columbia Impairment Scale	22.3 (10.4)**	24.7 (10.5)

Model variables	African American (*n* = 414)	Caucasian (*n* = 675)
Child Health Questionnaire (CHQ)	61.1 (22.5)	63.0 (22.4)
Percentage of youth reporting legal involvement (ever arrest by police)	19.3%	14.6%
Caregiver		
SF-12		
Physical Health	42.9 (12.6)	43.3 (12.7)
Mental Health	41.9 (12.0)	40.9 (11.9)
Substance use		
Drinking in past month		
Percentage reporting 1 to 2 drinks	56.6%	53.6%
Percentage reporting 3 to 4 drinks	27.9%	27.6%
Percentage reporting 5 or more drinks	6.5%	5.5%
Days of illegal drug use in last 30 days for those reporting usage	5.3 (7.9)***	15.9 (12.1)
Resources (bB)		
Number residing in household	4.7 (2.1)***	4.2 (1.6)
Monthly household income	$1,498 (932)	$1,541 (1016)
Service use in last 6 months		
Visited priest or minister	6.8%	6.0%
Visited self-help group	1.9%	1.8%
Attended parent support group	14.4%	14.5%
Adaptation (xX)		
Caregiver Strain Questionnaire (CGSQ)		
Objective Strain	2.04 (.981)***	2.25 (.995)
Subjective Strain, Externalizing	2.16 (.908)	2.21 (.907)
Subjective Strain, Internalizing	3.08 (1.10)**	3.28 (1.08)

†Response scale (1 = *Not at all*, 2 = *A little*, 3 = *Somewhat*, 4 = *Quite a bit*, and 5 = *Very much*)

* $p \leq .05$, ** $p < .01$, *** $p < .001$

Primary Analyses[6]

Question 1: When Compared to Caucasian Family Caregivers of Children with SED, do African Americans Report Differing Levels of Caregiver Strain?

This section presents descriptive statistics and regression analysis for the three caregiver strain subscales.

Table 9 shows CGSQ items and scale scores and indicates where there are significant mean differences between strain reported by African Americans and that reported by Caucasians. On 13 of 21 items, there were significant differences in the two samples with items in all three scales, with African Americans consistently reporting lower levels of strain. Table 10 reports the proportion of caregivers that reported high levels of strain distinguished by ratings on the Likert scale of 4 or 5. On 8 of the 21 items African Americans reported a lower percentage. Items were from all three scales, with the majority from the Objective strain scale.

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[6] Prior to analyses all variables were examined to ensure the data adequately met the assumptions for regression. A correlation matrix of variables used in regression analyses is provided in Appendix B.

Table 9. *Means and Standard Deviations for Responses to the Caregiver Strain Questionnaire Items by Race* (*N* = 1,089)

Scale item number and text† Item stem: *How much of a problem were the following items?*	African American (*n* = 414)	Caucasian (*n* = 675)
Objective Strain		
1. Interruption of personal time resulting from your child's problems?	2.73 (1.38)*	2.90 (1.40)
2. Your missing work or neglecting other duties because of your child's problems?	2.33 (1.42)	2.37 (1.41)
3. Disruption of family routines due to your child's problems?	2.35 (1.42)**	2.64 (1.35)
4. Any family member having to do without things because of your child's problems?	1.71 (1.20)*	1.89 (1.28)
5. Any family member suffering negative mental or physical health effects as a result of your child's problems?	1.70 (1.29)***	2.18 (1.43)
6. Your child getting into trouble with the neighbors, the community, or law enforcement?	1.81 (1.28)	1.67 (1.12)
7. Financial strain for your family as a result of your child's problems?	1.82 (1.34)	1.80 (1.24)
8. Less attention paid to any family member because of the attention given to your child?	1.95 (1.27)**	2.22 (1.40)
9. Disruption or upset of relationships within the family due to your child's problems?	2.00 (1.38)***	2.39 (1.39)
10. Disruption of your family's social activities resulting from your child's problems?	1.86 (1.29)***	2.32 (1.41)
11. How socially isolated did you feel as a result of your child's problems?	2.19 (1.41)*	2.42 (1.44)
Subjective- Externalized Strain		
13. How embarrassed did you feel about your child's problems?	2.08 (1.46)	2.11 (1.39)
14. How well did you relate to your child?	1.86 (1.15)***	2.15 (1.17)
15. How angry did you feel toward your child?	2.34 (1.43)*	2.51 (1.42)
19. How resentful do you feel toward your child?	1.58 (1.19)	1.62 (1.09)
Subjective- Internalized Strain		
12. How sad or unhappy did you feel as a result of your child's problems?	3.00 (1.53)	3.18 (1.47)
16. How worried did your feel about your child's future?	3.94 (1.38)**	4.08 (1.27)
17. How worried did you feel about your family's future?	3.16 (1.63)	3.18 (1.53)
18. How guilty did you feel about your child's problems?	2.69 (1.71)	2.85 (1.66)
20. How tired or strained did you feel as a result of your child's problems?	2.94 (1.63)**	3.29 (1.49)
21. In general, how much of a toll has your child's problems been on your family?	2.87 (1.54)**	3.15 (1.40)

†Response scale (1 = *Not at all*, 2 = *A little*, 3 = *Somewhat*, 4 = *Quite a bit*, and 5 = *Very much*)

*p≤.05 **, p< .01, *** p<.001

Table 10. *Percentage of Caregivers Indicating High Levels of Strain on the Caregiver Questionnaire Items* (Response = 4 or 5) *by Race* (*N* = 1,089)

