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The University of Southern Mississippi

PARENTING STRESS, BEHAVIOR, TREATMENT SATISFACTION, AND HOPE IN CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

by

Paige Cristin Schultz

Abstract of a Dissertation Submitted to the Graduate School of The University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

ABSTRACT

PARENTING STRESS, BEHAVIOR, TREATMENT SATISFACTION, AND HOPE IN CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

by Paige Cristin Schultz

May 2012

Parenting stress has been shown to be related to both negative parenting behaviors and child behavior problems in the general population as well as with children with developmental disabilities. With the majority of children with developmental disabilities participating in multiple treatments, little is known about the effect of treatment satisfaction on caregivers. Hope has also been shown to reduce stress in caregivers, yet little research has examined this relationship with respect to parenting stress specifically or in parents with children with developmental disabilities. Treatment satisfaction has also been associated with less parenting stress in other populations; however, no study has examined treatment satisfaction and parenting stress in parents with children with developmental disabilities. This study explored the relationship between parenting stress and parenting behaviors in caregivers of children with developmental disabilities to determine whether hope and treatment satisfaction are good predictors of parenting stress in this population. The current study also explored hope as a moderator in the relationship between parenting stress and parenting behavior while controlling for treatment satisfaction and child behavior problems. Hope and treatment satisfaction significantly predicted parenting stress, but when examined independently, only hope accounted for a significant portion of variance.

When examining both positive and negative parenting behaviors, hope and parenting stress each predicted parenting behaviors, but hope did not moderate parenting stress and parenting behaviors as previously thought. A relationship between hope, parenting stress, and parenting behaviors was confirmed for this population, but further analysis is needed to understand how these variables affect each other.

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CHAPTER I

LITERATURE REVIEW

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 legally defined developmental disability as "a severe, chronic disability of an individual that is attributed to a mental or physical impairment" before the age of 22 and will continue throughout the person's life (DD Act, 2000). The Center for Disease Control's National Center on Birth Defects and Defects and Developmental Disabilities estimated 17% of children under the age of 18 years old are diagnosed with a developmental disability (Bhasin, Brocken, Avchen, & Van Narden Braun, 2006). Diagnoses which are considered developmental disabilities involve substantial limitations in three or more of the following categories: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (DD Act, 2000). Diagnoses that meet these criteria include autism spectrum disorders, cerebral palsy, Down syndrome, mental retardation, epilepsy, hearing loss, and vision impairment (APA, 2000). Other conditions that may qualify for the developmental disability classification, but are not specified, include handicapping conditions that occur before 18 years of age and involve brain damage or dysfunction at birth, growth or nutrition problems, abnormalities of chromosomes and genes, premature birth, and drug or alcohol use during pregnancy (Antonacci, Manuel, & Davis, 2008; Barnhill, 2008). This definition does not include minor delays that can be resolved with treatment (e.g., speech delays, stuttering).

Children with developmental disabilities have symptoms that can be difficult for family members to cope with. Further, family members' behaviors can negatively influence these difficult children's behaviors. Very few studies have examined the

relationship between hope and stress as it relates to parenting behaviors, and no studies have quantitatively examined these factors as they relate to caregivers of children with developmental disabilities. Also, few studies have been conducted to assess caregiver's treatment satisfaction with services for children with developmental disabilities, and no studies have examined the interaction between hope and parenting stress on parenting behaviors. The purpose of this study was to examine the role of hope and treatment satisfaction in the prediction of parenting stress and secondly, to examine hope as a moderator in the relationship between parenting stress and behavior after controlling for treatment satisfaction and child behavior problems.

Developmental Disabilities and the Family

Children with developmental disabilities can exhibit behaviors that are problematic and difficult for caregivers to manage (Murphy et al., 2005; Lang et al., 2009; Thomas et al., 2009), and these difficulties for caregivers can result in negative consequences for children (Chadwick, Kusel, & Cuddy, 2008; Johnson, 2009; Scheyett, Vaughn, Taylor, & Parish, 2009). Children typically experience pervasive impairment with reciprocal social interaction, communication, sensory issues, repetitive stereotyped behaviors or interests (e.g., hand flapping, spinning in circles, repeating sounds), and self-injurious and aggressive behaviors which may jeopardize the child's safety (Affleck et al., 1982). The age of the child can also influence the severity of symptoms (Chadwick, Kusel, & Cuddy, 2008). Murphy et al. (2005) found that that as the age of the child increased, the severity of symptoms in the child decreased, indicating that problematic behaviors occur more frequently in younger children. Severe problematic behaviors have been found to reduce the child's ability to establish self-determining skills which allow them to identify their strengths, weakness,

and future goal, therefore requiring multiple forms of therapy each week for coping with daily life (Affleck, McGrade, McQueeney, & Allen, 1982; Carter, Owens, Trainor, Sun, & Swedeen, 2009).

Families of children with developmental disabilities experience more challenges than those of typically developing children (Glidden, 1993; Glidden, Billings, & Jobe, 2006; Schall, 2000; Shu, 2009). The confirmation of the diagnosis can be viewed as a trauma or crisis regarding the loss of future expectations and fears about how daily life will be changed (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Head & Abbeduto, 2007; Sanders & Morgan, 1997). Obtaining a diagnosis is often slow, inconclusive, or inaccurate (Knox, Parmenter, Atkinson, & Yazbeck, 2000; Wodehouse & McGill, 2009), and the unfamiliarity of treatment options and medical experiences causes stress (Cahill & Glidden, 1996; Hutton & Caron, 2005; Schall, 2000). Caregivers can experience a loss of hope for the child's future and the goals they had dreamed of for the child and for their own lives.

Regarding treatment, caregivers experience frustration when deciding on the appropriate treatment and services for their child's benefit that could include one or more of the following: speech, occupational and physical therapy, special accommodations within the schools, and social skills training (Dale, Jahoda, & Knott, 2006; Hutton & Caron, 2005; Knox, Parmenter, Atkinson, &Yazbeck, 2000; Wodehouse & McGill, 2009). Once initiated, caregivers reported continually evaluating the treatment quality and service providers' behaviors to determine the competency of the services received. Most caregivers admitted to the majority of the responsibility regarding transportation, paperwork and filing, and attendance at meetings regarding their child even when other professionals are involved or had

previously indicated services would be covered (Hutton & Caron, 2005). Caregivers also experienced feelings of powerlessness and frustration when encountering professionals who had very little knowledge of their child's disability, provided them with wrong information, or did not follow up on recommendations by others (Atkinson, & Yazbeck, 2000; Knox, Parmenter, Wodehouse & McGill, 2009). The importance of the quality and friendliness of the interaction the service provider exhibited to caregivers affected the likelihood that services would be continued. When the family was also included into treatment options, caregivers reported a better sense of control and increased results from these services (Dempsey & Keen, 2008).

Other family members' lives are affected as a result of a child being diagnosed with a developmental disability. The financial strain on the family becomes problematic because of the cost associated for various treatments the child may require and insurance does not cover (Emerson et al., 2008). Because vast amounts of services are needed for the child with developmental disabilities, the family's schedule is adapted, and other family members' activities are likely to be eliminated due to lack of time (Hutton & Caron, 2005). Schall (2000) interviewed families with autism and found that families spent a large amount of time working with the developmentally disabled child to increase his or her skills so that he or she can interact with the world outside the family, and siblings became active caretakers to help alleviate problematic behaviors when caregivers are unavailable (Hutton & Caron, 2005; Kao, Plante, & Lobato, 2009). Studies also have shown that caregivers experience a strain in marital relationships (Shu, 2009), but the effects appear to be linked with the severity of problematic behaviors exhibited in the child (Head & Abbeduto, 2007; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Urbano & Hadapp, 2007). Although divorce may

occur more frequently among parents of children with developmental disabilities than typically developing children, results indicate that more caregivers are likely to divorce within the first years of the child's life suggesting that initial problematic behaviors exhibited by the child, the reactions of the parent to the diagnosis, and stress of parenting the child significantly impact the quality of the marriage (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). While parenting a child with a development disability is stressful, little is known about the impact specifically on levels of parenting stress associated with these challenges.

Parenting Stress

Parenting stress has been described as the difficulty a parent feels or experiences while raising children and includes such aspects as parent psychological well-being, child characteristics, and negative life events (Abidin, 1992; Kwon, 2007). Many studies have shown that caregivers of children with developmental disabilities experience high levels of parenting stress (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Dumas & Wolf, 1991; Sanders & Morgan, 1997; Weiss, 2002). Estes, Munson, Dawson, and Koehler et al. (2009) postulated that the presence of problematic behaviors, as well as impaired adaptive functioning in the child, increases stress in the caregiver. Along with typical child-rearing responsibilities, a caregiver may be required to assist the child in daily living skills (e.g. dressing, bathing, and toileting) for extended periods of time and may lead to increases in parenting stress and psychological distress. Boyd (2002) in a literature review of parenting stress identified the three most stressful factors associated with parenting a child with developmental disabilities: concern about the permanency of the condition, lack of acceptance of characteristics of developmental disabled children by family members

and the public, and low levels of social support received by the caregivers. When caregivers experience higher levels of stress, they report higher levels of depression, social isolation, and restriction of their parental roles. They also tend to have less attachment to their child and feel less competent in dealing with him or her (Gupta, 2007), and fatigue, lowered self-esteem, anxiety, burnout, and interpersonal dissatisfaction are likely (Weiss, 2002). Caregivers also report increased moodiness with increased parenting stress and are more prone to illnesses (Gallagher, Phillips, Drayson, & Carroll, 2009).

