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Health Outcomes of Hispanic Parents Caring for Children with Disabilities

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FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

HEALTH OUTCOMES OF HISPANIC PARENTS CARING FOR CHILDREN WITH DISABILITIES

A dissertation submitted in partial fulfillment of
the requirements for the degree of
DOCTOR OF PHILOSOPHY
in
NURSING
by
Nelson Sanchez

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To: Dean Ora Strickland
College of Nursing and Health Sciences

This dissertation, written by Nelson Sanchez, and entitled Health Outcomes of Hispanic Parents Caring for Children with Disabilities, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this dissertation and recommend that it be approved.

Ora Strickland

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Tami L. Thomas, Major Professor

Date of Defense:

The dissertation of Nelson Sanchez is approved.

Dean Ora Strickland
College of Nursing and Health Sciences

Andrés G. Gil
Vice President for Research and Economic Development
and Dean of the University Graduate School

Florida International University, 2017

ABSTRACT OF THE DISSERTATION

HEALTH OUTCOMES OF HISPANIC PARENTS CARING FOR CHILDREN WITH DISABILITIES

by

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Florida International University, 2017

Miami, Florida

Professor Tami L. Thomas, Major Professor

The purpose of this correlational study is to investigate the impact of the child's functional status, family context, parent acculturation, and social support on parenting stress and, ultimately, on parents physical and mental health. A convenience sample of 50 Hispanic parents was recruited through a Facebook page and from agencies in South Florida providing services to children with disabilities and their families. The parents ages range from 21 to 62 years and the majority were mothers (n= 45). The majority of parents in this study live in low income households, have no college education, showed little participation in the workforce, and low acculturation. There were 30 boys and 20 girls between the ages of three to 21 years. Parents provided the data during an interview and through questionnaires. Data analysis included descriptive statistics and correlation analyses. Correlation analyses were conducted with the child's characteristics, family context, socioeconomic status, parent acculturation, social support, parenting stress, and parent's physical and mental health. The most frequent health problem reported by parents was neck and back pain. Parenting stress had a positive correlation with low acculturation and depression. The parents' physical and mental health had a positive correlation with parents' perception of social support. Parenting stress had a negative correlation with perceived social support, parents' mental health, educational achievement and years lived in the U.S. There was a negative correlation between parent depression, perceived social support, and parents' physical health. These parents reported low perceived social support and high levels of parenting stress. The results of this study indicate that parents with low acculturation reported higher level of parenting stress. Future research should continue exploring which interventions will better serve these parents and how cultural constructs influence their attitudes, expectations, decision making, and priorities.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Parents tending to children with special health care needs (CSHCN) experience challenges not experienced by the parents of typically developing children. These added stresses can lead to poorer health outcomes among these parents (Witt, Gottlieb, Hampton, & Litzelman, 2009). Multiple studies have shown that parenting CSHCN can undermine the parental emotional and physical health (Smith, & Grzywacz, 2014; Miodrag, Burke, Tanner-Smith, Hodapp, 2015). Hispanics are underrepresented in research even though they are a significant segment of the U.S. population. Few studies have explored the impact of caring for a child with a disability on the well-being and health outcomes of parents who belong to minority groups such as Hispanics (Zamora, 2016). This study aims to identify variables that might have a negative or positive influence on parenting stress and health outcomes of Hispanic parents caring for a child with a disability.

Studies have shown that Hispanic parents are at a higher risk of developing poorer health outcomes and have more unmet health care needs; some of the factors identified by these studies included acculturation issues, immigration status, and socioeconomic status (SES) (Inkelas, 2007; Meeske, 2013; Yu & Singh, 2012). In order to provide more effective interventions, health care workers must have a better understanding of how the cultural influences and cultural constructs of minority parents can alter how they cope and respond to the special challenges of caring for a child with a disability. Although cultural constructs of Hispanics parents will be discussed, this study does not intend to explore their potential influence in the health outcomes of these parents.

The National Survey of Children with Special Health Care Needs (NS-CSHCN) estimated that between 2009 and 2010, 10.2 million children (15.1%) in the U.S., 17 years of age or younger, had special health care needs (U.S. Department of Health and Human Services, 2010). The prevalence of CSHCN differs among racial/ethnic groups: 16.3% for non-Hispanic Whites, 17.5% for non-Hispanic Blacks, 13.6% for other non-Hispanic, and 11.2% for Hispanics (USDHHS, 2010). Remarkably, the prevalence of CSHCN among Hispanic households varies depending on the primary language spoken at home. Among Hispanic households with English as the primary language, the prevalence of CSHCN is 14.4%, very close to the national prevalence of 15.1%. Among Hispanic households with Spanish as a primary language, the prevalence of CSHCN was only 8.2% (USDHHS, 2010) The number of Hispanic children with disabilities will continue to grow, accentuating the need for research addressing this demographic group (Bureau, 2015).

Parents of CSHCN are often responsible for out-of-pocket expenses not covered by their health insurance and, consequently, low income parents tend to delay care. Parents caring for CSHCN experience significant financial difficulties. According to the results of the NS-CSHCN, over 18% of the households caring for a CSHCN reported experiencing financial burden directly related to the child's medical condition (USDHHS, 2008). Approximately 42% of the parents of CSHCN that reported financial problems had no insurance coverage. Approximately one third (33.8%) of the parents of CSHCN that reported financial problems had children with more severe disabilities. Parents of CSHCN spend a significant amount of time providing direct care or coordinating services, especially among low income parents and those caring for children with more severe conditions (USDHHS, 2010). Nineteen percent of parents classified as "poor" spend at least 11 hours per week caring for their CSHCN compared to only 4.3% among parents with incomes at 400% of the poverty level. About 24% of the parents caring for a child with a severe condition spend 11 or more hours per week providing direct care or coordinating services (USDHHS, 2010).

Purpose

The purpose of this study of Hispanic parents caring for children with disabilities was to investigate the effects of the degree of the child's age, child's functional status, and family context (SES, parental acculturation, and social support) on parenting stress and, ultimately, on the parent's physical and mental health. Parents caring for children with disabilities face multiple obstacles and difficulties that can have a negative impact on their well-being. The birth of a child with a disability forces parents to reassess their plans and expectations of parenthood. Some parents are able to manage well, while others have a difficult time adjusting to their child's challenges (Whiting, 2014). The demands of caring for these children have an undeniable and measurable impact on a parent's physical, emotional, financial, and social well-being (Brehaut, 2004; Raina et al., 2005; Spratt, 2007; Tong et al., 2002).