Scale item number and text[†] Item stem: *How much of a problem were the following items?*	African American (*n* = 414)	Caucasian (*n* = 675)
Objective Strain		
1. Interruption of personal time resulting from your child's problems?	32.8%	37.4%
2. Your missing work or neglecting other duties because of your child's problems?	24.2%	24.1%
3. Disruption of family routines due to your child's problems?	22.6%*	29.1%
4. Any family member having to do without things because of your child's problems?	12.4%	15.0%
5. Any family member suffering negative mental or physical health effects as a result of your child's problems?	11.2%***	21.4%
6. Your child getting into trouble with the neighbors, the community, or law enforcement?	14.9%*	10.0%
7. Financial strain for your family as a result of your child's problems?	15.0%	13.0%
8. Less attention paid to any family member because of the attention given to your child?	15.3%	19.5%
9. Disruption or upset of relationships within the family due to your child's problems?	17.2%**	24.6%
10. Disruption of your family's social activities resulting from your child's problems?	13.5%***	22.9%
11. How socially isolated did you feel as a result of your child's problems?	22.2%	25.9%
Subjective- Externalized Strain		
13. How embarrassed did you feel about your child's problems?	21.0%	19.9%
14. How well did you relate to your child?	12.9%	13.7%
15. How angry did you feel toward your child?	24.1%	26.3%
19. How resentful did you feel toward your child?	8.5%	7.5%
Subjective- Internalized Strain		
12. How sad or unhappy did you feel as a result of your child's problems?	40.5%*	46.6%
16. How worried did you feel about your child's future?	68.1%*	74.5%
17. How worried did you feel about your family's future?	46.7%	47.5%
18. How guilty did you feel about your child's problems?	35.5%	38.4%
20. How tired or strained did you feel as a result of your child's problems?	41.1%**	50.1%
21. In general, how much of a toll has your child's problems been on your family?	37.1%	43.8%

[†] Response scale (1 = *Not at all*, 2 = *A little*, 3 = *Somewhat*, 4 = *Quite a bit*, and 5 = *Very much*)

*p≤.05 **, p< .01, *** p<.001

The results of the bivariate and multiple regression analyses are presented in Table 11. In the bivariate analysis race was a significant predictor of strain on the Objective scale and the Subjective-Internalizing scale.

The results of the multiple regression analyses with the full model illustrate that some participant characteristics and variables of the ABCX model were significantly associated with caregiver strain. In only one of the three caregiver strain subscales did the information on race (cC) significantly add to the prediction of caregiver strain. Being Caucasian was a significant predictor of strain only on the Objective scale, where we saw in Table 9 that Caucasians reported higher strain.

Of the demographic variables, the older the child, the higher the caregiver strain reported on both the Subjective scales. Being a biological parent was a significant predictor on the Subjective-Internalizing scale. Higher levels of education were also a significant predictor on the Objective scale.

Several stressors (aA) were significant across the three scales. As in other studies (Angold, et al., 1998; Brannan & Heflinger, 2001; Brannan, Heflinger, & Bickman, 1997; Yatchmenoff, et al., 1998), the child’s emotional/behavioral problems were significant predictors of caregiver strain, with the greater the level of problems, the higher the level of strain reported. The child’s CBCL score was predictive of caregiver strain on the Objective Burden scale and Subjective Burden-Internalizing scales and the CIS score predictive on all scales. The CBCL internalizing score influenced caregiver strain in the opposite direction for the Subjective-Externalizing scale. On a domain where the caregiver reports negative feelings about the child’s problems, higher child internalizing problems were associated with lower levels of strain. Caregiver physical health (SF-12) was significant on the Objective and the Subjective-Internalizing scale with lower self-reported health indicative of higher strain. Lower reported child health (CHQ) was also indicative of higher caregiver strain on the Subjective-Internalizing scale. The child’s involvement with the legal system was only significant on the Objective scale. This variable is not frequently assessed in caregiving studies but it makes sense that it would be predictive of strain on this scale as it is a measure of observable events and occurrences experienced by the family/caregiver as a result of the child’s problems.

Only one of the resource (bB) variables was a significant predictor. Fewer numbers of people in the household was predictive of less strain on both of the Subjective scales which supports previous findings (Heflinger & Taylor-Richardson, 2004).

Table 11. *Ordinary Least Squares Regression Models by Caregiver Strain Outcome (N* = 1,089*)*

	OUTCOME 1 OBJECTIVE STRAIN				OUTCOME 2 SUBJECTIVE EXTERNALIZING STRAIN				OUTCOME 3 SUBJECTIVE INTERNALIZING STRAIN			
Independent variables	*B* (*SE*)	BETA*	*t*	*p*	*B* (*SE*)	BETA*	*t*	*p*	*B* (*SE*)	BETA*	*t*	*p*
Bivariate Model												
Caregiver Race (cC)	-.212(.063)	-.103	-3.38	.001	-.042(.058)	-.022	-.722	.471	-.201(.069)	-.089	-2.894	.004
Multivariate Model												
Participant												
Caregiver race (cC)	-.137(.056)	-.067	-2.45	.015	-.018(.060)	-.009	-.293	.769	-.082(.067)	-.036	-1.217	.224
Caregiver age	-.002(.003)	-.022	-.681	.496	-.002(.004)	-.026	-.672	.502	-.002(.004)	-.026	-.723	.470
Caregiver gender	-.005(.108)	-.003	-.137	.891	.051(.117)	.012	.433	.665	.122(.131)	.024	.932	.352
Caregiver relationship to child	.127(.079)	.051	1.62	.107	.109(.085)	.048	1.28	.200	.323(.095)	.118	3.40	.001
Caregiver marital status	.030(.015)	.051	2.08	.057	.019(.016)	.036	1.22	.222	.028(.018)	.043	1.59	.113
Caregiver education	.042(.010)	.102	4.20	.000	-.003(.011)	-.016	-.537	.592	.011(.012)	.023	.873	.383
Child gender	.024(.051)	.011	.465	.642	.041(.055)	-.021	-.747	.455	-.012(.062)	-.005	-.188	.851
Site												
Pennsylvania	-.119(.062)	-.058	-1.90	.057	-.464(.067)	-.241	-6.90	.000	-.075(075)	-.032	-998	.319
Ohio	.378(.110)	.007	3.44	.001	-.533(.113)	-.141	-4.70	.000	.274(.127)	.060	2.16	.031
New York	.006(.065)	.003	.922	.927	-.360(.069)	-.177	-5.20	.000	.090(.077)	.037	1.17	.243
Child age	.004(.008)	.013	.465	.642	.032(.009)	.114	4.98	.000	.024(.010)	.070	2.32	.020
STRESSORS (aA)												
CBCL												
Internalizing	.009(.003)	.094	2.92	.004	-.002 (.003)	-.023	-.592	.554	.016(.004)	.152	4.29	.000
Externalizing	.024(.003)	.314	9.15	.000	.018 (.003)	.260	6.38	.000	.014(.003)	.165	4.35	.000
CIS	.030(.003)	.322	9.40	.000	.022 (.003)	.252	6.20	.000	.034(.004)	.324	8.60	.000