Research has demonstrated that there is a link between increased parenting stress and problematic child behaviors (Abidin 1992; Gupta, 2007; Estes et al., 2009; Kwon, 2007; Sanders & Morgan, 1997; Putnick et al., 2008). Gupta (2007) examined the various levels of parenting stress across many different developmental disabilities and delays including ADHD, developmental disabilities, HIV infections, asthma, and typically developing children. While there is conflicting information regarding how caregivers react to stress when examining the type of disability or illness a child has, caregivers consistently reported higher levels of stress than parents of typically developing children. Caregivers of children with diagnoses that included disruptive behaviors, such as ADHD and developmental disabilities, reported higher levels of stress than individuals caring for children with chronic medical conditions. These children exhibited symptoms including being highly distractible, less adaptable, and did not reinforce the parent in the caregiver role. Overall high scores in total stress were highest in parents of children with developmental disabilities, which suggested isolation from formal and informal supports elevated stress to a significant level.

Problematic child behavior has been documented to contribute significantly to parental stress in caregivers of children with developmental disorders (Dumas & Wolf, 1991; Glidden, 1993; Kwon, 2007; Osborne, McHugh, Saunders, & Reed, 2008). Children who were matched based on lower daily living skills and higher problematic behavior levels resulted in higher parental stress and psychological distress in mothers. These findings are consistent with previous research that links child behavior with parental stress, which in return disrupts parenting behaviors (Estes et al., 2009). Weiss (2002) also examined parental stress in mothers of children with autism and found higher levels of distress. These mothers also reported higher levels of depressive symptoms, anxiety, and burnout when compared to mothers of typically developing children. Sanders and Morgan (1997) also found that parents with children with various developmental disabilities experienced a wide range of stress dependent on the severity of symptoms associated with the diagnosis, but all categories reported more stress than typically developing children.

When parental stress levels are reduced, benefits can be identified for the child. Hadadian (1994) found that mothers of children with developmental disabilities had lower levels of perceived stress when they received support from their spouses, and they reportedly related better emotionally to their child. Low stress levels also helped caregivers to engage in positive interactions with their child and relate positively to him or her. Caregivers that reported lower stress levels also were able to cope with their child's problematic behaviors better and were less likely to seek out-of-home placements for their child (Boyd, 2002). Levels of parental stress were also affected by the level of social support and hardiness a caregiver possessed. Hardiness was defined

as a personality characteristic that allows a person to cope while experiencing high levels of stress (Ben-Zur, Duvdevany, & Lury, 2005; Weiss, 2002).

The level of parental stress present in the primary caregiver also can affect the outcome in treatment of the child when multiple services are pursued (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; O'Neil, Palisano, & Westcott, 2001; Shu, 2009). Early educational interventions that have been shown to increase intellectual, educational, and adaptive behaviors in children with developmental disabilities and programs that focused on more time-intensive interventions that required high time-input from caregivers exhibited the most significant outcomes. When parents reported significant levels of parental stress as a result of increased time-input, these interventions produced fewer gains in children with developmental disorders (Osborne, McHugh, Saunders, & Reed, 2008). Fewer perceived benefits from these services can reduce parental treatment satisfaction and may result in increased levels of stress.

While a child's behavior can affect levels of parenting stress, parenting stress can affect the probability that stressful child behaviors can arise (Kwon, 2007; Osborne, McHugh, Saunders, & Reed, 2008). Children's problematic behaviors in developmental disorders have been linked to an increase in parental stress, and a reduction of stress showed improvements in problematic behaviors in children (Osborne, McHugh, Saunders, & Reed, 2008). This suggests a cyclical relationship between parental stress and problematic behaviors, indicating an increase in stress when problematic behaviors increased and vice versa. With increased stress and problematic behaviors, parenting behaviors are affected and will be discussed as it relates to caregivers of children with developmental disabilities.

Parenting Behaviors

With the relationship between parental stress and problematic behavior in children well documented, researchers have examined factors that affect this relationship. Parenting behaviors are considered to be expressed acts of what parents think about their children in different situations and about their relationship with the child (Kwon, 2007). Although many types of parenting behaviors have been examined, common factors include harsh discipline, controlling behaviors, less positivity, inconsistent paring, harsh parenting, hostility, sense of parenting competence, inductive reasoning, positive child management, and warmth/supportiveness (Abidin, 1992; Hastings, 2002; Cui & Conger, 2008; Huth-Bocks & Hughes, 2008; Simons, Lorenz, Wu, & Conger, 1993).

In an attempt to provide clarification, the relationship between coercive parenting behavior and child behavioral problems has been examined with regards to children with developmental disabilities (Hastings, 2002). Problematic behaviors occur when the child experiences negative parenting behaviors, such as lack of attention or the presence of demands. Once the aversive behavior occurs in the child, the parental stress increases and leads to a change in parenting behaviors. More often than not, the change in these behaviors reinforces the child's negative behaviors in that attention has now been given to the child by the parent or the request for compliance is no longer present. The child's problematic behaviors continue as they are being reinforced, causing more parental stress, and leading to changes in parental behaviors (Oliver, Guerin, & Coffman, 2009).

Caregivers that exhibit harsh, authoritarian parenting behaviors can negatively affect children's behaviors and can have long lasting effects (Bailey & Snyder, 2009;

Brotman et al., 2008; Brotman et al., 2009; Fletcher et al., 2008; Heidgerken, Hughes, Cavell, & Willson, 2004; Mazefsky & Ferrell, 2005). When caregivers are more punitive, children are less likely to regulate their emotions, and aggressive behaviors increase (Brotman et al., 2008). Children who experience negative parenting behaviors when they are young are more likely to continue aggressive behaviors as they develop, and they are at higher risk for developing more serious behavior problems into late childhood and adolescence (Heidgerken et al., 2004). When a child is labeled as noncompliant, caregivers experience more stress that in return increases more problematic behaviors.

Several studies have demonstrated the effect of stress on parenting behaviors (Abidin, 1992; Cui & Conger, 2008; Mash & Johnston, 1990; Kwon, 2007; Neppl, Conger, Scaramella, & Ontai, 2009). Those parents who reported high levels of parental stress had higher reports of children with behavioral problems, and these negative child behaviors were found to be predictive of parenting stress (Mash & Johnston, 1990). Recent research has examined how parenting behaviors mediate this relationship and how parenting behaviors lessen the negative affect between parenting stress and problematic child behaviors (Karazsai & Wildman, 2009). When caregivers utilize authoritative parenting styles, children are able to regulate their behaviors, therefore reducing the parental stress related to problematic behaviors (Phetrasuwan & Miles, 2009). Abidin's model (Abidin, 1992) suggested that parenting behaviors mediate the relationship between parenting stress and children's emotional and behavioral difficulties. The level of parenting stress directly affects parenting behaviors, which in turn influences a child's adjustment. Jaffe, Gullone, and Hughes (2009) identified that nurturing and supportive behaviors in parents are important in

developing emotional regulation in children. Parenting behaviors, specifically involvement, can affect a child's behavior and self esteem. Parents of chronically anxious children often exhibited increased negativity and maternal over-involvement (Hudson, Doyle, & Gar, 2009). Negative parenting behaviors and parental distress affected self-esteem and familial functioning therefore increasing negative behaviors (Kashdan et al., 2002).

Problematic behaviors in children impact parental stress which in return affects parenting behaviors. Until recently, research regarding caregivers of developmental disabilities has focused on negative parenting factors, ignoring the role positive factors (Hastings, 2002). Given the risk children with developmental disabilities are subject to, it is suggested that positive factors be examined to see how they affect parenting stress and parenting behaviors.

Positive Factors Related to Parenting a Child with a Developmental Disability

The vast majority of research in the area of children diagnosed with developmental disabilities has focused on weakness, deficiencies, and the problems the child and the family may face in the future. Caregivers of a child with a developmental disability face an uphill battle regarding gaining accurate diagnoses, finding educated professionals, obtaining quality treatment, and managing the emotional and financial strain multiple treatments can bring. However there are also positive accounts of how a child with developmental disabilities has changed families' lives for the better. Helff and Glidden (1998) examined the literature regarding developmental delays to identify changes in language and approaches. Most significant was the shift away from the disability-oriented language (i.e. the mentally retarded) to a person centered language (i.e. persons with developmental disabilities). They also noted that recently more

research focused on positive impacts on the family a child with developmental disabilities can foster. Researchers have moved away from viewing these diagnoses as a catastrophic event that results in significant damage to the family that was commonplace in the literature prior to 1980 (Stainton & Besser, 1998). Instead, positive factors are becoming the primary focus to determine how a family copes positively. Families with a child diagnosed with a developmental disability are becoming more common and are exhibiting similar characteristics and problems as families with typically developing children. Strengths in parents of children with developmental disabilities were identified to help future families facing these diagnoses. When compared to parents with typically developing children, caregivers of a child with a developmental disability do not possess special characteristics and strengths that are absent in others. Instead, they utilize personality strengths and strong social support to cope with the changes. Caregivers that report an increase in family unity, strength, and closeness often choose to depend on members of that family in times of stress instead of independently handling it (Abbott & Meredith, 1986). Such transformations are often reported to coincide with the diagnosis of a disability and would not have occurred otherwise (Oyersman, Bybee, Mowbray, & MacFarlane, 2002; Scorgie & Sobsey, 2000).

When caregivers focused on positive ways to cope with the diagnosis of a developmental disability with their child, benefits have been identified for themselves and the child (Boyd, 2002; Head & Abbeduto, 2007; Glidden & Floyd, 1997). Boyd (2002) found that caregivers that sought out support programs increased factual knowledge of the disorder, acquired information about stress and coping mechanisms, and became aware of programs and advocacy issues. Raif and Rimmerman (1993)

found that caregivers that received support from their extended family members and friends had low stress levels and were less depressed. Dunst, Trivette, and Cross (1986) identified that parental satisfaction with social support networks was associated with better personal well-being, more positive attitudes about the child, more positive interactions in parent-child play opportunities, and higher scores of their children on developmental tests. When support is received from professionals in regards to their child's treatment, caregiver stress is reduced, and achievements in treatment are increased, therefore factors that increase treatment satisfaction need to be understood.