Conceptual Framework

The task of caring for a child with a disability is complex and challenging and it is not clear which factors or variables are associated with the health outcomes of these parents. Caregiving is a complex process that can be influenced by the characteristics of the caregiver, in this case the parent, and the characteristics of their children (Raina et al., 2005). Raina et al. (2004) developed a comprehensive multidimensional model based on previous research and theoretical models to explain factors influencing parental health outcomes in homes where a child with a disability lives; the theoretical models reviewed included the risk resilience model (Wallander et al., 1989) and the caregiving stress process model (Pearlin, Lieberman, Menaghan, & Mullan, 1981). These models agree that background variables (SES), caregiver characteristics, social factors, and the caregiving situation have an impact in the caregiving process and caregiving burden. They describe the caregiving process in the fields of pediatrics and geriatrics (Wallander at al., 1989; Pearlin at al., 1981). The multidimensional model proposed by Raina et al (2004) focuses on formal and informal caregiving, child's disabilities, socio-ecological factors, and the physical and mental health of the parents. This multidimensional model combines the two models mentioned earlier, the caregiving stress process model, and the risk-resilience model. The conceptual model used in this study (see Figure 1) is a modified version of the model developed by Raina et al. (2004). This model did not address child behavior, perception of formal care, or the parents' self-perception as a caregiver.

This research study uses the adapted framework to guide the research Aims, recruitment, methodology, and analysis. It posits that a child's characteristics (functional status and age) and parenting stress will have a direct effect on the parent caregiver's physical and mental health. Parenting stress refers to the stress that the parent experiences in the parent-child relationship.

Child characteristics, SES, parent acculturation, and social support are hypothesized to have a direct effect on parenting stress and on the parents' physical and mental health. Child functional status refers to how the child's disabilities are manifested, which can have a direct effect on the parents' physical and emotional health.

The family context refers to characteristics of the family, such as SES, parent acculturation, and social support. Higher SES is associated with better support systems, such as access to health care services and a more positive perception of social support. Another component of the family context in this conceptual framework is parent acculturation. Parent acculturation can have an influence on parenting styles and how Hispanic parents interact with health care providers (HCP) (Cook, Brown, Loder, & Wissw, 2014). Research shows that Hispanic parents tend to put more emphasis on good behavior and less emphasis on their children becoming independent which might interfere with the acquisition of functional skills and independence (Schulze, 2001). In this study, parental English language proficiency will be use an indicator of acculturation. Social support is the third and last component of the family context. Parents with a more positive perception of social support tend to report better physical and mental health outcomes (Porterfield, & DeRigne, 2011).

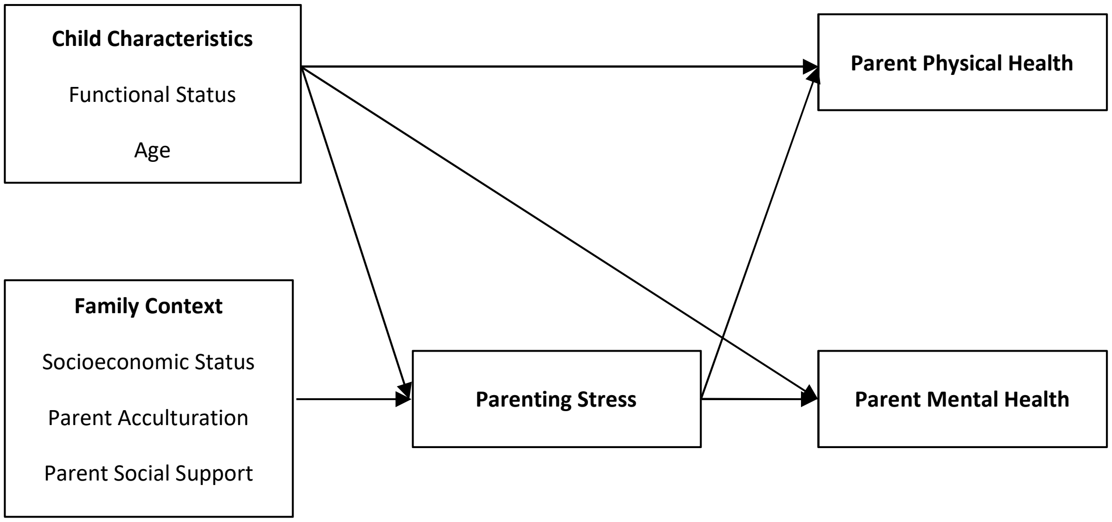

Figure 1. **Conceptual Framework**

Propositions of the Conceptual Framework

1. Impact of Child Characteristics on Parental Physical Health

Parents caring for children with a low functional status are at higher risk of experiencing musculoskeletal injuries which increases as the child grows and becomes more physically challenging to provide direct care for. The literature documents that a child's disability has a negative impact on the parents' health outcomes. Furthermore, the child's disability can contribute to financial difficulties and social isolation (Porterfield, & DeRigne, 201; DeRigne, 2012; Ngui & Flores, 2006). In most families, the care of children with physical and cognitive challenges is provided by mothers. Mothers of children with movement disorders perform tasks such as transfers (e.g. from bed to wheelchair) and handling activities (e.g. positioning) multiple times each day, increasing the chances of sustaining musculoskeletal injuries (Tong et al., 2002). The chance of such injuries increases as the children grow and the parents get older. Emotional distress has also been identified as a risk factor for musculoskeletal injuries such as low back pain (Tong et al., 2003).

2. Impact of `Child Characteristics on Parental Mental Health

The child's functional status and age can have a negative impact on the parents' mental health. In a study by Murphy, Christian, and Young (2006), primarily non-Hispanic parents who have children with disabilities reported that their physical and mental health was adversely affected by the long-term effects of caregiving and the omnipresent anxiety about the future. These parents reported significant challenges in maintaining their own health due to the lack of time and the tendency to place their own needs at a lower priority level. They mentioned the lack of respite care as a contributing factor to their negative mental health outcomes. The prospect of progressive deterioration of their own health and the potential inability to care for their children in the future added to their anxiety.

A study conducted by Eddy and Engel (2008) with primarily non-Hispanic parents suggested that when their children had conditions such as spina bifida, cerebral palsy, and other neuromuscular diseases, they experienced higher levels of anxiety. Those parents who had children with significant physical limitations, such as congenital limb deficiency and amputations, reported more interruption in family activities. They also found that neuromuscular disorders tend to worsen over time, causing a higher level of anxiety among the parents.

3. Impact of Child Characteristics on Parenting Stress

Parents caring for children with low functional status can experience an increase in parenting stress which can increase as the child gets older and their health care needs become more complex and challenging. Parents caring for children with more severe disabilities tend to experience higher levels of parenting stress and more difficulties coping with their child's disability (Glenn, Cunningham, Poole, Reeves, & Weindling, 2009).

Spratt, Saylor, and Macias (2007) conducted a study assessing parenting stress among four groups of primarily non-Hispanic parents of children between four and 12 years of age who had different diagnoses and disabilities. The first group of children had a combination of developmental, behavioral, neurological, and emotional problems; the second group of children had Intraventricular hemorrhaging. The third group of children had learning and/or attention deficit problems, and the fourth group of children had neural tube defects. All four groups reported that a combination of children's behavioral issues, as well as perceptions of inadequate resources and support, accounted for a higher parental stress level. However, the sample was only 1% Hispanic, prohibiting analysis of racial/ethnic differences.