	OUTCOME 1 OBJECTIVE STRAIN				OUTCOME 2 SUBJECTIVE EXTERNALIZING STRAIN				OUTCOME 3 SUBJECTIVE INTERNALIZING STRAIN			
Independent variables	*B* (*SE*)	BETA*	*t*	*p*	*B* (*SE*)	BETA*	*t*	*p*	*B* (*SE*)	BETA*	*t*	*p*
CHQ	-.001(.001)	-.029	-1.11	.265	.002 (.001)	.060	1.96	.067	-.003(.001)	-.062	-1.82	.034
Legal involvement	.113(.050)	.058	2.27	.024	.009 (.053)	.005	.174	.862	.058(.059)	.027	.977	.329
SF-12 physical health	-.005(.002)	-.066	-2.69	.007	.000 (.002)	-.004	-.126	.900	-.005(.002)	-.063	-2.34	.020
RESOURCES (bB)												
# People in Household	-.014(.014)	-.026	-1.16	.310	-.033 (.015)	-.067	-2.22	.027	-.043(.017)	-.072	-2.55	.011
Total family income	1.41E-005(.000)	.014	.553	.580	1.59E-005(.000)	.000	.017	.578	1.93E-005(.000)	.017	.627	.531
Visited priest/minister	.007(.048)	.004	.156	.876	.044(.052)	.023	.836	.404	.028(.058)	.012	.471	.638
Attended self-help	.300(.176)	.040	1.70	.089	.060(.052)	.023	.836	.404	-.095(.212)	-.012	-.449	.653
Attended parent support	.030(.044)	.016	.674	.500	.007(.048)	.004	.136	.892	.009(.054)	.004	.174	.862

Question 2: When Compared to Caucasian Family Caregivers of Children with SED with Similar Risk Profiles, do African Americans Report Lesser Caregiver Strain?

Preparing the Propensity Score

As discussed in Methods Section (Chapter III), using propensity scores to balance groups on observed covariates can produce improved estimates over conventional OLS regression methods. A necessary step in propensity score methodology is to evaluate the distribution of the propensity scores to determine whether the groups overlap on the full set of observed covariates (Dehejia & Wahba, 2002; Winship & Morgan, 1999; Rosenbaum & Rubin, 1984; Rubin, 1997). Figure 3 demonstrates that there is adequate overlap of the distribution of propensity scores for African American and Caucasian caregivers.

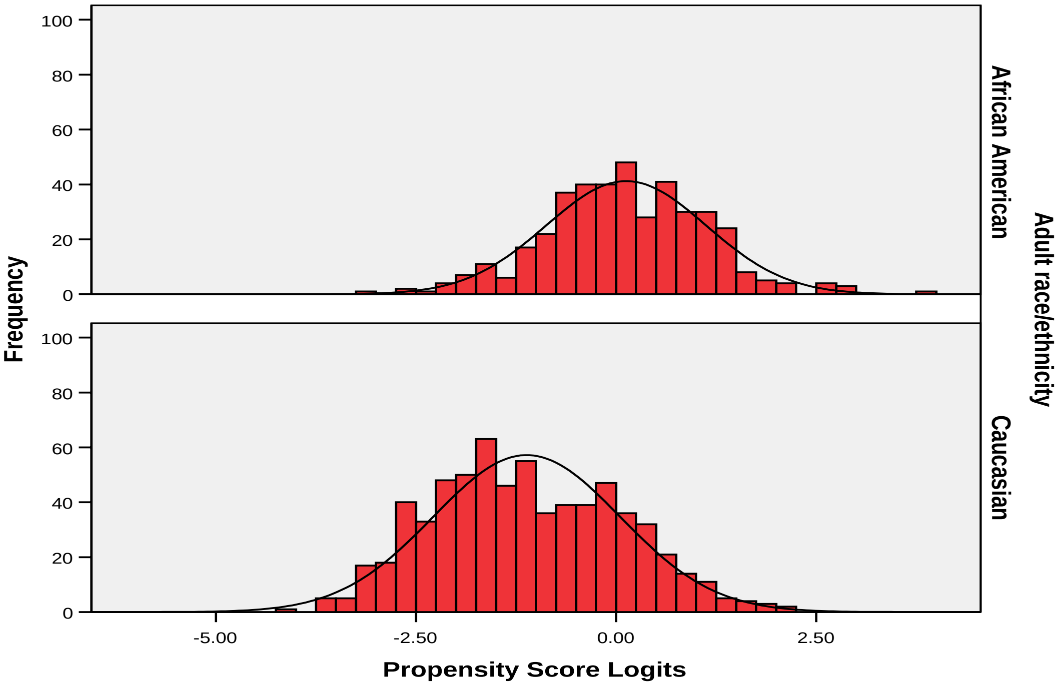

Figure 3. Density Plots of Distribution of Propensity Scores for African Americans & Caucasians

Next, I assessed the balance on the using univariate analyses of variance to relate the covariates (participant characteristics, stressors, and resources) to the exposure (race) and propensity score (independent variables). Of the covariates used in this analysis seven were significantly different between the groups. The descriptive results (Tables 7 and 8) presented earlier discussed the significant differences on the variables in each category (i.e. participant characteristics, stressors, and resources). In other words, after balancing on the propensity score there were no detectable differences in these covariates. The F-values for all of the covariates were non-significant (range .053 to .979). This indicates that the propensity score is an adequate/useful adjustment in further analysis with this data set.