Treatment Satisfaction. Treatment satisfaction among clients receiving health services has been frequently researched as it has been shown to be related to treatment outcomes (Clearly & McNeil, 1998; Galil et al., 2006; Heppner & Heesacker, 1983; Trotter, 2008; Mitchell & Penny, 1998; Ong, De Haes, Hoos, & Lammes, 1995; Schwab, DiNitto, Aureala, Simmons, & Smith, 1999). When clients are satisfied with their services, they are more likely to be compliant with treatment, utilize additional services, and note health improvements (Galil et al., 2006; Mitchell & Hauser-Cram, 2008). Prior research in treatment satisfaction has primarily focused on medical interventions or treatments with a wide variety of populations (Biderman, Noff, Harris, Friedman, & Levy, 2009; Evans et al., 2004; Kaminetsky et al., 2009; Patrick, Martin, Bushnell, & Pesa, 2003). Such research examined treatment satisfaction of patients as a result of drug intervention (Biderman, Noff, Harris, Friedman, & Levy, 2009; Evans et al., 2004; Howorka et al., 2000), treatment for specific health problems (Evans et al., 2004; Hareendran & Abraham, 2005; Kaminetsky et al., 2009), and characteristic of programs that increased client satisfaction and participation (Biderman, Noff, Harris,

Friedman, & Levy, 2009; Dearing, Barrick, Dermen, & Walitzer, 2005; Fontana, Rosenbeck, Ruzek, & McFall, 2006).

While the research regarding adult treatment satisfaction is vast, studies focused on caregiver's treatment satisfaction related to their child are lacking (Galil et al., 2006; Liptak et al., 2006; Mitchell & Penny, 2008; Weller, 2009), especially related to caregivers of children with developmental disabilities. Galil et al. (2006) identified a strong relationship between parent's treatment satisfaction and the role of the physician. In cases where the physician provided information, spent time with the parents, and exhibited caring and friendly characteristics, satisfaction increased significantly. In continuous treatment settings, communication and the ability for the physician to foster a collaborative environment with the parent was found to be an important part in overall parent satisfaction.

A shift towards family-centered therapies for children with developmental disabilities also has shown to be an essential element in treatment satisfaction, perceived quality of treatment (Liptak et al., 2006), and decreased parenting stress (Dempsey & Keen, 2008; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; O'Neil, Palisano, & Westcott, 2001). Interventions formerly were controlled primarily by professionals, leading caregivers and family members to be at the mercy of programs that were deemed appropriate by others. Because of the increase of children with developmental disabilities but a decrease in quality services that are available, caregivers pushed for more involvement (Boyd, 2002). Family-centered therapies emphasize the interpersonal aspects of therapy and include three domains of care: information exchange, respectful and supportive care, and an enabling and partnership. O'Neil, Palisano, and Westcott (2001) defined informational exchange as the

characteristics of communication between providers and parents where providers solicit as well as offer information to parents. Respectful and supportive care refers to interpersonal sensitivity on the part of the provider to ensure that parents feel respected and supported. Enabling and partnership refer to the provider practices that encourage collaborations with parents and support their roles as decision makers and advocates for their child. High levels of parental stress also negatively affected perceptions of treatment (Dale, Jahoda, & Knott, 2006). When caregivers became more involved in treatment decisions and were provided with more information, their stress decreased and increased the satisfaction of services. Treatment providers in return were able to achieve more goals and reported better attitudes regarding services for the family (O'Neil, Palisano, & Westcott, 2001; Shu, 2009).

Dempsey, Keen, Pennell, and O'Reilly, et al. (2009) reported a link between family-centered interventions, treatment satisfaction, and parental stress. Those caregivers that participated in treatment with professionals reported lower levels of parental stress. Specifically, higher scores related to the level of comfort experienced by caregivers with service providers decreased their stress level. Consequently, caregivers that maintained complete control of their child's therapies due to doubts and uncertainty of the treatment reported higher levels of parental stress. When caregivers viewed themselves as autonomous from professionals, they reported feelings of increased responsibility and did not utilize information or help that professionals offered. In other words, caregivers experienced higher levels of stress when they felt they made the best treatment decisions about their child and took credit themselves for any progress that was made.

Parental empowerment by helping professionals contributes to treatment satisfaction and positive coping styles in parents of children with developmental disabilities (Dempsey & Dunst, 2004; Nachshen & Minnes, 2005). Individual empowerment is defined by a process by which families access knowledge, skills, and resources that enable them to gain positive control over their lives and to improve their quality of life (Dempsey & Dunst, 2004). Studies including this variable confirm the need for treatment professionals to clearly communicate with parents regarding goals, parents' rights and responsibilities, respect caregiver's knowledge, and support their hopes for their child so that caregivers are able to feel they are participating in treatment and contributing to the well-being of their child (Nachshen & Minnes, 2005). When caregivers experienced negative talk from professionals about the diagnosis that included the disabling diagnosis to discussion that focused only on the deficits each child had, caregivers' stress levels increased, and more effort was needed to define how the child positively benefits the family (Stainton & Besser, 1998).

In interviews with caregivers of children with developmental disorders, Schall (2000) identified stages a family progressed through when faced with the diagnosis and treatment. When professionals focused on treatment satisfaction and the strengths of the child, caregivers reported increased hope. Although goals for the child changed, each parent described hope for the future that the child's life would improve and quality of life would be better, and the treatment they sought would better their child's life. They also expressed the hope that their child would emerge from the constraints of the developmental disability, and it further motivated treatment and interventions to help their child. While studies have shown the benefit that treatment satisfaction can have on caregivers, further research is needed to understand how it affects parenting

stress as well as other possibly influencing other variables that increase parenting stress levels and behaviors. This study attempted to fill this gap.

Hope. The importance of hope has been recognized by many cultures, with the myth of Pandora's Box being the most widely recognized. In this story, hope is described as the force that makes all distress and hardships bearable (Snyder et al., 1991). Further research on hope as a psychological concept has expanded the definition to include a positive perception that goals can be met (Snyder et al., 1991; Snyder et al., 2000).

Snyder and his colleagues introduced a cognitive, motivational model of hope that incorporates a person's ability to conceptualize and achieve goals (Snyder et al., 1991; Snyder, Lopez, Shorey, Rand, & Feldman, 2003). According to hope theory, a goal can be anything a person desires from short term to long term, and the probability of goal attainment is moderate to high (Snyder, 2002). Positive emotions result from perceived achievement of a goal, whereas negative emotions result from a perceived goal failure (Cheavens, Feldman, Michael, & Snyder, 2006; Pueschel, 2001). In order to achieve these goals, pathways (i.e. plans to accomplish the goals) must be developed. In the event that problems arise, high-hope people are able to problem solve and determine alternative pathways while low-hope people face more goal impediments (Snyder et al., 1991).

Along with pathways, a person must have agency, or a motivational component about a person's own ability to begin and continue progress on a selected pathway until it is completed (Snyder, 2002). Agency thoughts serve to motivate and often appear as affirming statements. When a pathway towards a goal is disrupted, agency motivates the individual to alternative open pathways (Snyder et al., 2000). Both pathways and

agency are reciprocal and additive meaning the more a person believes the goal is achievable, the more pathways are identified. As more pathways are available, the motivational belief, or agency, that the goal is attainable increases therefore inspiring new pathways (Cheavens, Feldman, Michael, & Snyder, 2006; Snyder et al., 1991). According to hope theory, both components are necessary for movement toward a given goal, and a decrease in either pathways or agency results in lower hope (Snyder et al., 2000).

While some researchers have used the terms hope and optimism synonymously, Synder and colleagues (Shorey, Snyder, Rand, Hockemeyer, & Feldman, 2002; Snyder et al., 1991; Snyder, 2002) argued that hope is a separate concept. They stated that optimism and other concepts similarly used in positive psychology (Snyder et al., 2000) are focused on the individual's expectations of the future, specifically a person's behaviors that help avoid negative outcomes (Bruininks & Malle, 2005; Snyder, 2002). Hope theory varies from this in that it emphasizes the cognitive ways to accomplish these goals through pathways and agency (Snyder et al., 1991; Snyder et al., 2000). In their study of optimism, pessimism, agency, and pathways, Bryant and Cvengros (2004) found that hope focused more directly on personal attainment of specific goals, and optimism focused more broadly on the expected quality of future outcomes in general.

Hope has been associated with positive outcomes in several research studies. Higher levels of hope were associated with increased academic and athletic performance (Adelabu, 2008; Chang, 1998; Curry, Snyder, Cook, Ruby, & Rehm, 1997; Gilman, Dooley, & Florell, 2006; Synder et al., 2002; Snyder, Lopez, Shorey, Rand, & Feldman, 2003) and higher pain tolerance (Drach-Zahavy & Somech, 2002;

Irving, Snyder, & Crowson, 1998; Synder et al. 2005). An increase in positive outcomes during treatment among various illnesses were identified (Clayton et al., 2008; Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2001; Wong & Heriot, 2008), and individuals higher in hope achieved more short term goals during rehabilitation after an injury or surgery (Hartley, Vance, Elliott, Cuckler, & Berry, 2008; Warren & Manderson, 2008). Barnum, Snyder, Rapoff, Mani, and Thompson (1998) examined the effect of hope and social support on children who have survived burn injuries. As with previous research, hope was positively correlated with increased self-worth and decreased disruptive behaviors, allowing the children a positive environment to express their frustrations about their injuries and disfigurements. Regarding mental health treatment outcome, techniques that foster a sense of hope were related to decreased depression and anxiety when compared to pretreatment levels (Cheavens, Feldman, Michael, & Snyder, 2006; Larsen, Edey, Lemay, 2007; Stone, 1998). Also, specific populations have been identified that are vulnerable to lower hope levels and would benefit from treatments to increase hope (Bailey & Snyder, 2007; Moraitou, Kolovou, Papasozomenou, & Paschoula, 2006; Perry, Taylor & Shaw, 2007).