4. Impact of Family Context on Parenting Stress and Parental Physical and Mental Health

Parents with lower SES, low acculturation and poor perceive social support can experience higher levels of parenting stress as well as poorer physical and mental health outcomes. Hispanic parents experience multiple risk factors including low SES, limited access to health care services due to lack of health insurance and language and cultural barriers (Bureau, 2015). Having multiple risk factors can have a greater negative impact on the health outcomes of Hispanic parents caring for children with a disability. Moreover, being a member of an ethnic minority might have greater repercussions for the parents' health outcomes (Eddy, 2008).

According to the U.S. Census Bureau (2015), Hispanics have a high poverty rate; the median income of a Hispanic family is $38,818 compared with $33,137 for African-American households, $53,340 for non-Hispanic White households, and $66,286 for Asian-American households. Lack of health insurance contributes even more to the vulnerability of the Hispanic population. In 2011, over 15 million Hispanics had no health insurance coverage (CDC, 2013). One of the reasons for this significant gap in health insurance coverage is the low educational achievement of the Hispanic demographic. In 2006, only 63.2% of Hispanic adults had a high school diploma compared to 91% of non-Hispanic White, 87% of Asians, and 81% of Black adults (Bureau, 2015). Additionally, the literature suggests that the lack of health insurance among Hispanics is also related to poverty and immigrant status of the parents. Lack of health insurance is not necessarily determined by the lack of employment; the percentage of employed Hispanics is equal to or higher than other ethnic groups (Flores, 2006).

It is indicated in the literature that there are differences in how members of various racial/ethnic groups cope with chronic diseases and disability. A study by Njoku, Jason, and Torres-Harding (2005) found that Hispanics tend to use denial more often than other racial/racial groups as a coping strategy. They explained these findings as innate cultural and religious beliefs among Hispanics.

Raina et al. (2005) examined the health and well-being of primarily non-Hispanic parents caring for children with special needs and found that their physical and psychological health was negatively affected. Mothers, who made up the majority of the parents participating in this study, stated that their health was directly influenced by their child's behavior and the caregiving demands. Parents caring for children with more behavioral problems reported poor perceived psychological and physical health. Their perceived physical and psychological health was associated with their perceived caregiving demands.

Access to quality health care services is indispensable in order to have optimal health outcomes. Hispanics have significantly lower access to health care services compared with other racial/racial groups in the U.S. (Flores, 2006). Some of the barriers to accessing health care services experienced by Hispanics include: lack of insurance, language barriers, lower income, and cultural constructs and beliefs (Asamoa, 2004). Hispanics share common cultural constructs or ideas that define and guide human behaviors, and social norms (Bracero, 1998) and they can have an impact on the relationship between Hispanics and HCP (Gance-Cleveland, 2006). Moreover, these cultural constructs and beliefs also influence the parenting styles of Hispanic people. Having knowledge of their parenting styles can help HCP understand the complex behaviors and attitudes of Hispanic parents and how these relate to the parents' and children's health outcomes (Domenech Rodriguez, 2009).

Significance of the Proposed Study

Parents belonging to at-risk and vulnerable populations are more likely to experience a greater negative impact in their lives (Ngui & Flores, 2006). Furthermore, these parents are at higher risk to experience burden of care, more financial difficulties, less access to health care services, and poor health outcomes (Reid, et al, 2011; Yu, Nyman, Kogen, Huan, & Schualber, 2004). Few studies have explored the impact of caring for a child with a disability on the well-being and health outcomes of parents who belong to minority groups such as Hispanics. This study aims to identify variables that might have an influence on parenting stress and health outcomes of Hispanic parents caring for a child with a disability. A better of understanding of which variables influence parenting stress and health outcomes of Hispanic parents caring for children with disabilities will help guide future research and the development of more effective interventions.

Definition of Key Variables

In the following section, the operational definition of the independent and dependent variables are defined in the context of the conceptual framework used in this study.

Child Characteristics

1. **Age:** This variable was be measured in years. The child's age at the time of the interview was reported by the parents participating in the study.
2. **Functional Status:** The child's functional status refers to the child's ability to perform activities of daily living. The expected child's functional status was

measured using the Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) (Haley, 2010). This test consists of four domains of function: Daily Activities, Mobility, Social/Cognitive Ability, and Responsibility. The daily activity domain includes: getting dressed, keeping clean, home tasks, and eating and mealtime. The mobility domain includes: basic movement and transfers, standing and walking, steps and inclines, and running and playing. The social/cognitive ability domain includes: interaction, communication, everyday cognition, and self-management. The responsibility domain assesses the extent the child is able to manage life tasks that enable independence in areas such as organizing and planning, care of daily needs, health management, and staying safe.

Family Context

1. **Socioeconomic Status:** This variable was measured by participants' self-report household income and highest education level achieved.
2. **Parent Acculturation:** Acculturation was measured using the Bidimentional Acculturation Scale (BAS). This instrument consists of three domains: general language use, language proficiency, and language use in media, within two subscales (Hispanic and non-Hispanic) (Marin & Gamba, 1996).
3. **Parent Social Support:** This variable of perceived social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS). This instrument measures the parents' perception of support from family members, friends, and significant others (Zimet, 1988).

Parenting Stress: This variable is defined as the stressful aspects of the parent-child interaction. The Parenting Stress Index Short Form (PSI-SF) was used to measure this variable. The instrument focuses on three major domains of stress: child characteristics, parents' characteristics, and situation/demographic life stress (Abidin, 1995).

Parent Physical Health: Physical health can be defined as the individual general state of well-being and the ability to perform all aspects of daily actives. In this study, this variable was measured using the Short Form (36) Health Survey (SF-36). This questionnaire measures quality of life in eight domains: physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health.

Parent Mental Health: Mental health can be defined as a state of well-being in which the individual is able to cope with life stressors and live a productive life (Galderisi, Heinz, Kastrup, & Sartorius, 2015). Mental illness is the opposite of mental health. Depression is the most common type of mental illness and was therefore used to measure this variable (Kessler, Chiu, Demler, & Walters, 2005). The Center for Epidemiological Studies Depression Scale (CES-D) was used to measure any symptoms associated with depression. This scale was originally used to measure how often parents experienced symptoms associated with depression (Lewinsohn, 1997).

Specific Aims

The specific aims of this study are listed as follows:

Aim 1: To explore the relationship of the child's characteristics (functional status and age) and family context (SES, parent acculturation, and social support) related to the parenting stress of Hispanic parents caring for children with disabilities.

Hypothesis 1: Parents caring for children with a low functional status requiring more direct care and assistance during daily activities will experience higher levels of parenting stress. Caring for these children as they get older becomes more challenging, contributing to higher levels of parenting stress.