Applying the Propensity Score

The regression model is summarized in Table 12 relating race to strain adjusted for propensity score. After adjusting for propensity score race was not associated with caregiver strain on either of the subjective strain scales. Also, propensity score adjusted race was no longer associated with caregiver strain on the Objective strain scale. Based on these results, adjusting for the propensity score did affect the association of race with caregiver strain. After balancing the distribution of measured covariates between African Americans and Caucasians in this sample there was no longer a significant difference in reported caregiver strain.

Critics of propensity score adjusted models point out that a real problem may be underspecified models (i.e. unobserved variables). However, unobserved covariates are an issue in all observational studies when there is an association between exposure and outcome.

The use of a rich set of covariates in this study has reduced this potential problem as much as possible.

Table 12. *Propensity Score Adjusted Regression Models by Caregiver Strain Outcome (N* = 1,089*)*

	OBJECTIVE STRAIN				SUBJECTIVE EXTERNALIZING STRAIN				SUBJECTIVE INTERNALIZING STRAIN			
Independent variable	B (SE)	BETA*	t	p	B(SE)	BETA*	t	p	B (SE)	BETA*	t	p
Race (cC)	-.137(.071)	-.067	-1.937	.056	-.020(.066)	-.011	-.312	.755	-.066(.078)	-.029	-.840	.401

Question 3: Does Caregiver Mental Health and Substance Abuse Affect the Relationship Between Race and Caregiver Strain?

This study was interested in the additional influence of mental health and substance abuse problems as it relates to caregiver strain and its relationship to race. Two models were evaluated, an unadjusted OLS regression model and a propensity score model. The results of the unadjusted analysis (Table 13) showed that caregiver race was a significant predictor of caregiver strain on the Objective and Subjective-Internalizing scales. None of the substance abuse variables were significant predictors of caregiver strain. However, the SF-12 mental health score was a significant predictor of strain on all three scales with lower mental health scores predictive of higher levels of strain.

As shown in Table 14, propensity score adjusted race still did not account for significant variability between race and caregiver strain. Similar to the unadjusted model, the substance abuse variables were not significant predictors of strain on any of the strain subscales. However the caregiver SF-12 mental health scores were significant predictors of caregiver strain. As self-reported mental health problems increase, there is a corresponding increase in caregiver strain on all the caregiver strain outcomes consistent with the unadjusted models. This is consistent with the literature that has found that lower caregiver mental health status is correlated with higher levels of strain (Brannan & Heflinger, 2001). Although research has shown that this may not be a clear-cut relationship and caregiver strain may mediate the relationship between child problems (Heflinger & Brannan, 2001; Sales, Greeno, Shear, & Anderson, 2004).

Table 13. *Ordinary Least Squares Regression Models for Substance Abuse and Mental Health Variables by Caregiver Strain Outcomes (N =* 1,089*)*

	OBJECTIVE STRAIN				SUBJECTIVE EXTERNALIZING STRAIN				SUBJECTIVE INTERNALIZING STRAIN			
Independent variable	B (SE)	BETA*	t	p	B (SE)	BETA*	t	p	B (SE)	BETA*	t	p
Race (cC)	-.181(.059)	-.088	-3.059	.002	-.027 (.058)	-.014	-.470	.638	-.162 (.064)	-.072	-2.519	.012
STRESSORS (aA)												
Adult-past month drinking	-.001(.010)	-.004	-.137	.891	.001 (.010)	.002	.055	.956	-.002 (.011)	-.005	-.174	.862
Adult-past month use of illegal drugs	.001(.008)	.003	.095	.924	-.001 (.007)	-.006	-.201	.841	.004 (.008)	.016	.541	.589
SF-12 mental health	-.032(.002)	-.380	-13.174	.000	-.016 (.002)	-.210	-6.815	.000	-.038 (.003)	-.416	-14.567	.000

Table 14. *Propensity Score Adjusted Race Regression Models for Substance Abuse and Mental Health Variables by Caregiver Strain Outcomes (N =* 1,089*)*

	OBJECTIVE STRAIN				SUBJECTIVE EXTERNALIZING STRAIN				SUBJECTIVE INTERNALIZING STRAIN			
Independent variable	B (SE)	BETA*	t	p	B (SE)	BETA*	t	p	B (SE)	BETA*	t	p
Race (cC)	-.129(.076)	-.063	-1.695	.090	-.019(.065)	-.011	-.292	.770	-.063(.072)	-.028	-.871	.384
STRESSORS (aA)												
Adult-past month drinking	-.002(.011)	-.006	-.177	.860	-.002(.010)	-.005	.169	.866	.-008(.011)	-.020	-.709	.478
Adult-past month use of illegal drugs	-.001(.008)	-.004	-.122	.903	-.003(.007)	-.013	-.426	.670	-.002(.008)	-.006	-.204	.838
SF-12 mental health	-.031(.003)	-.377	-12.05	.000	-.015(.002)	-.204	-6.587	.000	-.037(.003)	-.401	-14.123	.000

CHAPTER V

DISCUSSION

The goal of the present study was to examine the role of race in the perception of caregiver strain among a Medicaid sample of African American and Caucasian caregivers caring for children with serious emotional disorders (SED) by using the ABCX model. This study examines three aspects of the experiences of strain of caregivers in a Medicaid sample in terms of the influences of race on perception of strain.