Hope also has been positively correlated with positive experiences in parents and families of children with various disabilities. Wong and Heriot (2008) stated that the parent's level of hope, despair, and social support affected the mental health and coping levels of children with cystic fibrosis. Depression and anxiety in family members of patients with obsessive-compulsive disorder were negatively correlated with hope, with social support and religiosity accounting for part of the variance as well (Geffken, Storch, Duke, Monaco, Lewin, & Goodman, 2006). High-hope parents of young children with type 1 diabetes also exhibited lower levels of anxiety and were

more able to cope with stress (Mednick et al., 2007). Shorey, Snyder, Yang, and Lewin (2003) examined the relationship of parenting styles, mental health, and hope in adults. Hope was determined to be a mediator in the relationship between attachment and mental health, and adult attachment mediated the relationship between parenting and hope. It is suggested that individuals develop hope while having a supportive adult relationship during childhood, and the existence of hope increases positive mental health in adults and positive parenting style (Shorey, Snyder, Yang, & Lewin, 2003). Those parents who have higher levels of hope are able to construe events more positive and are better able to adjust to changes in the future (Pratt, Norris, Van de Hoef & Arnold, 2001).

Although research utilizing hope theory has gained popularity over the recent years, research specific to the relationship of hope and parenting children with disabilities is limited. In a study that examined hope and social support in mothers who have a child with a physical disability, hope was negatively correlated with stress and maladjustment. Caregivers were then able to appropriately manage their stress as it related to their child and handle problematic behaviors exhibited by the child. In return, high-hope mothers were able to problem solve during times of stress so that their behaviors did not increase negative behaviors in the child (Horton & Wallander, 2001). Parents' level of hope also was found to significantly predict the severity of their child's symptoms of Attention/Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), or Conduct Disorder (CD) (Banks, Ninowski, Mash, & Semple, 2008). When the levels of hope were high, the children exhibited less problematic behaviors, suggesting that hope altered the caregivers' negative perceptions and behaviors that negatively affected the child's symptoms. Although

the previous studies reveal an important relationship between parenting and hope, neither included developmental disabilities.

Few studies have examined the levels of hope in caregivers of children with developmental disabilities, and gaps in the literature have been identified. In an attempt to examine how the diagnosis of a developmental disability can have on caregivers, a study of 29 parents of children with autism or childhood dementia assessed vicarious futurity, or the hope and despair that a person has for another's future, and found that hope was negatively affected. Specifically, 80% of parents in the autism sample and 71% in childhood dementia sample were found to have low hope and high despair for his/her child in the future after receiving the diagnosis (Wong & Heriot, 2007). A qualitative investigation of hope in families with developmental disabilities was conducted by examining the responses of 19 parents to a structured interview. Higher levels of hope present in their responses were associated with helping parents to positively reframe their lives with a special needs child (Kausar, Jevne, & Sobsey, 2003). The child's problematic behaviors became tolerable, and the family identified ways they coped with the negative symptoms. King et al. (2006) also examined the belief system of families with a child diagnosed with autism or Down syndrome and found that over time positive reframes can occur after experiencing a loss of future goals for the child, family, and parenting style. While themes in this study were consistent with previous hope research, hope was not specifically measured, so it is unclear how hope may have factored into the positive reframes. Carol (2008) found that hope predicted parenting sense of competence in mothers of children with autism but stopped short of identifying the relationship of parenting behaviors and hope. This study addressed the gaps in the literature and

examined how hope affects the relationship between parenting stress and behaviors when controlling for treatment satisfaction and child behavior problems.

Purpose of this Study

Parenting stress has been correlated with increased problematic behaviors in children (Dumas & Wolf, 1991; Glidden, 1993; Kwon, 2007; Osborne, McHugh, Saunders, & Reed, 2008). When a caregiver experiences higher levels of stress, he or she is less likely to establish and maintain positive parenting behaviors (; Abidin, 1992; Cui & Conger, 2008; Karazsai, 2009; Mash & Johnston, 1990; Kwon, 2007; Neppl, Conger, Scaramella, & Ontai, 2009; Phetrasuwan & Miles, 2009), and harsh parenting behaviors emerge (Bailey & Snyder, 2007; Brotman et al., 2008; Brotman et al., 2009; Fletcher et al., 2008; Heidgerken, Hughes, Cavell, & Wilson, 2004; Mazefsky & Ferrell, 2005). As a result, children are more likely to exhibit problematic behaviors which may, in turn, increase parenting stress. Because caregivers are more likely to be involved with multiple treatments for the child (Dale, Johoda, & Knott, 2006; Hutton & Caron, 2005; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Wodehouse & McGill, 2009) and have more demands placed on them due to the diagnosis (Glidden, Billings, & Jobe, 2006; Schall, 2000; Shu, 2009, Glidden, 1993), they are more prone to increased stress (Clearly & McNeil, 1998; Galil et al., 2006; Heppner & Heesacker, 1983; Mitchell & Penny, 1998; Ong, De Haes, Hoos, & Lammes, 1995; Schwab, DiNitto, Aureala, Simmons, & Smith, 1999; Trotter, 2008) and subsequently may engage in more harsh parenting.

When treatment satisfaction increases, caregivers' parenting stress decreases (Dempsey & Keen, 2008; Dempsey et al., 2009; O'Neil, Palisano, & Westcott, 2001). When individuals are confident in the services received and involved in their treatment,

positive treatment outcomes are achieved and stress is decreased (Clearly & McNeil, 1998; Galil et al., 2006; Heppner & Heesacker, 1983; Mitchell & Penny, 1998; Ong, De Haes, Hoos, & Lammes, 1995; Schwab, DiNitto, Aureala, Simmons, & Smith, 1999; Trotter, 2008). While the majority of research has focused on adult populations, results are also applicable for caregivers of children (Dempsey & Dunst, 2004; Nachshen & Minnes, 2005). Treatment satisfaction can reduce parenting stress (Dale, Jahoda, & Knott, 2006; Dempsey & Keen, 2008; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; O'Neil, Palisano, & Westcott, 2001; Shu, 2009) and increase hope (Schall, 2000), but further information is needed regarding parenting developmental disabled children.

Levels of hope have also been associated with positive outcomes (Adelabu, 2008; Chang, 1998; Clayton et al., 2008; Curry, Snyder, Cook, Ruby, & Rehm, 1997; Drach-Zahavy & Somech, 2002; Gilman, Dooley, & Florell, 2006; Irving, Snyder, & Crowson, 1998; Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2001; Synder et al., 2002; Snyder, Lopez, Shorey, Rand, & Feldman, 2003; Synder et al. 2005; Wong & Heriot, 2008) and positive experiences in parents and families including children with disabilities (Geffken, Storch, Duke, Mednick et al., 2007; Monaco, Lewin, & Goodman, 2006; Pratt, Norris, Van de Hoef & Arnold, 2001; Shorey, Snyder, Yang, & Lewin, 2003; Wong & Heriot, 2008). Hope in caregivers have also been related to decreased stress and reduced problematic behaviors in children (Banks, Ninowski, Mash, & Semple, 2008; Horton & Wallander, 2001) as well as positively affect a caregiver's perception of the child's diagnosis and treatment. While the presence of hope in caregivers of children with developmental disabilities is identified as important (Carol, 2008; Kausar, Jevne, & Sobsey, 2003; King et al., 2006; Wong & Heriot,

2007), levels of hope have not been quantitatively examined in this population nor has the relationships between hope and parenting behaviors been examined in this population.

Very few studies have examined the relationship that hope has on parenting stress and behaviors with caregivers of children with developmental disabilities, and no study has investigated how treatment satisfaction affects parenting stress and behaviors in the developmental disability population. This study addressed such voids in the literature by examining how hope and treatment satisfaction are related to parenting stress and examined the hypothesis that hope moderates the relationship between parenting stress and behaviors. Because higher treatment satisfaction and fewer child behavior problems may positively affect results, these variables were controlled to better determine the strength hope has on parenting stress and behaviors.

Research Questions

The research questions for the proposed study were as follows:

- 1. Do hope and treatment satisfaction predict levels of parenting stress in parents of children with developmental disabilities?
- 2. Does hope moderate the relationship between parenting stress and positive parenting behaviors when controlling for treatment satisfaction and child behavior problems?
- 3. Does hope moderate the relationship between parenting stress and negative parenting behaviors when controlling for treatment satisfaction and child behavior problems?

CHAPTER II

METHODS

Participants

After completing a power analysis, a minimum of 138 completed surveys were needed to measure moderate relationships and achieve 95% power (Faul, Erdfelder, Buchner, & Lang, 2009), and 150 surveys were obtained by caregivers of children identified with developmental disabilities and were currently seeking services at Cole Therapy in Houston, Texas, for one or more of the following services: speech therapy, occupational therapy, or physical therapy. Two surveys were initially excluded due to incomplete responses on more than half of the questions, and although data were not maintained on those declining participation, it is estimated that approximately 10-20% of caregivers meeting criteria declined to participate. Participant's children's diagnoses were confirmed by their treatment plan to have a diagnosis of a developmental disability as defined by the DD Act 2000, which specifies impairment in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic selfsufficiency. Specific diagnoses that were included are the following: Autism, Asperger's Disorder, Down Syndrome, Intellectual Disability, Pervasive Developmental Disorder, Epilepsy, Rhett's Disorder, Childhood Disintegrative Disorder, and Cerebral Palsy. Only caregivers whose children met these criteria were approached for this study.