Hypothesis 2: Hispanic parents with low SES, low acculturation, and poor perceived social support will experience higher levels of parenting stress.

Aim 2: To explore how the child's characteristics (functional status and age) and parenting stress are related to the physical and mental health of Hispanic parents caring for children with disabilities.

Hypothesis 1: Hispanic parents caring for children with a low functional status, older children, and those experiencing higher levels of parenting stress will report poorer physical health.

Hypothesis 2: Hispanic parents caring for children with a low functional status, older children, and those experiencing higher levels of parenting stress will report poorer mental health.

Aim 3: To explore how the child's characteristics and parenting stress are related to the physical and mental health of Hispanic parents when their SES, acculturation, and social support are controlled.

Hypothesis 1: Parents caring for older children, children with low functional status, low SES, low acculturation and low perceived social support will report poorer physical health.

Hypothesis 2: Parents caring for older children and/or children with low functional status who have low SES, low acculturation and low perceived social support will report poorer mental health.

Summary

This first chapter introduces the need to better understand the effects of caring for a child with a disability among Hispanic parents. Even though Hispanics are the largest minority group in this country, they are underrepresented in research (Bureau, 2015). Hispanics have significant risk factors for poor health outcomes. Some of these risks factors include: less health insurance coverage, low SES, and cultural and language barriers.

Parents caring for CSHCN tend to have poorer health outcomes than other parents (Murphy, 2006). The mental health of these parents can be negatively affected due to higher parenting stress and anxiety about the future. These parents have a high risk for developing musculoskeletal injuries, especially mothers tending to children with movement disorders (Tong et al., 2003). Although Hispanics are very diverse, they share common cultural constructs, such as *familism* and *allocentrism*. These constructs might influence the parenting styles of Hispanic parents and their interactions with HCP (Gallo, 2009). The influence of these constructs will not be explored in this study.

The theoretical framework model used in this study is based on the one proposed by Raina et al. (2004). The study aims address the variables proposed in the theoretical framework.

The second chapter will include a literature review addressing all the variables included in the conceptual framework and what is known about scientific evidence related to child disabilities, parenting stress, and parental mental and physical health. The third chapter will discuss the subjects, setting, statistical analysis, and other methodological matters. The fourth chapter will present the results obtained in the study, and finally, the fifth chapter will discuss the results.

CHAPTER 2

LITERATURE REVIEW

Introduction

Caring for CSHCN has a negative impact on the physical and mental health of parents (Raina et al., 2005). Parents caring for children with movement disorders often perform tasks such as transfers and handling activities multiple times each day, increasing their chances of sustaining musculoskeletal injuries; these parents have a higher incidence of musculoskeletal problems (Tong et al., 2003). Children's disruptive or maladaptive behaviors are also a source of stress and a contributor to poor parental emotional health. Often the children's maladaptive behaviors accompany neuromuscular disabilities, such as impaired ambulation, communication, and information processing (Lach, 2009). Parents caring for children with movement disorders and behavioral problems tend to have negative outcomes with their physical and mental health. Interventions must be geared towards addressing these challenges in a comprehensive manner, examining the children's maladaptive behaviors and the potential physical challenges of caring for a child with a movement disorder.

The care of CSHCN is now primarily performed by parents in their homes, particularly when those children have severe disabilities and require assistance with mobility and activities of daily living. Parents are expected to develop technical skills to carry on medical treatments and perform other interventions at home and these tasks can add to the burden of care (Brown, 2011). Parents who engage in the care of children with more severe disabilities perform many complex and technical tasks. These parents need interventions and support to help them cope with this expanded role in order to minimize negative outcomes. However, the unique needs of Hispanic parents of children with disabilities is not known.

Parental concerns and expectations change as the child grows older. These parents feel anxious planning for the child's future care arrangements (Knox, 2008). As their children become older, it is more difficult to the make necessary modifications in their homes, find babysitters, and respite care providers (Palissano, 2009). These parents need help planning for the future, especially during transition periods. Professionals working with these parents can assist by providing information regarding services and resources available in their communities.

Hospice care services for CSHCN delivered by trained staff for a specific period of time provides needed temporary relief for their parents. Respite care can be provided at home or at institutional settings (Eaton, 2008). The need for respite care services evolves as the child gets older and the demands for care change. Physical demands increase as the child grows and becomes more difficult to handle during activities of daily living. As children with mobility deficits grow, it becomes more difficult for parents to handle the physical demands of their care (Yilmaz, 2004).

Parents caring for children with significant movement and cognitive disabilities experience isolation and disruption in family life (Brown, 2011). Having adequate respite care is very important because it allows these parents to spend more time with other children in the family, nurture the relationships with their partners, go away on vacation, and prevent social isolation (MacDonald, 2004).

Parents of children with disabilities tend to have a lower level of full-time employment, have lower incomes, are more likely to be a single parent, usually a mother, and receive Medicaid coverage instead of employer sponsored insurance coverage (Heck, 2000). Parents with a lower SES and lower education level were less likely to access specialized health care services for their children than parents with higher SES and insurance coverage (Porterfield & McBride, 2007). Additionally, parents caring for children with disabilities who belong to minority racial/ethnic groups are more likely not to have adequate insurance coverage. Not having adequate insurance prevents these parents from getting the necessary support and services, causing them to have more out-of-pocket expenses than parents with better insurance coverage (Yu et al., 2004).

These parents report dissatisfaction concerning the knowledge of and communication with HCP regarding resources and services available in the community. These parents often have to become a liaison between all service providers and to act as case managers for the child's health care (Wood, 2009); consequently, they frequently report dissatisfaction with health care services and care coordination services as well as having a higher number of unmet needs associated with lower SES, lower child functioning status, lower perception of social support, and greater perception of burden (Farmer, 2004). The dissatisfaction with services verbalized by these parents must be addressed by providing programs designed to reduce the challenges they encounter. Improving these interventions can promote better outcomes among the parents and their children, having a positive impact for the entire family. Special attention should be directed at parents with a lower SES, those reporting low social support, and racial/ethnic minorities. The interaction of SES and cultural constructs must be explored, particularly amongst parents that belong to racial/ethnic minorities.

Cultural constructs could have an impact on how Hispanic parents use health care services as well as their perceived needs and expectations (Gannotti, 2004). Hispanics tend to have a less confrontational communication style that is common of collective societies. Hispanics are usually reluctant to leave their child under the care of somebody else and avoid direct confrontations with members of the health care team.

Multiple factors contribute to higher levels of stress and difficulties developing effective coping strategies. Severity of diagnosis combined with inadequate family support has a negative impact on the ability of parents to cope successfully (Glenn, 2009), but developing effective coping skills can help decrease stress on parents caring for children with disabilities (Churchill, 2010). Parents caring for children with disabilities tend to experience higher parenting stress. They need assistance to develop effective coping skills to help them minimize potential problems with their mental health.