The results using the unadjusted covariates show that African American caregivers reported less strain than Caucasians. However, after using propensity score analysis, African Americans with similar risk profiles to the Caucasians perceived similar levels of caregiver strain. Although there were no differences in race perceptions, caregivers with higher levels of self-reported mental health problems reported more strain; and caregivers' substance abuse problems were not a significant predictor of strain for African Americans or Caucasians. This dissertation takes the novel approach of using propensity score methodology and is one of few studies where race is overtly tied to the perception of caregiver strain in caregivers of youth with emotional and behavioral problems.

Results from this study provide evidence that perceptions of caregiver strain when caring for a child with an SED are similar for African Americans and Caucasians when differences in observed covariates are controlled, demonstrating that caregiver strain may be universal among U.S. caregivers. These results lend credibility to the current trends in the literature on caregiver strain that suggest using race without sufficient controls on covariates may give a false picture of the amount of caregiver strain experienced in terms of differences for African Americans and Caucasians. The specific results of the study are discussed relative to three research questions.

Question 1: When compared to Caucasian family caregivers of children with SED, do African Americans report differing levels of caregiver strain?

In this study, African American caregivers reported statistically significant lower strain on 13 of 21 items (Table 9) on the Caregiver Strain Questionnaire (CGSQ) in uncontrolled descriptive analysis. Previous work with a subset of these data (Kang et al., 1995) also found statistically significant mean differences on the CGSQ items with African American caregivers typically reporting less caregiver strain.

In terms of predictive value, the findings in this study contradict Kang et al., (1995) which found no differences. While in this bivariate regression analysis, race was a significant predictor of caregiver strain for the Objective strain and Subjective-Internalizing strain subscales of the CGSQ (see Table 11), when other variables predictive of caregiver strain were added to the model, race only remained significant on the Objective Strain scale where African Americans reported less strain than Caucasians in this study (Table 11). Objective Strain measures observable negative events and occurrences experienced as a result of the child’s emotional or behavioral problems: interruption of personal time, financial strain, missing work or neglecting other duties, disruption of family routines, feeling isolated, and the child getting into trouble. Subjective-Internalized Strain measures feeling internalized by the caregiver as a result of the child’s problems: sadness/unhappiness, worry, guilt, resentment, fatigue, and toll taken on the family.

As established in the existing literature, the fact that African Americans in this study reported lower levels of caregiver strain is a consistent finding. This along with some studies reporting that race is a significant predictor of caregiver strain has been a puzzlement to researchers (Morycz, Malloy, Bozich, & Martz, 1987). These findings lead to expounding on this research, particularly in terms of caregiver Objective Strain, to attempt to improve our understanding of racial differences in caregiver strain.

There are several possible explanations why these results differ from Kang et al. (2005) with regard to the significant finding on the Objective Strain scale: 1) although this study used some of the same child and family variables more than twice as many were used, 2) this sample was potentially more generalizable because it was a multi-site sample where their sample was only from the Tennessee/Mississippi site, 3) with a larger sample size, this study had more power to detect differences (n = 715 vs. n = 1089), 4) their sample was inherently more balanced on the covariates used in their study compared this study (with the differences disappearing in this sample after balancing).

Question 2: When Compared to Caucasian Family Caregivers of Children with SED with Similar Risk Profiles, do African Americans Report Lesser Caregiver Strain?

By using the propensity score approach to balance African Americans and Caucasians on observed covariates the previous race findings are not supported. Race was no longer a significant predictor of caregiver strain. This study demonstrated that the estimate of the race effect is sensitive to model specification when the distribution of all the covariates is not the same across groups.

A challenge in conducting credible research is how best to design studies so that groups are comparable. Race continues to thrive as a category of analysis in social research despite concerns that it is a misleading proxy for a number of other variables such as social inequality and culture.

This study took the approach that perception of strain by race was an artifact of social factors that are mutable. Here propensity score stratification was used to investigate the differences between African Americans and Caucasians when balancing was used on observed covariates. The OLS regression containing all of the predictors discussed previously and the propensity score adjusted regression produced the same results for the subjective-internalizing and subjective-externalizing subscales. However, race was non-significant in the regression with the propensity score suggesting that it improved the causal interpretation.

Question 3: Does Caregiver Mental Health or Substance Abuse Affect the Relationship Between Race and Caregiver Strain?

As shown by the descriptive statistics in Table 8, there were differences in substance abuse between African Americans and Caucasians with African Americans reporting significantly fewer days of illegal drug use. Due perhaps to social desirability and potential consequences of reporting (e.g., losing custody of the child), only a small percentage of caregivers reported using illegal substances, therefore this measure may not have been as a good an indicator of actual drug use. Table 8 also shows there were no significant differences between African Americans and Caucasians in terms of reported mental health problems.

In the conventional OLS regression model (Table 13) race was a significant predictor of caregiver strain on the Objective Strain and Subjective Internalizing scales after accounting for substance abuse variables and self-reported mental health. Interestingly, substance abuse variables were not significant predictors, but mental health status was highly predictive of strain.

The significant race finding in the OLS model is consistent with the stereotypic patterns of racial differences reported in the literature. For example, literature shows that African American caregivers are often lower educated and unmarried compared to Caucasians (Neighbors et al., 1983), and this is born out in the current sample (see correlation matrix, Appendix B). But, when the propensity score is used to adjust for constructs like education and marital status that are typically confounded with race (Table 14), race no longer accounts for a significant portion of the variability in the caregiver strain outcomes.

In the regression model adjusted by the propensity score, the only thing that changed was the significance of race. Caregiver mental health remained a significant predictor of caregiver strain, with higher mental health scores associated with higher levels of strain, and the magnitude of this affect, as indicated by the betas, was relatively unchanged. This highlights the importance of caregiver mental health and suggests that it cuts across the stereotypical boundaries of race that are confounded by a diverse constellation of individual social characteristics.