Participant ages ranged from 19 to 67 with children ages ranging from 3 to 13, and all children were confirmed to have a developmental disability as defined by the DD Act 2000. Table 1 illustrates the frequency of demographic variables. The entire

sample comprised of 121 mothers (80.7%), 13 fathers (8.7%), and 16 other caregivers (e.g. grandparents; 10.7%). Forty-two percent of the sample was White, 33% was Hispanic, 18% was African American, 3% was Asian, 3% was Multi-Racial, and 1% identified as Other.

Table 1

Demographic Statistics

| Variable | N | Percent | | |
|------------------------------------|-----|---------|--|--|
| Gender of Child | | | | |
| Boy | 105 | 70.0 | | |
| Girl | 45 | 30.0 | | |
| Highest Education Completed | | | | |
| Some High School | 8 | 5.3 | | |
| Graduated High School | 93 | 62.0 | | |
| Graduated College | 43 | 28.7 | | |
| Master's Degree | 5 | 3.3 | | |
| Doctoral Degree | 1 | 0.7 | | |
| Marital Status | | | | |
| Never Married/Living Alone | 24 | 16.0 | | |
| Never Married/ Living with Someone | 14 | 9.3 | | |
| Married | 93 | 62.0 | | |
| Divorced | 18 | 12.0 | | |
| Widowed | 1 | 0.7 | | |
| Annual Income | | | | |
| Less than \$10,000 | 23 | 16.1 | | |
| \$10,000 - 20,000 | 34 | 23.8 | | |
| \$20,001-30,000 | 15 | 10.5 | | |
| \$30,001 - 40,000 | 16 | 11.2 | | |
| \$40,001 - 50,000 | 17 | 11.9 | | |
| \$50,000 + | 38 | 26.6 | | |

Table 1 (continued).

| Variable | N | Percent |
|--|----|---------|
| Child's Diagnosis | | |
| Autism | 25 | 16.7 |
| Asperger's Syndrome | 12 | 8.0 |
| Down Syndrome | 11 | 7.3 |
| Mental Retardation/Intellectual Disability | 36 | 24.0 |
| Pervasive Developmental Disability | 43 | 28.7 |
| Epilepsy | 2 | 1.3 |
| Childhood Disintegrative Disorder | 1 | 0.7 |
| Cerebral Palsy | 15 | 10.0 |
| Other | 5 | 3.3 |

Note. n = 150.

Measures

Demographic Questionnaire. (Appendix A) The demographic questionnaire was used to obtain socioeconomic and cultural information about the child and his or her caregivers. Information gathered included the child's age and gender, as well as the caregiver's gender, education level, and marital status. Questions regarding the number of services the child is receiving, the length of treatment, and the child's diagnosis helped to assess the severity of symptoms within the child with developmental disabilities.

Hope Scale (HS; Synder et al., 1991). The Hope Scale is a self-report measure that examines a person's ability to establish goals and his or her determination towards achieving them. The 12 items are scored on an 8-point Likert scale ranging from 1 indicating definitely false to 8 indicating definitely true and include questions such as I meet the goals that I set for myself, Even when others are discouraged, I know I can find a way to solve the problem, and I can think of many ways to get out of a jam.

Total scores can range from 8 to 96 with higher scores indicating more hope due to four items identified as filler questions. Cronbach's alpha from previous research ranged from .74 to .84 (Synder et al., 1991).

In the first stage of development, 45 items were administered to college students to narrow down items with the highest internal consistency. Fourteen items were identified with the best consistency, and eight hope items and four filler questions were chosen to create the 12-item scale. Six separate groups of college students were given the 12-item Hope Scale as well as two sets of people seeking psychological treatment. Regarding test-retest reliability, four samples of undergraduate students' scores were obtained, and correlations were .85 over a 3-week interval, .73 over an 8-week interval, and .82 over a 10-week interval indicating sufficient temporal stability in scores (Synder et al., 1991).

Multiple studies have subsequently examined the validity and reliability of the Hope Scale. Roesch and Vaughn (2006) examined the factorial validity in a multiethnic sample of students, and no significant differences were found regarding race, ethnicity, or gender. Babyak, Snyder, & Yoshinobu (1993) conducted a large scale factor analysis with the Hope Scale using more than 2,500 college students. A pathway factor and agency factor emerged, and no significant differences in gender differences were found. Other studies examined this scale with international populations (Abdel-Khalek & Snyder, 2007; Kato & Synder, 2005), various languages including Slovakian (Halama, 2001), people with physical disabilities (Barnum, Synder, Rapoff, Mani, & Thompson, 1998; Kortte, Gilbert, Gorman & Wegener, 2010; Kortte, Veiel, Batten, & Wegener, 2009), and caregivers of children with developmental disabilities (Horton & Wallander, 2001).

Alabama Parenting Questionnaire (APQ; Frick, 1991). The Alabama Parenting Questionnaire is a measure of parenting practices where parents rate 42 items that best describe their parenting practices. Items are rated on a 5-point Likert scale ranging from 1 indicating *never* to 5 indicating *always*, and examples of items include *You have a friendly talk with your child, You let your child out of a punishment early*, and *You feel that getting your child to obey you is more trouble than it's worth* (Frick, 1991). Items then load onto the following six scales: Involvement, Positive Parenting, Poor Monitoring/Supervision, Inconsistent Discipline, Corporal Punishment, and Other Discipline Practices. All scales except for Corporal Punishment ($\alpha = .46$) showed adequate internal consistency: Involvement ($\alpha = .80$), Positive Parenting ($\alpha = .80$), Poor Monitoring/Supervision ($\alpha = .67$), and Inconsistent Discipline ($\alpha = .67$; Shelton, Frick & Wootton, 1996).

While three versions of the APQ exist, the parent rating form was utilized in the current study. Positive and Negative Parenting Composite scores were calculated by combining the z-scores with the respective scales. Positive Parenting and Involvement scales will be used for the Positive Parenting Composite, and Poor Monitoring/Supervision, Inconsistent Discipline, and Corporal Punishment scales were combined for the Negative Parenting Composite as past research as indicated (Barry, Dunlap, Lochman, & Wells, 2009; Barry, Frick, & Grafeman, 2008; Frick, Christian, & Wootton, 1999; Frick, Kimonis, Dandreaux, & Farell, 2003; Shelton, Frick & Wootton, 1996).

The APQ has been used in a wide array of settings and populations. It has been proven to detect treatment effects after parenting interventions (Feinfeld & Baker, 2004; Lockman & Wells, 2002). It has also been utilized with parents of children

referred for treatment in clinics (Frick, Christian, & Wooton, 1999; Hinshaw, 2002; Shelton, Frick & Wootton, 1996), adolescents (Dadds et al., 2004; Frick, Christian, & Wooton, 1999; Lengua & Kovacs, 2005), and children not involved in programs (Colder, Lochman, & Wells, 1997; Frick, Christian, & Wooton, 1999). While it has been primarily utilized with children with behavioral problems (Dadds, Maujean, & Fraser, 2003; Frick, Christian, & Wooton, 1999; Shelton, Frick & Wootton., 1996) or ADHD (Baldwin & Dadds, 2008; Chronis-Tuscano et al., 2008; Ellis & Nigg, 2009; Wells et al., 2000), the APQ has initial support with children with developmental disabilities (Brubaker & Szakowski, 2000; Karande & Kuril, 2011).

The Parental Stress Scale (PSS; Berry & Jones, 1995). The Parental Stress Scale is a measure of parental stress containing 18 items measured on a 5-point Likert scale, ranging from Strongly Disagree (1) to Strongly Disagree (5) (Berry & Jones, 1995). Parents rate each item based on how descriptive it is of their situation regarding emotional benefits, self-enrichment, personal development, demands on resources, and opportunity costs and restrictions. Eight items are reverse-scored, and total scores range from 18 to 90 with higher scores indicating greater stress. Cronbach's alpha in previous research was reported as .83, and test-retest reliability was .81 over a 6-week period. Convergent validity was also evaluated using the Perceived Stress Scale, and results supported a significant positive relationship with a correlation coefficient of .50 (Berry & Jones, 1995).

Multiple studies have utilized PSS in their research. It has been used to evaluate parental stress in a medical setting to determine effects on infants (Dudek-Shriber, 2004; Turan, Basbakkal, & Senay, 2008) and continued parenting styles following medical procedures (Van Balen, 1996). It has also been utilized in other

languages (Leung & Tsang, 2010; Oronoz, Alonso-Arbiol, & Balluerka, 2007) and has support with parents of children with developmental disabilities assessing effective interventions (Norizan & Shamsuddin, 2010; Sharry, Guerin, Griffin, & Drumm, 2005).

Parent Satisfaction Scale (PS Scale; Gerkensmeyer & Austin, 2005). The

Parent Satisfaction Scale is a measure designed to assess parents' or other caregivers'

perceptions of their child's mental health services regarding the interactions with staff

and how it meets perceived needs, expectations, and desires. This 12-item measure is

measured on a 5-point Likert scale ranging from 1 indicating strongly agree to 5

indicating strongly disagree, and it consists of 11 items focusing on parent interaction

with the staff, decision making about treatment, staff availability, and helpfulness. One
additional item focused on cultural sensitivity was added after validity and reliability

studies (Rush, Jr., First, & Blacker, 2008). Total scores range from 12 to 60 with
higher scores indicating more satisfaction.

Reliability and validity of the original 11-item PSS were assessed using 120 parents of children receiving treatment in various inpatient and outpatient programs. The overall internal consistency reliability of the PSS was strong (α = .96), and analysis of subgroups of participants were also high, ranging from .90 to .98. Convergent validity was also evaluated using the Client Satisfaction Questionnaire (CSQ-8), which has been widely used in research to measure client satisfaction. Results supported a significant positive relationship with a correlation coefficient of .86 (Gerkensmeyer & Austin, 2005). Initial research utilized caregivers of children with serious illnesses and developmental disabilities (Rush, Jr., First, & Blacker, 2008).