Independent Variables

Child's Characteristics: Age and Functional Status

The care of children with physical disabilities who require assistance with mobility and activities of daily living have shifted from institutionalized care to home-based care in the second half of the 20th century (Brown, 2011). The actual physical demands experienced during daily care activities have a negative impact on the physical and emotional health of parent (Tong et al., 2003). These care demands affect the health of the parents and the impact becomes more evident as the children grow (Raina et al., 2005).

Parents of children with disabilities experience high levels of anxiety as they anticipate what is going to happen to their child when they become older and are no longer able to care for them. Older parents might experience failing health, financial pressures, and a constant worry about the future. Dillenburger and McKerr (2011) conducted a study to explore the concerns of older parents related to the burden of care and planning for the future of their children in Northern Ireland. The parents' race or ethnicity was not reported. They selected a convenience sample of 29 parents (20 mothers, eight fathers, and one sister) caring for 27 adults with developmental disabilities. The average age of the parents was 65.2 years (range 47-84), and the average age of the sons and daughters was 33.5 years (range 12-59). The researchers conducted semi-structured interviews using open-ended questions and the General Health Questionnaire (GHQ-12) to obtain quantitative data on their psychological health. The majority of the parents owned their homes and made alterations to them to better care for their children. One of the challenges mentioned by the parents was dealing with behavioral problems. They also mentioned that their own health was a challenged as they got older. The scores of the GHQ-12 indicated that 35% of the participants needed a psychological assessment and interventions.

They reported that they received support mainly from close family members. Daycare and respite services were available, but they voiced concerns regarding the quality of care received by their sons and daughters at these places (Dillenburger, 2011). The majority (72%) had not made plans for the future and voiced concern about not being able to take care of their children as they got older. These parents communicated feeling guilty that the other children in the family had to live their lives accommodating for the needs of the child with disabilities and having to take the responsibility of caring for their siblings when the parents eventually became physically unable or had passed away. Many of the parents voiced frustration with the services available to them, stating that they could not depend on any institutional support. The results of this study confirm that the lack of support, respite care, and assistance planning for the future contribute to the high stress levels experienced by parents caring for older children. It is vital that researchers and HCP working with older parents help them make plans for the future.

A parent's concerns and expectations change as his or her child grows older. Many parents experience anxiety about the future of their children, especially those parents of children that require assistance with activities of daily living. Knox (2008) conducted a study investigating the concerns of parents of children with cerebral palsy according to the type of cerebral palsy, age of the child, and functional status. The study found that concerns were significantly different for parents of different age groups. Parents of older children were more concerned with skills such as standing balance, acquisition of a functional gait, and communication skills.

Palissano et al. (2009) conducted a multisite study to investigate how a child's age and functional status influence the family needs expressed by parents of children with cerebral palsy. The sample consisted of 501 parents of children and youth with cerebral palsy, 75.2% White, 7.2% African American, 8% Hispanic, and 7.2% other. The majority (77.6%) of the participants were mothers, with a mean age of 40.3 years (SD= 9.3). The children's ages ranged from two to 21 years, with a mean of 10.8 (SD= 4.5). The researchers used the Gross Motor Function Classification System (GMFCS) to assess the child's functional status. This instrument has five levels: level I represents those children able to walk without assistance; levels II and III represent children that walk with limitations; and level IV and V those that need a wheelchair and assistance.

Parents caring for children in levels IV and V sited more needs than those parents caring for children in levels I, II, and III. Many of these parents expressed information needs regarding services required by their children (68%) and present availability of services (59.6%). Information regarding planning for their child's future was expressed by 57.7% of the parents and 51.5% needed help finding community camps, sports, recreational, social and leisure activities. Moreover, parents with children in levels IV and V were more likely to express needs for help paying for equipment and home modifications, finding babysitters, and respite care providers. The sample consisted of only 8% Hispanics and 7% African-Americans; findings may not apply to these groups. The parents in this study stated that as their children became older they required assistance identifying services available in the community, making home modifications, obtaining necessary equipment and finding appropriate respite care (Palissano, 2009).

Chiarello et al. (2010) conducted a study exploring the differences in parents' priorities based on the child's age and function level. The sample consisted of 585 children and their parents (80% mothers), 73% White, 9% African American, 4% Hispanic, and 14% other. The sample was divided in three groups: children six years old or younger (n= 91), six to 12 (n= 296), and 13 to 21 (198). The parents' ages ranged from 20 to 74 years of age with a mean of 40.3 (SD=9.3). The Canadian Occupational Performance Measure (COPM) 3rd edition was used to identify and qualify the clients' priorities in regards to self-care activities, productivity, and leisure. Productivity included activities such as paid or unpaid work, independence in household management, school-work, and play. The GMFCS was used to measure and classify the children's gross motor function.

The majority (70%) of the parents of children six years of age and younger identified the most important priorities as those related to daily activities and the lowest priority (8%) being productivity. Among parents of children between six to 12 years, 59% identified daily activities as a priority; among parents of children 13 to 21 years, 44% identified daily activities as priority. Concerns with productivity increased with age, with 31% of the parents of children ages 13 to 21 identifying productivity as a priority versus only 8% of the parents of children six years of age and younger. Parents of younger children prioritize meeting the needs of daily activities and self-care. Parents of older children were also concerned about meeting the self-care and daily needs of their children; however, they were also concerned with their children's ability to participate in school and in the workforce (Chiarello et al., 2010).

Andrews, Bolt, Braun, and Benedict (2013) conducted a study comparing objective and subjective measures of energy exertion experienced by caregivers during their tasks. The sample consisted of 19 children and young adults with cerebral palsy who require significant physical assistance with transfer activities and dressing. The majority of the children (67%) were classified in level V on the GMFCS. The objective measures used to assess the physical effect on the parents included oxygen consumption (VO2) and heart rate (HR). The subjective perceived exertion during these activities was measured using the Borg's Rating of Perceived Exertion Scale (Borg RPE). The authors observed that those parents caring for older and bigger children showed an increase in VO2 and Borg RPE. They also observed that older parents reported higher perceived energy exertion during care activities. The correlation of VO2 with HR was 0.63 ($p<.01$), and with Borg RPE was 0.43 ($p<.01$). The correlation of VO2 with the parents and child's age was 0.64 ($p<.01$); with child's weight was 0.57 ($p<.05$); and with child's height was 0.59 ($p< .05$).

The authors noted that the correlation between VO2 and child's weight increased significantly, especially, with those parents caring for children with a weight greater than 23 kilograms (Andrews, Bolt, Braun, & Benedict, 2013). Physical exertion is an important factor that has a direct impact on parents' health outcomes and the ability of these parents to care for their children. The findings of this study suggest that there is an association between parents' perceived physical effort and/or caregiving burden and their physical and mental health.