It is important to point out, that as shown in previous research, caregiver strain and mental health are distinct constructs with distinct correlates and should be measured separately (Brannan & Heflinger, 2001). Brannan and Heflinger demonstrated that caregivers were able to distinguish between strain and distress (i.e. caregiver mental health) with the best predictor of caregiver strain being child problems and other life stressors predicting caregiver mental health.

Most previous research and intervention strategies have focused exclusively on the child even though issues such as depression and role strain are important to address in caregiving. While the association of depression with medical comorbidity and with illicit drug use has been described in the general population, these may represent aspects of the informal caregiver's life that complicate their caregiver role (Pirraglia et al., 2005). The findings in this study that lower mental health predicted higher caregiver strain is difficult to interpret due to a lack of temporal data. In other words, one cannot make a causal inference about the direction of the effect—strain compromised mental health or compromised mental health increased strain. Although research has shown that this may not be a clear-cut relationship and caregiver strain may mediate the relationship between child problems (Brannan & Heflinger, 2001; Sales, Greeno, Shear, & Anderson, 2004) and caregiver mental health, attempts must be made to parse out the temporal relationship in order to aid in forming interventions to help the caregiver cope.

Summary of All Three Research Questions

Race continues to thrive as a category of analysis in social research. Despite concerns that using race is misleading as it is a proxy for social inequalities and genetic differences, studies of race have produced overwhelming documentation of inequalities from birth to education, income, crime, punishment, disease, treatment, and death. The U.S. Census collects race and ethnicity data to promote equal employment opportunity, assess racial differences in health outcomes, identify underserved populations, and evaluate financial institutions' requirements for serving specific populations (US Census, 2006). As Dilworth-Anderson pointed out, until we define contexts of African Americans that are similar to Caucasians, research making black-white comparisons is flawed. This study demonstrates that when African American and Caucasian caregivers are similar on characteristics that are commonly used in caregiver strain research, then race alone is no longer a significant contributing factor.

Strengths and Limitations of this Study

This study works with a large sample (*N*= 1089) from multiple states. It uses an analysis plan that maximizes the data, despite limitations, by using a sophisticated methodology to extract the most useful information by matching African Americans and Caucasians on all possible relevant factors related to caregiver strain. It also uses methodological techniques to preserve data by imputing values for income where missing.

Several limitations should be kept in mind when interpreting the findings of this study that involve limitations of the overall study and the inability to either include or measure all of the covariates that could influence caregiver strain as discussed below.

These data also may not be generalizable to other Medicaid samples as there is variability among Medicaid program eligibility across states (Semansky, Koyanagi, & Vandivort-Warren, 2003). However, Medicaid eligibility categories for children are similar nationally and this study included children from four different state Medicaid programs. There are potential sampling biases among the children and sites included in this study, given that there were differences in both settings and service availability within those settings, as well as between the severity of problems and demographic characteristics of the children studied. Because of this, the study's findings cannot necessarily be considered representative of all children and youth with SED enrolled in all types of Medicaid financed behavioral health care plans.

There is always a possibility that additional factors not measured in this study would impact the appraisal of caregiver strain between African Americans and Caucasians. In spite of balancing the groups by statistically adjusting for a substantial number of covariates, there are important factors known to predict caregiver strain that are not included. For instance, research has show that caregiver self-efficacy/mastery and caregiver satisfaction with the caregiving role account for some of the variance in caregiver strain (Baronet, 1999; Lawton et al., 1992).

However, it is important to note that the degree to which these factors influence caregiver strain is also dependent on the population of caregivers even in studies that evaluated racial group differences. It was found that African American caregivers at higher income levels reported less satisfaction with caregiving more resembling their Caucasian counterparts (Lawton et al., 1992). Research on caregivers for dementia patients centering around self-efficacy/mastery has found racial differences among daughter caregivers (Haley, Roth, Coleton, Ford, West, Collins et al, 1996) and family caregivers (Lawton et al., 1992) but the former study may not have had an adequate sample size and therefore interpretations are made with caution. Nonetheless, this is an omitted variable that warrants further investigation.

Other variables in this study may not fully capture the nature of the construct they are meant to measure, such as social support. Dilworth-Anderson, Williams, and Gibson (2002) noted that “many of these studies failed to capture the multidimensional nature of social support. In particular, asking caregivers to list the number of informal helpers or to give the frequency of using informal support services does not capture the complexity of a caregiver’s support system.

Implications

Researchers have continued to argue that there is evidence that race is an important determinant of caregiver strain. Specifically, a number of studies in the adult literature suggest that African Americans experience less strain when caring for relatives independent of the type of illness (Guarnaccia & Parra, 1996; Horwitz & Reinhardt, 1995; Stueve, Vine, & Struening, 1997). McCabe and colleagues (2003) found similar results in a study of children. To date it is not clear why this difference exist and whether they would remain if African Americans and Caucasians groups selected into studies were comparable. Previous research and theories have suggested it may be the instrumentation (i.e., measurement invariance), social support, religious involvement, illness perceptions, methodology, sample size, conceptualization of strain, and timing of assessment (Kang, Brannan, & Heflinger, 2005; Stueve et al., 1997). This study found it was an analytic issue. Findings are inconclusive across the spectrum, with some studies finding no race differences (Cook, Lefely, Pickett, & Cohler, 1994) and others finding differences on various dimensions of strain (Heflinger & Taylor-Richardson, 2004; Song, Biegel, & Milligan, 1997). Because of these unexplained differences in caregiver strain the topic to merits further attention. Apart from researchers’ pursuit to determine whether racial differences exist, caregiver strain remains a documented concern for caregivers of children with SED and deserves to be addressed in policy, practice and research.

Policy

Addressing caregiver strain is an important policy issue. Increased strain has been shown to predict more expensive treatment, more days of care, and higher levels of care (Brannan, Heflinger, & Foster, 2003). Prevention specialists have become sensitive to designing meaningful and contextually appropriate interventions. In an era with limited resources it has become increasingly important that we are on target with the populations services are designed to assist. Despite the limitations, this study offers evidence that what research has often described as different types of caregivers based solely on race may not be an accurate way of distinguishing caregivers of children with emotional and behavioral problems.