Although there is strong initial support for the PSS, further research has not been conducted with varying populations.

Nisonger Child Behavior Rating Form—Parent Version (Nisonger CBRF; Aman, Tasse, Rojahn, & Hammer, 1996; Tasse, Aman, Hammer, & Rojahn, 1996). The Nisonger Child Behavior Rating Form—Parent Version is a caregiver-report behavior rating scale designed to assess behavior in children with developmental disabilities ages 3-16 years (Aman, Tasse, Rojahn, & Hammer, 1996). Two scales can be derived from the results of the 76-item measure: Positive Social Behavior and Problem Behavior. The Problem Behavior Scale is then categorized into six subscales measuring conduct problems, insecure/anxious behavior, hyperactivity, selfinjury/stereotypic behavior, self-isolated/ritualistic behavior, and overly sensitive behavior. Each item of the 76-item Problem Behavior scale is rated on a 4-point Likert scale ranging from did not occur or was not a problem (0) to behavior occurred a lot or was a severe problem (3). Because the 16-item Conduct Problem Subscale accounted for the highest variance among the subscales (27.6%) and has been utilized independently in prior research (Aman, Tasse, Rojahn, & Hammer, 1996; LeBlanc et al., 2005; Tasse, Aman, Hammer, & Rojahn, 1996), only this scale will be utilized. Total scores for the Conduct Problem Subscale range from 0 to 48, with higher scores indicated more frequent behavior problems (Tasse, Aman, Hammer, & Rojahn, 1996).

Internal reliability for the Nisonger CBRF Conduct Problem Subscale was reported in previous studies as .93. Concurrent validity was also evaluated using the Aberrant Behavior Checklist, which has been widely used in research to measure behavior problems. Results supported a significant positive relationship with a correlation coefficient of .72 (Aman, Tasse, Rojahn, & Hammer, 1996). The Nisonger

CBRF has been utilized in research regarding evaluation of problematic behaviors in children with developmental delays while on medication (Aman, Buitelaar, De Smedt, Wapenaar, & Binder, 2005; LeBlanc et al., 2005; Reyes, Croonenberghs, Augustyns, & Eerdekens, 2006). While initial support is strong for the Nisonger CBRF, further research has not been conducted with varying populations.

Procedure

Human subjects approval was obtained from the Institutional Review Board at The University of Southern Mississippi and maintained throughout the study (see Appendix B). Identified employees of Cole Therapy trained in the screening criteria identified potential caregivers as participants. One caregiver from each of the identified families was approached in person by the designated employee to participate in this research study utilizing the same script (see Appendix C). Participation was completely voluntary, no monetary compensation was given, and clinic staff reassured caregivers that their decision to participate or not would in no way impact the quality of services provided to their child. Given the concern that participation rates might be affected by concerns of the privacy of their responses, caregivers were verbally informed the surveys would not be shared with Cole Therapy employees. Additionally, caregivers were given the option of sealing their surveys in the return envelope so staff would not have access to their responses. Consenting participants signed a consent form (see Appendix D) detailing the nature of the study and contact information for the researcher and supervisor, and an additional copy of the consent form was provided to the participants. The set of questionnaires, which included the Hope Scale (HS), the Alabama Parenting Questionnaire (APQ), the Nisonger Child Behavior Rating Scale—Parent Version (Nisonger CBRS), the Parental Stress Scale

(PSS), the Parent Satisfaction Scale (PS Scale), and demographic information, was given to participants to complete in the waiting room while they waited for their child to receive therapy. To protect confidentiality, caregivers were instructed to not place identifying information on the questionnaires, and emphasis was communicated to participants to answer each question to the best of their ability without omitting items. Upon completion, consent forms were handed to staff separately from the survey, who maintained them in a secure, locked cabinet until there were collected.

Research Questions and Hypotheses

- Do hope and treatment satisfaction predict levels of parenting stress in parents of children with developmental disabilities?
 Hypothesis: Hope and treatment satisfaction will predict levels of parenting stress in parents of children with developmental disabilities.
- 2. Does hope moderate the relationship between parenting stress and positive parenting behaviors when controlling for treatment satisfaction and child behavior problems?
 - Hypothesis: Hope will moderate the relationship between parenting stress and positive parenting behaviors when controlling for treatment satisfaction and child behavior problems. Specifically, higher levels of hope will significantly strengthen the relationship between lower parenting stress and increased positive parenting behaviors when controlling for treatment satisfaction and child behavior problems.
- 3. Does hope moderate the relationship between parenting stress and negative parenting behaviors when controlling for treatment satisfaction and child behavior problems?

Hypothesis: Hope will moderate the relationship between parenting stress and negative parenting behaviors when controlling for treatment satisfaction and child behavior problems. Specifically, higher levels of hope will significantly strengthen the relationship between lower parenting stress and decreased negative parenting behaviors when controlling for treatment satisfaction and child behavior problems.

CHAPTER III

RESULTS

All data analyses in this study were performed using SPSS 19. Means, standard deviations, and other descriptive information for each measure are presented in Table 2. Overall, scores on the PSS, APQ, and Nisonger CBRF were within a standard deviation of those means reported in similar samples (Aman, Tasse, Rojahn, & Hammer, 1996; Barry, Dunlap, Lochman, & Wells, 2009; Berry & Jones, 1995; Frick, Christian, & Wootton, 1999; Frick, Kimonis, Dandreaux, & Farell, 2003; Sharry, Guerin, Griffin, & Drumm, 2005; Shelton, Frick & Wootton, 1996). The Hope scale and the PS Scale were consistently one standard deviation higher than the means in previous research, suggesting higher levels of hope and treatment satisfaction in this sample (Gerkensmeyer & Austin, 2005; Horton & Wallander, 2001; Synder et al., 1991).

Before Hypotheses 1 through 3 were tested, the data were screened for outliers and missing data and the parametric assumptions of multiple regression were tested. Scale reliability was also assessed using Cronbach's alpha and are presented in Table 2. The data were screened for univariate outliers by transforming raw scores to z-scores and comparing z-scores to a criterion of \pm 0.001 (Tabachnick and Fidell, 2007). One univariate outlier was detected in the treatment satisfaction variable and was removed from the data set. Multivariate outliers were evaluated using Mahalanobis distance computed for each variable, and these scores were compared to a critical value from the chi square distribution table. For Research Question 1, with two predictor variables and p < 0.001, the critical value for Mahalanobis distance was 13.816, and no multivariate outliers were identified. For Research Questions 2 and 3

with 5 predictor variables and p < .001, the critical value for Mahalanobis distance was 20.515, and two multivariate outliers were detected and removed as well. No missing data was detected; however, three cases had scores on the child behavior problems variable that were not within the possible range therefore these cases were removed. Normality, linearity, and homoscedasticity were evaluated visually using histograms and scatterplots and multicollinearity was assessed using Pearson product moment correlations. Results indicated that all assumptions were met.

As previous research suggested, both child behavior problems (r = -0.29; r = 0.23) and treatment satisfaction (r = 0.24; r = -0.22) were significantly correlated with positive and negative parenting behaviors respectively. Due to the concern that these variables will affect the results of the moderated regression with parenting stress, hope, and parenting behaviors, child behavior problems and treatment satisfaction will be controlled for in these analyses.

Table 2
Summary of Means, Standard Deviations, and Intercorrlations for Study Measures

| Measure | M(SD) | Cronbach's Alpha | 1 | 2 | 3 | 4 | 5 | 6 |
|---------------------|-------------|---------------------|---|-------|--------|--------|--------|--------|
| 1. Hope Scale | 51.83(6.32) | 0.74 | 1 | 0.25* | -0.25* | -0.26* | 0.12 | -0.03 |
| 2. APQ- Positive | 67.24(7.87) | 0.82 | | 1 | -0.27* | -0.39* | 0.24* | -0.29* |
| 3. APQ- Negative | 30.60(6.93) | 0.72 | | _ | 1 | 0.36* | -0.22* | 0.23* |
| 4. PSS | 33.89(9.15) | 0.85 | | | _ | 1 | -0.15* | 0.4* |
| 5. PS Scale | 54.22(6.71) | 0.86 | | | | _ | 1 | 0.54 |

Table 2 (continued).

| Measure | M(SD) | Cronbach's Alpha | 1 | 2 | 3 | 4 | 5 | 6 |
|-------------|------------|---------------------|---|---|---|---|---|---|
| 6. Nisonger | 7.44(7.45) | 0.91 | | | | | _ | 1 |

Note. APQ = Alabama Parenting Questionnaire; PSS = Parental Stress Scale; PS Scale = Parent Satisfaction Scale; Nisonger CBRF = Nisonger Child Behavior Rating Form; n = 149. Asterisk (*) indicates correlation is significant at p < .05

Hypothesis 1 Findings

HA₁: Hope and treatment satisfaction will predict levels of parenting stress in parents of children with developmental disabilities.

Hypothesis 1 was evaluated using a multiple regression with hope and treatment satisfaction entered simultaneously as a predictor of parenting stress. The regression model was statistically significant (R = 0.290, $R^2 = 0.084$, F (2, 146) = 6.717, p < 0.05). The two predictor variables, taken together, explained approximately 8% of the variance in parenting stress. When the predictor variables were examined individually, only hope had a unique, statistically significant effect on parenting stress (b = -0.361, $\beta = -0.249$, p < .05), while treatment satisfaction did not (b = -0.186, $\beta = -0.121$, p = 0.132). Based on this information, the hypothesis that hope and treatment satisfaction scores predict parenting stress scores was supported.