Parents caring for children with more severe disabilities, resulting in low functional status and an inability to perform daily tasks appropriate to their chronological age, experience substantial challenges. Parents caring for children with movement disorder can sustain musculoskeletal injuries secondary to the physical effort of caring for their children. The physical effort becomes more challenging as the child gets older and physically bigger (Tong et al., 2003). Parents caring for children with disabilities experience anxiety about the future of their children and worry about who will look after their disabled child when they are no longer able. As the child gets older, anxiety about the future and the need to make arrangements becomes a more significant objective (Murphy, 2006).

In this next section, family context (SES, parent acculturation and perceived social support) and child characteristics (functional status and age) are detailed. Finally, this section will explain how they contribute to parenting stress and physical and mental health as proposed in the theoretical model.

Family Context: Socioeconomic Status

Some studies find that parents of CSHCN have a lower level of full-time employment than parents caring for typically developing children. Parents caring for CSHCN have lower incomes and are more likely to be headed by a single parent, usually a mother, and receive Medicaid coverage instead of employer sponsored insurance coverage (Loprest, 2004).

Heck and Makuc (2000), using data from the 1994 NHIS, examined parental employment and insurance coverage of parents caring for CSHCN. They compared 1,604 CSHCN and 19,811 children without special health care needs, with ages ranging between five and 17 years. The three major racial/ethnic groups were represented among the CSHCN: 69.4% were White, 15.1% African-American, and 12.1% Hispanic. Among the sample of children without special health care needs, 68.1% were White, 13% African-American, and 14.1% Hispanic. Parents of CSHCN were more likely not to work full-time; two parent families had a ratio of 1.27 (95% CI, 1.07-1.51) and single-parent families were at 1.66 (95% CI, 1.33-2.07) compared to parents with children who have no special health needs with an odd ratio of one. CSHCN were 2.65 times more likely to have Medicaid coverage than children without special health care needs. The added caregiving challenges experienced by parents caring for CSHCN contribute to a lower full-time employment and makes them less likely to have private insurance. This might impact the parents' income and their ability to access services.

A study conducted by Porterfield and McBride (2007) found a correlation between lack of knowledge regarding the necessary services required by their children and variables such as low SES and lower education. The researchers used data from the 2001 NS-Children with Special Needs (NS-CSN). The survey was completed by parents of CSHCN, with ages ranging from newborn up to 17 years. The number of interviews totaled 38,866 from urban and rural areas in 34 states. The majority (74.7%) of the parents were White, 14.9% African-American, 11.5% Hispanic, and 6.5% were classified as other. Parents with a lower SES and lower education level were less likely to have access to specialized health care services for their children than parents with higher income and insurance coverage. When parents were asked why they did not access the health care services needed by the children, they mentioned two major reasons: one was the high out-of-pocket cost and the second was related to insurance coverage. Another reason for not accessing services was lack of information to help the parents understand what services are needed and how to access them. This study supports the need for a coordinated and strategic effort to educate parents of CSHCN about necessary and available services. Parents with a lower SES are less likely than parents with a higher SES to access specialized services for their children. Parents with a lower SES might need help learning about required services, finding which services are available in their communities, and learning ways to become a more effective advocates for their children (Porterfield, & McBride, 2007).

Moreover, parents caring for children with severe functional impairments experience more financial challenges and time constraints. Children with more severe conditions require more professional services. These parents have to coordinate the delivery of multiple health care services (Rocha, 2008). Bumbalo, Ustinich, Ramcharran, and Schwalber (2005) used data from the NS-CSHCN to study the influence of SES and health related factors on parents with a CSHCN in New Hampshire. The sample consisted of 750 CSHCN and 2,975 children without special health care needs, race/ethnicity not reported. They found that more parents with CSHCN live below 100% of the Federal Poverty Level (FPL), 12.4%, compared to 7.2% among parents with children without special health care needs. A larger percentage of parents with a CSHCN have public insurance, 21%, compared to 12% among parents who have children without special health care needs. Inadequate health insurance was reported by 31% of the parents with CSHCN. Among parents with a CSHCN, 21% reported financial problems and 27% reported cutting work hours. When the researchers examined the impact of income on parents with CSHCN, among those below the 100% of FPL, 47% reported having inadequate insurance, 38.5% reported cutting work hours, 28.7% reported that a family member stopped working, and 17.7% reported needing professional care coordination. Similar results were found when they examined parents with CSHCN who have public insurance; 39.1% reported inadequate insurance coverage, 31.7% reported financial problems, 37.5% reported cutting work hours, 16.2% reported one member of the family stopped working, and 21.6% reported needing help with care coordination. When they examined the impact of the child's severity, they found that parents caring for children with severe deficits reported inadequate insurance coverage (50.6%), financial problems (40.9%), cutting work hours (52.4%), one member of the family stopped working (19.3%), and needing help with care coordination (32.4%). This study shows that the severity of the child's condition and functional status has a strong impact on the family. Parents caring for children with more severe disabilities and lower functional status reported insufficient insurance coverage, more financial problems, having to cut back work hours, and having greater needs for professional health care coordination.

Porterfield and McBride (2011) examined how receiving care through a medical home service model influences the out-of-pocket expenses of parents with CSHCN with 2005-2006 NS-CSHCN data. The medical home service model includes having the usual physician and/or source of care, family centered care, receiving care coordination services, and no problem getting referrals. The sample used for this study consisted of 31,808 children, 23,175 with private insurance and 8,633 with public insurance (newborn to 17 years). Parents with public insurance reported a higher percentage of children with more severe conditions (18.4%) versus parents with private insurance (8.9%). The education level was lower among mothers with public insurance: 15.1% did not complete high school and only 45.5% had post high school education/training. Among the mothers with private insurance, only 1.8% had not completed high school and 83.8% had post high school education/training. The percentage of minorities was higher in the public insurance group, showing 53.2% White, 29.9% African-American, 15.9% multiracial, and 21.4% Hispanic. In the private insurance group, 80.4% was White, 9.3% African-American, 9.8% multiracial, and 10.5% Hispanic. Among parents with private insurance, 54.4% reported receiving services through a medical home service model versus 41.5% among parents with public insurance. Parents without a medical home service model reported higher out-pocket expenses, delayed care, and more unmet needs in both groups. Parents caring for CSHCN tend to have lower incomes and less private insurance than parents caring for children developing typically. These socioeconomic factors combined with caring for child with a more severe disability contributes to financial problems, less access to services, time constraints, and increased need for service coordination (Porterfield, & DeRigne, 2011).

Studies have shown that well-coordinated services have a positive impact on parent's satisfaction with HCP and employment status. Designating a member of the health care team, e.g. a social worker, as a coordinator of services would guarantee that the health care needs of the child and the family are met (Palfrey, 2004).