Practice

Current mental health practice focuses on treating the child's problems. When family members are included, it is often in family therapy. This study builds on previous research to illuminate the need to address the caregiver's problems as well. Even if the relationship is mediated and the strains of caregiving wear down the caregiver's mental health, the impact of the child's problems may not be so grave if the caregiver's issues are addressed. Since caregiver strain can negatively impact a persons ability to carry out daily tasks, attempts to address overall caregiver well-being including reduction of role strain and caregiving concerns are likely to result in better outcomes for the child and the caregiver.

One implication of this research for practitioners is to consider how they tailor interventions. Practitioners should be aware of the multiplicative similarities and differences among caregivers beyond simple racial differences in an attempt to be sensitive. To alleviate strain, caregivers' should be evaluated for a variety of supports based on their needs such as respite, support, and individual intervention (Kang, 2006). Additionally, there is growing support for a system-of-care that has an individualized, family-focused, community-based approach to service delivery (Holden, Santiago, Manteuffel, Stephens, Brannan, Soler, et al., 2003; Stroul & Friedman, 1996).

Research

Implications from this study for future research focus on two issues; 1) the use of race as a variable and 2) issues of caregiver strain. Propensity score analysis revealed that conventional OLS regression analysis produce misleading results because there may be other covariates that are important predictors of the outcome (caregiver strain), which are imbalanced across the levels of exposure (in this case race). In this study, balancing African Americans and Caucasians on the observed covariates demonstrated that when Caucasians perceive caregiver strain more like African Americans (counterfactual), there is no significant difference in reported caregiver strain. More research needs to address issues of group differences using better data sets that can test more complete models and that allow exploration of caregiver mental health over time.

When appropriate, researchers should consider the use of propensity score methodology in caregiver strain research as a primary method or in conjunction with methods like OLS regression. Propensity score methods may be a useful tool in future studies with large samples where there is a concern about imbalances between exposed and unexposed.

In general, this study suggests that the racial gap in reports of caregiver strain maybe narrowed if caregiver studies' take care to select participants that are similar on important characteristics. Conversely, there could be unobserved variance related to racial perceptions due to measures that were not collected and thoughtful consideration should be taken in thinking through what those measures may be.

Whenever possible self-report of race data is the preferred method (Mays et al., 2003). Studies should include data collection on complex social variables for which race or ethnicity is often used as a proxy. This might include social status, neighborhood context, perceived discrimination, social cohesion, social capital, social support, types of occupation, employment, emotional well-being, and perceived life opportunities (Mays et al., 2003) Future research should also make an effort to use racial comparisons beyond African American/Caucasian comparisons (Dilworth-Anderson et al., 2002).

Future investigations should explore specifically how the deleterious effects of caregiving manifest differentially in various groups of caregivers. Using the growing number of available data sets that include information on caregiver strain, future studies could be designed to predict strain by controlling for meaningful characteristics that go beyond simple African American Caucasian distinctions. For example, researchers may want to look at differences in strain in terms of the relationship between the child and the caregiver (e.g., biological parents vs. other relatives vs. foster parents) across different samples. Future investigations need to gather additional data to help explain the unique strengths and coping mechanisms that other relative caregivers bring to the caregiving role.

Using an established measure such as the Social Support Questionnaire, allows researchers not only to determine the number of potential helpers, but the caregiver's satisfaction with the level of support received (Dilworth-Anderson et al., 2002, p 3)." Such a measure was not available in this data set.

Despite similarities, racial groups can differ in a variety of ways including experience, living context, and beliefs. These differences can lead to varying interpretations of the same measurement instrument across groups. In order to conduct meaningful comparisons between racial groups, researchers must assure that the instrument used to measure the construct of interest has the same meaning including measurement error and equivalence across groups (Ramirez, Ford, Stewart, & Teresi, 2005). Differential Item Functioning (DIF) can contribute to observed difference in outcome indicators that are attributable to item non-invariance across groups as opposed to true between-group differences (Fleishman & Lawrence, 2003). Kang et al. (2005) found potential differential item functioning (DIF) among the Objective strain and Subjective-Internalized strain subscales. Specifically, some items on these subscales may provide different (in fact more) information for Caucasians than African Americans. Therefore, when comparing the mean CGSQ score between African Americans and Caucasians there may exist a difference in overall score due to DIF as opposed to true differences in caregiver strain.

Conclusion

Balance is a good thing! This study demonstrates that by carefully matching the two self-identified racial groups of caregivers on all available risk factors that may contribute to caregiver strain, both races reported similar levels of caregiver strain and race dropped out of the picture in predicting caregiver strain on all subscales of the CGSQ.

APPENDIX A

Caregiver Strain Questionnaire

CAREGIVER STRAIN QUESTIONNAIRE (CGSQ)

Please look back over the past six months and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.