Hypothesis 2 Findings

HA₂: Hope will moderate the relationship between parenting stress and positive parenting behaviors when controlling for treatment satisfaction and child behavior problems. Specifically, higher levels of hope will significantly strengthen the relationship between lower parenting stress and increased positive parenting behaviors when controlling for treatment satisfaction and child behavior problems.

Hypothesis 2 was evaluated using hierarchical moderated multiple regression. Scores on the Hope Scale and PSS were centered prior to running the analysis based on recommendations by Frazier, Tix, and Barron (2004). The interaction term was computed by multiplying the centered PSS (predictor) times the centered Hope Scale (moderator) variable. The Nisonger CBRF and PS Scale were entered in Block 1 of the model. The centered hope and centered PSS variables were entered in Block 2 of the model and the interaction term was entered in Block 3 of the model. The dependent variable was APQ Positive Parenting Behaviors. Note that a significant R^2 change at step three is indicative of a significant moderation effect. Although the total model accounted for 16.5% variance in the APQ Positive Parenting Behaviors, the third step interaction was not significant ($\Delta R^2 = 0.003$, p = 0.481; $\beta = -0.057$, p = 0.481), indicating that the effects of parenting stress on positive parenting behaviors are consistent across levels of hope.

Table 3
Summary of Moderated Multiple Regression for Hypothesis 2

| Variables | ß | R^2 | ΔR^2 |
|----------------------|----------|---------|--------------|
| Step 1 | | 0.047 | |
| Nisonger CRBF | -0.213* | 0.017 | |
| PS Scale | 0.050 | | |
| Step 2 (Main Effect) | | 0.162** | 0.115** |
| Норе | 0.174* | | |
| PSS | -0.266** | | |
| | | | |

Table 3 (continued).

| Variables | В | R^2 | ΔR^2 |
|---------------------------------|--------|-------|--------------|
| Step 3 (Interaction) Hope X PSS | -0.057 | 0.165 | 0.003 |

Note. Nisonger CBRF = Nisonger Child Behavior Rating Form; PS Scale = Parent Satisfaction Scale; Hope = Hope Scale; PSS = Parental Stress Scale; DV: Positive Parenting Behaviors; n = 144; *p < .05, **p < .01.

Hypothesis 3 Findings

HA₃: Hope will moderate the relationship between parenting stress and negative parenting behaviors when controlling for treatment satisfaction and child behavior problems. Specifically, higher levels of hope will significantly strengthen the relationship between lower parenting stress and decreased negative parenting behaviors when controlling for treatment satisfaction and child behavior problems.

Hypothesis 3 was evaluated using hierarchical moderated multiple regression. Scores on the Hope Scale and PSS were centered prior to running the analysis based on recommendations by Frazier, Tix, and Barron (2004). The interaction term was computed by multiplying the centered PSS (predictor) times the centered Hope Scale (moderator) variable. The Nisonger CBRF and PS Scale were entered in Block 1 of the model. The centered hope and centered PSS variables were entered in Block 2 of the model and the interaction term was entered in Block 3 of the model. The dependent variable was APQ Negative Parenting Behaviors. Note that a significant R^2 change at step three is indicative of a significant moderation effect. Although the total model accounted for 16.4% variance in the APQ Negative Parenting Behaviors, the third step interaction was not significant ($\Delta R^2 = 0.000$, p = 0.884; $\beta = 0.012$, p = 0.884),

indicating that the effects of parenting stress on negative parenting behaviors are consistent across levels of hope.

Table 4
Summary of Moderated Multiple Regression for Hypothesis 3

| Variables | β | R^2 | ΔR^2 |
|----------------------|----------|---------|--------------|
| Step 1 | | 0.056 | |
| Nisonger CRBF | -0.208* | 0.000 | |
| PS Scale | 0.208 | | |
| Step 2 (Main Effect) | | 0.164** | 0.108** |
| Норе | -0.150* | | |
| PSS | 0.272 ** | | |
| Step 3 (Interaction) | | 0.164 | 0.000 |
| Hope X PSS | 0.001 | | |

Note. Nisonger CBRF = Nisonger Child Behavior Rating Form; PS Scale = Parent Satisfaction Scale; Hope = Hope Scale; PSS = Parental Stress Scale; DV: Negative Parenting Behaviors; n = 144; *p < .05, **p < .01.

CHAPTER IV

DISCUSSION

The purpose of this study was to examine how hope and treatment satisfaction were related to parenting stress in caregivers of children with a developmental disability and if hope moderates the relationship between parenting stress and positive and negative parenting behaviors in caregivers of children diagnosed with a developmental disability. It was hypothesized that (1) hope and treatment satisfaction would predict levels of parenting stress in parents of children with a developmental disability; (2) hope would moderate the relationship between parenting stress and positive parenting behaviors when controlling from treatment satisfaction and child behavior problems; and (3) hope would moderate the relationship between parenting stress and negative parenting behaviors when controlling for treatment satisfaction and child behavior problems.

Results from this study provided support for the first hypothesis, showing that hope and treatment satisfaction predicted parenting stress. Although both variables were correlated with parenting stress, only hope explained unique variance in parenting stress. The significant association between hope and parenting stress in parents with children with developmental disabilities is consistent with prior research (Geffken et al., 2006; Mednick et al., 2007; Shorey, Snyder, Yang, and Lewin, 2003; Wong and Heriot, 2008). High levels of hope are consistently associated with lower levels of distress. The current results paralleled these findings and showed an inverse relationship between caregivers' stress levels and hope. It should be noted that although significant, the overall effect of hope on parenting stress was relatively small.

The relationship between treatment satisfaction and parenting stress varied from previous findings. A strong relationship was identified between treatment satisfaction and parenting stress in other samples where lower levels of stress were associated with higher levels of satisfaction and involvement in their child's treatment (Dempsey, Keen, Pennell, and O'Reilly, et al.; 2009; Galil et al., 2006). Treatment satisfaction was negatively correlated with parenting stress in the current study, but when examined with hope, treatment satisfaction did not contribute unique variance to parenting stress. Caregivers may have been unlikely to continue treatment for their child in a setting that was voluntary and causing them stress, therefore, one might expect treatment satisfaction to be higher in this sample and resulted in a restricted range of responses. Lastly, while caregivers' satisfaction with the staff and quality of the treatment received may be high, improvements with child behaviors may be minimal due to the diagnosis of the child and severity of symptoms. Caregivers can become accustomed to little progress but still maintain hope that their child will make improvements in the future. As a result, hope was a better predictor of parenting stress than treatment satisfaction.

Results of the second and third set of analyses did not support the hypotheses that hope would moderate the relationship between parenting stress and positive and negative parenting behaviors. Instead, hope was consistently important over all levels of parenting stress and not only for highly stressed individuals. Caregivers of children with developmental disabilities experienced elevated levels of parenting stress when compared to parents of typical children due to atypical, aggressive, or other problematic behavior of the child (Dumas & Wolf, 1991; Glidden, 1993; Kwon, 2007; Osborne, McHugh, Saunders, & Reed, 2008). Because of this elevation, the restriction

in range of stress scores implies that parenting is similarly stressful for these families and that hope is likely similarly beneficial regardless of the levels of stress. While hope was not found to moderate these relations, there was evidence of hope having a significant main effect on both positive and negative parenting behaviors. Perhaps in a more diverse sample of parents, hope may moderate the relationship between parenting stress and behaviors, but in the current, somewhat homogeneous sample, hope was not found to moderate these relationships.

This was contrary to previous findings where hope was found to mediate or moderate the relationships between parenting stress and related outcomes. For example, some researchers (Rodenburg, 2007; Valle, Huebner, & Suido, 2006) showed hope or optimism affecting the relationship between parenting stress and behaviors in various samples including childhood illnesses. These studies did not include parents of children with developmental disabilities, and so it is likely that this sample is unique and may have affected the results. In studies that included developmental delays or pervasive illnesses (Baker, Blacher, & Olsson, 2005; Rentinch, Ketelaar, Jongmans, & Gorter, 2006) the moderating relationship of hope was examined with parenting stress and the effect on problematic behaviors in children. Hope was found to moderate the relationship of child behavior problems and parent stress and well-being. Additionally, higher levels of behavior problems in children resulted in higher stress and lower hope. In these studies, parenting behaviors were not specifically assessed and therefore additional research is needed to examine this relationship further. Shorey et al. (2003) examined hope as a mediator of parenting and mental health but did not examine caregivers of children with a developmental disability. The current study did not

examine hope as a mediator; future researchers may want to explore the viability of this idea in light of the current study.

Limitations

Although care was used in planning and gathering data for this study, some limitations have been identified. First, it is not known whether the present findings generalize to other locations. Data were collected in Texas where demographic characteristics of residents include higher numbers of Hispanic individuals and fewer African American people than in national statistics. Differing cultural components that can have a stronger perceived family support among Hispanic families (Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987) could affect levels of stress and hope among caregivers. Furthermore, the sample was not randomly selected and utilized the first 150 caregivers that met criteria and agreed to complete the questionnaire. This could have positively affected levels of hope and treatment satisfaction by including only people who were content and willing rate their experience. By finding people in various stages of treatment, a wider variety of responses may have been obtained.

The present study utilized self-report methodology, and results could have been positively affected. While participants were instructed that Cole Therapy employees would not see or have access to their results, administering and completing the questionnaires at the location their child was receiving treatment could have positively influenced them. As discussed previously, higher than expected means for hope and treatment satisfaction suggest that this could have occurred.