DeRigne and Porterfield (2010) conducted a study examining the impact of having services provided through a medical home service model on employment decisions of married and single mothers of CSHCN. They used data from the 2005-2006 NS-CSHCN. The sample consisted of 23,380 married parents and 8,814 single mothers and included parents of children between newborn to 17 years. The majority of the children were White (80.3%), 8.4% African-American, 9.9% Hispanic, 3.5% multiracial, and 7.2% other race. Receiving care coordination through a medical home service model reduced the risk of parents cutting back their work hours by 43% for married parents and 39% for single mothers. Parents of children with more severe medical conditions and higher out-of-pocket expenses had a higher probability of cutting hours or stopping employment than parents caring for children with milder disabilities. This probability was even higher among parents not receiving care through a medical home service model.

Parents caring for CSHCN who belong to minority racial/ethnic groups are more likely not to have adequate insurance coverage. Lacking appropriate insurance deprives parents of the necessary support and services and causes them to have more out-of-pocket expenses than parents with better insurance coverage (Davidoff, 2004).

Yu et al. (2004) conducted a study exploring the effect of language on access to health care among Hispanic parents with CSHCN. They used data from the 2001 Maternal and Child Health Bureau (MCHB) of the Health Resources and Services

Administration and the National Center for Health Statistics (NCHS). The sample consisted of 38,866 CSHCN, 3.4% had a non-English speaking parent. The majority (92.7%) of the non-English speaking parents were Hispanic. Non-English speaking parents were less likely to have a college education or a higher degree (11.2% versus 54.2%). They were more likely to be below poverty level (43.3% versus 12.3%) and to be without health insurance (21.2% versus 4.7%). In addition, non-English speaking parents were more likely to report that the child's condition affected their activities a great deal (36.3% versus 22.7%) and that they had inadequate health insurance (86.5% versus 33.1%) compared with English speaking parents. Furthermore, non-English speaking parents reported that their children had more unmet needs (33.6% versus 17.4%), problems with specialty referrals (40.4% versus 21.2%), and not having family-centered care (64.4% versus 33%). Financially, non-English speaking parents had more financial problems (27.3% versus 20.6%) and employment difficulties (56.6% versus 29%). These results support that non-English speaking parents of CSHCN with a lower SES have more financial challenges and difficulties accessing services than English-speaking parents caring for CSHCN. Researchers and HCP must consider the special challenges experienced by parents with lower SES and language barriers.

Family Context: Parent Acculturation and Cultural Constructs

One of the challenges researchers face when working with the Hispanic community is its considerable diversity, which makes generalizations very difficult. Different groups might have different experiences with the process of acculturation to the U.S. Despite this diversity, most Hispanics share certain cultural constructs such as *familism* and *allocentrism*. The terms “cultural construct” and “cultural values” at times are given the same meaning. Cultural constructs are a precise belief or understanding that explains interactions, expectations and behaviors of members of a specific cultural group. On the other hand, cultural values stands for what is acceptable or unacceptable within a specific cultural group (Gilbert, 2013).

Familism is defined as the obligation of the individual to the family. One of the expectations of *familism* is that there will be frequent contact and reciprocity among family members. All members of the family are expected to show respect and devotion to each other, especially to the elderly. A level of conformity to parental and extended family authority is also expected (Rodriguez et al., 2007).

Allocentrism, another important cultural construct in the Hispanic community, is defined as an orientation of the individual to consider the needs, objectives, and points of view of the group rather than the individual. This construct fosters empathy and willingness to sacrifice for the benefit of others. *Allocentrism* places strong emphasis on conforming and striving for harmony, avoiding negative behaviors, and emphasizing positive behaviors in interpersonal relationships. Another component of this cultural script is the willingness to seek out the well-being of the family as a group first and placing the needs of the individual second (Gallo, 2009). *Allocentrism* and the strong desire to strive for harmony within interpersonal relationships might influence some of the child-rearing practices among Hispanics.

The constructs of *familism* and *allocentrism* can promote coping mechanisms to support parents caring for children with disabilities by sponsoring supportive attitudes from the extended family members and those that form part of the support system. On the other hand, these two cultural constructs could promote over-protectiveness that interferes with the promotion of independence (Gallo, 2009).

Hispanic culture also places a high value on motherhood, and there is a tendency to accept and adjust to high levels of care as well as long-term dependency of a child with a disability. The ability to endure high levels of caregiving responsibilities is seen as a positive attribute. Having this quality helps mothers of children with disabilities to endure and become passively resigned to their fate as a caregiver of a child with a disability (Castillo, 2010).

Schulze, Harwood, and Schoelmerich (2001) conducted a study exploring within- and between-group differences among Anglo and Puerto Rican middle-class mothers' beliefs and practices regarding the attainment of developmental milestones, such as feeding at the age of 12 months. The sample consisted of 32 middle class Anglo mothers and 28 middle class Puerto Rican mothers; the two groups were comparable in age and education. They found that Anglo mothers valued long-term goals that emphasized autonomy and independence and expected their children to be able to self-feed at a younger age than Puerto Rican mothers. Long term goals valued by Puerto Rican mothers emphasize behaviors that demonstrated respect and appropriate interpersonal relationships. This study is significant because it compared mothers that, except for their ethnicity, were compatible in other significant characteristics. It supports the idea that there are different cultural normative beliefs and expectations for goal attainment.

Rodriguez, Donovick, and Crowley (2009) conducted a study to examine parenting styles and dimensions in a sample of Hispanic parents using the two usual dimensions (warmth and demandingness) and adding autonomy granting. The parenting style of these Hispanic parents was observed and rated using the Parenting Style Observation Rating Scale (P-SOS) used to measure parenting dimensions and parenting styles. The parenting dimensions include: warmth, demandingness, and autonomy granting. Parenting styles were classified as authoritarian, authoritative, permissive, and neglectful. Parents' scores in the different parenting dimensions were used to classify them into one of eight parenting categories. The sample consisted of 50 Hispanic parents caring for children between the ages of four and nine. The majority were two parent families (88%) of Mexican descent (81%) that tested as having low levels of acculturation (79.9%). The majority (61%) of the Hispanic parents in this study was classified as protective parents, meaning that they scored high on warmth and demandingness, and low on autonomy granting. The other parenting styles included 31% authoritative, 6% affiliative, 1% permissive, 1% neglectful and 0% for authoritarian.

Varela and Vernberg (2004) compared the parenting practices of Mexican parents living in Mexico City with those of Mexican-Americans, Mexican Immigrants and non-Hispanic White American parents. They found that non-Hispanic White American parents used a less authoritarian parenting style than Mexican-Americans. There was no difference in authoritarian parenting style between Mexicans living in Mexico City and non-Hispanic White parents in the U.S. These results suggest that minority status, including SES, might have as much of an impact as culture in the parenting practices of minority groups in the U.S.