In the past 6 months, how much of a problem were the following:

	Not at all	*A little*	*Somewhat*	*Quite a bit*	*Very much*
1. Interruption of personal time resulting from your child's problems?	1	2	3	4	5
2. Your missing work or neglecting other duties because of you problems?	1	2	3	4	5
3. Disruption of family routines due to your child's problems?	1	2	3	4	5
4. Any family member having to do without things because of your child's problems?	1	2	3	4	5
5. Any family member suffering negative mental or physical health effects as a result of your child's problem	1	2	3	4	5
6. Your child getting into trouble with the neighbors, the community, or law enforcement?	1	2	3	4	5
7. Financial strain for your family as a result of your child's problems?	1	2	3	4	5
8. Less attention paid to any family member because of the attention given to your child?	1	2	3	4	5
9. Disruption or upset of relationships within the family due to your child's problems?	1	2	3	4	5
10. Disruption of your family's social activities resulting from your child's problems?	1	2	3	4	5

In the past 6 months:

	Not at all	*A little*	*Somewhat*	*Quite a bit*	*Very much*
11. How socially isolated did you feel as a result of your child's problems?	1	2	3	4	5
12. How sad or unhappy did you feel as a result of your child's problems?	1	2	3	4	5
13. How embarrassed did you feel about your child's problems?	1	2	3	4	5
14. How well did you relate to your child?	1	2	3	4	5
15. How angry did you feel toward your child?	1	2	3	4	5
16. How worried did you feel about your child's future?	1	2	3	4	5
17. How worried did you feel about your family's future?	1	2	3	4	5
18. How guilty did you feel about your child's problems?	1	2	3	4	5
19. How resentful did you feel toward your child?	1	2	3	4	5
20. How tired or strained did you feel as a result of your child's problems?	1	2	3	4	5
21. In general, how much of a toll has your child's problems been on your family?	1	2	3	4	5

For more information see: Brannan, A. M., Heflinger, C. A., & Bickman, L. B. (1997). The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. Journal of Emotional and Behavioral Disorders, 5, 212-222. Permission to use the CGSQ is granted by the authors if you cite the article listed above and send information on the study to: Dr. Craig Anne Heflinger, c.heflinger@vanderbilt.edu, Vanderbilt University,

Appendix B

Bivariate Correlation Matrix for Variables Used in the Regression Analyses

Appendix B

Zero Order Correlation Matrix for Variables Used in the Regression Analyses

Model variables	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*	*14*	*15*	*16*	*17*
1. Caregiver race (cC), 0 = Cauc, 1 = AA.	-.15*	.04	-.04	.02	.17*	-.16*	-.10*	-.04	-.05	-.04	-.11*	.02	-.01	.04	-.01	-.07*
Participant Characteristics																
Child																
2. Age	--	.04	.24*	.05	-.00	.07*	.07*	.03	.10*	-.02	.07*	.29*	-.08*	-.05	.01	-.04
3. Gender		--	.04	.08*	.04	-.02	.06	-.04	.02	-.15*	-.12*	-.12*	-.02	.02	.02	.01
Caregiver																
4. Age			--	-.09*	.62*	.24*	-.02	.03	.04	-.06	-.03	.03	-.23*	.07*	.15*	-.07*
5. Gender				--	.02	-.09*	.01	-.07*	.03	.04	.03	-.00	.01	-.06	.02	-.05
6. Relationship to child					--	.10*	-.10*	.09*	-.03	-.05	-.02	.04	-.12*	.11*	.11*	-.06
7. Marital status						--	.01	-.01	.07*	.01	.04	.00	-.16*	-.09*	-.03	.02
8. Education							--		-.07*	-.05	.03	.00	.09*	.10*	-.08	.05
Stressors (aA)																
Child																
9. CHQ								--	-.34*	-.14	-.21*	.06	.14*	.18*	-.03	-.02
10. CBCL Internalizing									--	.56*	.55*	.01	-.18*	-.35*	.03	.04
11. CBCL Externalizing										--	.68*	.11*	-.10	-.29*	-.04	.02
12. CIS											--	.11*	-.12*	-.30	.01	.03
13. Legal involvement												--				
Caregiver																
14. SF-12 Physical Health													--	.09*	-.09*	-.08*
15. SF-12 Mental Health														--	.01	-.08
16. Alcohol Use															--	-.12*
17. Drug Use																--

Model variables	*18*	*19*	*20*	*21*	*22*	*23*	*24*	*25*
1. Caregiver race (cC), 0 = Cauc, 1 = AA.	.12*	-.02	-.03	.01	.01	-.10*	-.02	-.09*
Participant								
Child								
2. Age	-.03	.04	.03	.06*	.02	.07*	.10*	.11*
3. Gender	-.04	.00	-.02	-.05	.04	-.08*	-.09*	-.06*
Caregiver								
4. Age	-.16*	.06	-.01	.06	.02	-.04	-.03	-.06*
5. Gender	.00	-.06*	.03	-.03	.00	.01	.04	.04
6. Relationship to child	-.03	.09*	-.01	.03	-.03	-.09*	-.05	-.15*
7. Marital status	-.15*	-.08*	-.00	.08*	.04	.09*	.06	.08*
8. Education	-.10*	.16*	.06	.05	.04	.09*	.00	.02
Stressors (aA)								
Child								
9. CHQ	.04	.07*	-.03	-.02	-.05	-.18*	-.05	.22*
10. CBCL Internalizing	-.09*	-.05	.10*	.07*	.01	.47*	.30*	.47*
11. CBCL Externalizing	.08*	-.03	.08*	.01	.03	.60*	.43*	.49*
12. CIS	.03	.02	.08*	.02	.02	.61*	.43*	.54*
13. Legal Involvement	.02	.04	.01	.07*	.01	.15*	.09*	.10
Caregiver								
14. SF-12 Physical Health	.06	.07*	-.04	-.06	-.02	-.15*	-.08*	-.14*
15. SF-12 Mental Health	-.01	-.07*	-.04	-.04	-.03	-.38*	-.21*	-.42*
16. Alcohol Use	.06*	-.02	.05	-.01	.01	-.01	.00	-.01
17. Drug Use	-.03	.02	-.01	-.02	-.04	.04	.01	.06
Resources (bB)								
18. #HH	--	.28*	.02	.01	-.01	-.01	-.03	-.07*
19. Income		--	-.02	.03	.03	.01	-.02	-.03
20. Priest			--	.05	.05	.08*	.07*	.07*
21. Self help				--	.06*	.08*	.01	.02
22. Support group					--	.05	.01	.03
Adaptation (xX)								
23. Objective						--	.48*	.71*
24. Subjective-Internalizing							--	.51*
25. Subjective-Externalizing								--

$^*p \leq .05$

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