For this study, caregivers were required to be the primary caregiver of a child with a developmental disability, and the types of diagnoses included varied. Diagnoses

that met the specified criteria included autism spectrum disorders, cerebral palsy, Down syndrome, mental retardation, epilepsy, hearing loss, and vision impairment (APA, 2000). Other conditions that may qualify for the developmental disability classification, but are not specified, include handicapping conditions that occur before 18 years of age and involve brain damage or dysfunction at birth, growth or nutrition problems, abnormalities of chromosomes and genes, premature birth, and drug or alcohol use during pregnancy (Antonacci, Manuel, & Davis, 2008; Barnhill, 2008). While individuals with these diagnoses experience impairment, the severity of symptoms can greatly differ. For example, a child with Down syndrome can have weak muscles, heart problems, and cognitive impairments while a child with autism can have severe language impairment, self-injurious behaviors, and repetitive behaviors. Additionally, children diagnosed with autism spectrum disorders can range in symptoms as well from severely impaired to high functioning, and this range can affect the stress a parent may experience. Because different types of diagnoses that met the developmental disability criteria were included in this study, children's problematic behaviors varied greatly and could have affected parenting stress and behaviors. Over 53% of caregivers in this study had children with an autism spectrum disorder, and further examination of each diagnosis independently is needed to observe if the results of this study continue to be present when impairment is minimal.

The sample consisted mostly of mothers, and 70% of the children with a developmental disability were male. Although elevated, the number of male children in this study is consistent with previous statistics that report males are four times as likely to be diagnosed with a developmental disability, specifically an autism spectrum disorder. Research has also shown a link between mothers and higher levels of

parenting stress, depression, and other negative symptoms as related to their child with a developmental disability (Dabrowska, Pilsudski, & Pisula, 2010; Dumas & Wolf, 1991). It is unclear the extent to which gender impacted results.

Suggestions for Future Research

Because of its significant impact of the variables in this study, further examination of hope may be beneficial to help understand the relationship with parenting stress in caregivers of children with a developmental disability. Because caregivers in this study were very satisfied with treatment and reported fairly high levels of hope, future research should include caregivers in various stages of seeking therapeutic services for their child and different setting that may result in greater variability on these variables.

Additionally, future studies should focus on further examination of parenting behaviors in the developmental disability population. While this study included parenting stress, hope, and treatment satisfaction, additional variables, such as the child's or caregiver's gender and individual diagnoses should be examined to determine their effects on parenting behaviors.

Lastly, further examination is needed in the relationship between hope, parenting stress, and parenting behaviors. Previous research suggested a strong relationship between these variable in other populations, but this study found that hope did not moderate parenting stress and behaviors. Further analysis of caregivers in different stages of treatment and having various levels of hope is needed to understand these results with the developmental disability population. Because of the wide variability in reported child behavior problems among participants and the diagnoses

included that meet criteria for a developmental disability, future studies should examine each diagnosis independently to determine if these results remain.

Implications for Practice

Regarding therapeutic implications from this study, parenting stress predicts parenting behaviors that can escalate problematic behaviors in children with developmental disabilities. When caregivers are able to decrease their stress levels, positive parenting behaviors increase and can decrease behaviors in children that cause stress to the parent. Hope was identified as an important predictor of parenting stress and parenting behaviors, although the relative effects of hope were somewhat small. Hope may be an important consideration in the treatment planning of families of children with disabilities that may be often overlooked. Currently, services are aimed towards the child and do not incorporate or assess factors in caregivers that may impact treatment. By including an assessment of caregivers' hope along with other factors that are shown to affect parenting stress and behaviors, the child's treatment outcome may be improved.

Conclusion

This study provides information regarding how hope and treatment satisfaction predict parenting stress in caregivers of children with a developmental disability and if hope moderates the relationship between parenting stress and parenting behaviors.

The significance of this research is its focus on caregivers of children with developmental disabilities and the difficulties they experience. Findings provide continued support for the relationship between parenting stress and parenting behaviors and shed new light on the importance of hope and treatment satisfaction.

APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE

| Child's Age: | | Child's Gender: \square B | oy 🗀 Girl |
|------------------------------|--------------------------|------------------------------------|------------------|
| The person completing | g this form is: (check | one) | |
| ☐ Mother ☐ Fatl | her | lease specify): | |
| Your age: | | | |
| Race/Ethnicity: Af | sian Vhite | ☐ Hispanic ☐ Native Ar ☐ Multi-Rac | eial |
| Highest Education Yo | | | |
| | ligh School G | | |
| ☐ Earned Mast | ter's Degree | arned Doctoral Degree | |
| Marital Status: ☐ No Someone | ever Married/Living A | Alone | ried/Living with |
| | arried | rced | |
| If divorced, are you the | child's primary guard | ian? ☐ Yes ☐ No | |
| If no, indicate the numb | per of hours you spend | l weekly with your child: | |
| Annual Income (check | ŕ | \$10,000 | |
| Number of people in h | nome: | Number of childre | en |
| What therapeutic serv | vices is vour child rec | ceiving? (Please check all | that apply) |
| - | □Occupational Ther | - , | al Therapy |
| | _ | | |
| How many years has y | our child been recei | ving these services? | |
| What diagnosis does y | our child currently l | have? (Please check all th | at apply) |
| ☐ Autism | ☐ Asperger's Disc | ` | ☐ Down Syndrome |
| ☐ Mental Retardation | ☐ Pervasive Devel | opmental Disorder (PDD) |) |
| ☐ Rhett's Disorder | ☐ Childhood Disir | ntegrative Disorder | ☐ Cerebral Palsy |
| Other Developmental D | Disability (please speci | ify): | |

APPENDIX B

HUMAN SUBJECTS APPROVAL



THE UNIVERSITY OF SOUTHERN MISSISSIPPI

Institutional Review Board

118 College Drive #5147 Hattiesburg, MS 39406-0001

Tel: 601.266.6820 Fax: 601.266.5509 www.usm.edu/irb

HUMAN SUBJECTS PROTECTION REVIEW COMMITTEE NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Human Subjects Protection Review Committee in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects
 must be reported immediately, but not later than 10 days following the event. This should
 be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months.
 Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: 11071203

PROJECT TITLE: Parenting Stress, Behavior, Treatment Satisfaction, and

Hope in Caregivers with Developmental Disabilities

PROPOSED PROJECT DATES: 08/01/2011 to 08/01/2012

PROJECT TYPE: Dissertation

PRINCIPAL INVESTIGATORS: Paige Schultz

COLLEGE/DIVISION: College of Education & Psychology

DEPARTMENT: Counseling Psychology

FUNDING AGENCY: N/A

HSPRC COMMITTEE ACTION: Expedited Review Approval

PERIOD OF APPROVAL: 07/14/2011 to 07/13/2012

Lawrence A. Hosman, Ph.D.

HSPRC Chair

7-24-2011

Date

APPENDIX C

ORAL PRESENTATION OF STUDY

| My name is | , and I am a | (position at |
|---------------------------|------------------------------------|----------------------------------|
| Cole Therapy) assisting | g Paige Schultz, a doctoral studen | nt at The University of Southern |
| Mississippi, in conduct | ing research. She is examining h | now hope and satisfactions of |
| treatment services affe | ct positive parenting experiences | of a child with developmental |
| disability, and she wou | ld appreciate parents of children | with developmental disabilities |
| to spend about 45 minu | ites completing these questionnai | res. While we hope that you |
| participate in this study | y, your services at Cole Therapy a | are not contingent on your |
| participation. | | |

Please do not put your name on the questionnaires. Completing the questionnaires will take approximately 30-45 minutes. If you have questions while completing the questionnaires, please contact me.

Confidentiality will be maintained throughout the study. No names will be used on the questionnaires. Questionnaires will be kept in a secure location at Cole Therapy and then transferred to a secure location at The University of Southern Mississippi, and after 3 years, they will be destroyed.

Participation in this project is completely voluntary, and subjects may withdraw from this study at any time without penalty. Questions concerning this research should be directed to Paige Schultz, M.A., LPC, NCC at 281-210-6945 or Bonnie Nicholson, Ph.D. at 601-266-4598. This project and its consent form have been reviewed by the Institutional Review Board of The University of Southern Mississippi, which ensures that research projects involving human subjects follow federal regulations.

APPENDIX D

INFORMED CONSENT FORM

The University of Southern Mississippi Authorization to Participate in Research Project Consent Form

The purpose of this study is to examine certain factors which contribute to positive outcomes for parents of children with developmental disabilities. You will be asked to complete a series of questionnaires. You are invited to participate in this research study and you can withdraw at any time without penalty.

Your assistance with this project is greatly appreciated, and should take you about 30 - 45 minutes. All that is needed is that you complete the surveys, place them in the provided envelope, and return the packet to the designated Cole Healthcare employee. Please read this consent form, keep one copy, sign the other copy and return the signed copy to the researcher. These consent forms are kept separately from completed research packets to ensure anonymity. When you complete the packet, please do not put your name anywhere on the demographics form or the questionnaires. All information is anonymous and confidential. All data collected will be secured in locked cabinets and password protected computers, and will be only available to the researchers. Research results will be reported in aggregate form and we will have no way of identifying you. Your participation in this study is voluntary; SERVICES THROUGH COLE HEALTHCARE **ARE** NOT CONTINGENT PARTICIPATION IN THIS STUDY. Your participation is voluntary and you can discontinue participation at any point.

The information gathered from this study will be helpful for increasing helping professionals' knowledge of positive factors related to parenting children with developmental disabilities. There is no foreseeable risk in participating in this study.

By returning this packet, you are consenting to participate in this study. Please keep this consent form for your personal records, which contains the name and phone number of the principal investigators and contact information for the Human Subjects Protection Review Committee at The University of Southern Mississippi.

Questions concerning the research, at any time during or after the project, should be directed to Paige Schultz at 281-210-6945 or Dr. Bonnie Nicholson of the University of Southern Mississippi (USM) at 601-266-4598; bonnie.nicholson@usm.edu. This project and consent form have been reviewed by the Human Subjects Protection Review Committees at USM, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about your rights as a research participant should be directed to the Director of Research and Sponsored Programs (USM) at 601-266-4119.

Participant's Signature

Presenter's Signature

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