Cultural constructs might have an impact on how Hispanic parents caring for children with disabilities respond to their children's challenges. The cultural constructs of *familism* and *allocentrism* might promote the tendency of Hispanic parents to assist children to problem solve to prevent the child from experiencing upsets. The tendency to overprotect children might slow the acquisition of functional skills and independence. A study conducted by Gannotti and Handwerker (2002) examined the validity of the Spanish translation of the Pediatric Evaluation of Disability Inventory (PEDI) for children living in Puerto Rico. They concluded that cultural variations could lead to inaccurate evaluation of the child's functional status and the level of independence.

Very few studies have examined the relationship between these cultural constructs and the coping strategies used by Hispanic mothers caring for CSHCN in the U.S. Johns et al**.** (2009) examined the coping strategies of Latina and European-American mothers of children with cancer. The sample consisted of three Hispanic mothers and three European American mothers; the country of origin for the Hispanic mothers was not reported. The results of this qualitative study show some important differences in these mothers' coping strategies with their caregiving challenges. Latina mothers in this study stated that gathering information from other parents in similar situations was very helpful. They also stated that interactions with other Latina mothers experiencing similar challenges were very beneficial. Another important difference indicated by the Latina mothers was the tendency to agree and conform to the medical team goals without expressing doubts or asking questions. The authors link these differences to the cultural construct of *simpatia*, i.e. the need to have smooth and agreeable social interactions.

Cultural constructs could have an impact on how Hispanic parents use health care services and their perceived needs and expectations. A study conducted by Gannotti, Kaplan, Handwerker, and Groce (2004) examined the perceived needs and expectations of Hispanic and Euro-American parents of CSHCN. In this study, Euro-American parents expressed a higher emphasis on services, such as respite, daycare, and home health assistance, than Hispanic parents. Hispanics were reluctant to leave their child under the care of somebody else and avoided direct confrontations with members of the health care team.

The cultural constructs of *familism* and *allocentrism* might explain why these parents show less interest in services such as daycare and respite care. They might feel that it is their sole responsibility to care for their child. The tendency to avoid confrontations with members of the health care team might also come from the value of *simpatia*. This cultural construct promotes a more indirect and less confrontational communication style that is common of collective societies such as the Hispanic culture. This communication style might not help these parents become effective advocates for their CSHCN.

Family Context: Social Support

Parents caring for CSHCN report that the majority of their support comes from family members such as spouses, parents, siblings, and friends (Pfeifer, 2014). As the child gets older, the need for social support for the family increases. Parents report the need for accurate information about the child's disability and diagnosis as well as the availability of services as a priority. Support and guidance are important when the child has to transition to a different level of care or educational institution. They might also need psychosocial interventions to help better adapt and cope with the child's disability or diagnoses. Parents caring for children with a low functioning status may require help with daily activities such as the use of equipment to facilitate transfer activities. They also need assistance with vacation, facilitating social interactions, and helping prevent social isolation. Some parents might also need financial support, adapted transportation, and respite services. These interventions can promote optimal family functioning (Tétreault et al., 2014).

Parents caring for CSHCN report dissatisfaction with the knowledge of and communication with HCP regarding resources and services available in the community. Lack of coordination of services forces these parents to become the liaison between all service providers and to act as case managers for the child's health care (Wood, 2009).

Farmer et al. (2004) conducted a study to investigate the type and frequency of unmet needs experienced by parents caring for CSHCN; another purpose of this study was to identify risk factors that contribute to unmet needs. Primary care physicians referred parents of 175 CSHCN. Of these, parents of 149 children met the criteria for this study, 37 declined to participate and 29 did not complete the research measures. The final sample consisted of 83 children with an average age of 7.1 years (SD= 5). The majority of the children were White (72%), followed by African-American (13%), Hispanic (4%), Native American (4%), and others (7%). This study was conducted in the central Midwest of U.S. The majority of the parents were of low SES and 52% had a yearly income of less than $20,000. All the children in this study had insurance coverage; 66% had Medicaid (managed care or fee for service) and 34% had commercial insurance.

The researchers examined the family needs, health care service needs, child functional status, social support, and perceived burden. The majority (93%) of the mothers reported one or more unmet needs, with the need for information about services and ways to promote their child's health as the most common. More than half reported a need for more caregiver support, community services, help with family relationships and financial costs. These mothers also reported dissatisfaction with mental health care services and care coordination services. A higher number of unmet needs were associated with lower SES, lower child functioning status, lower perception of social support, and greater perception of burden (Farmer, 2004). This sample was not representative of the entire U.S.; it was only 4% Hispanic. Nationally, Hispanics represent 17% of the total U.S. population (Bureau, 2015). Increased perception of parents' unmet needs and dissatisfaction with services should prompt professionals to increase efforts to assess these needs and help parents obtain appropriate services and support.

Hummelinck and Pollock (2006) conducted a qualitative study to examine the information needs of parents caring for CSHCN, the parents' perceptions regarding the information received by the HCP involved in their child's care, and changes in their information needs over time. They conducted semi-structured interviews with 20 sets of parents of 21 CSHCN; one set of parents had twins. The children's ages ranged from newborn to 16 years. The chronic conditions included asthma, cystic fibrosis, diabetes, epilepsy, severe eczema, leukemia, and other cancers. All children required one or more medications daily and lived with their parents. The information needs changed over time; initially, parents wanted to know about medical diagnosis, prognosis, and treatment options but that gradually shifted to issues such as information about daily management and adjustment to the future. Parents stated that at the time of diagnosis disclosure that the excessive amount of information could be overwhelming and the use of medical jargon made it difficult for them to process and understand the information. The parents stated that receiving appropriate amounts of information allowed them to feel involved in their child's care, understand the care received, cope better with their child's condition, and gain a sense of control. In order to provide better information to parents caring for CSHCN, professionals must improve their communications skills and awareness of the parents' needs and must also remember that these information needs are highly individual.

Another study that explored the relevance of information given during diagnosis disclosure was conducted by Klein et al. (2011). The study participants included 12 HCP representing the complete range of a multidisciplinary assessment team and nine couples whose children were assessed by the diagnostic team. The children's ages ranged from three years three months to five years five months. First, the HCP answered an open-ended written survey regarding the information provided to the parents during the assessment process. Then the parents were interviewed to find out what information given by the HCP they considered to be relevant. The HCP felt that they provided extensive information about diagnostic findings, interventions, and community resources options. The parents agreed that they received extensive information regarding their child's diagnosis but stated that the diagnostic assessment process was emotional, overwhelming, and anxiety provoking. Readiness to receive the information during the diagnostic process varied among the parents. These parents expressed the need to receive information about services, community programs, and intervention strategies. Most of the parents agreed that receiving proper information would help them cope with their child's diagnosis. Parents also expressed the need to hear their child's strengths and potential as well as what to expect in the future. The racial/ethnic composition and SES of the sample was not reported.

A study that explored the concept of having a designated member of the health care team as the key worker, gate keeper or coordinator of services was conducted by Sloper, Greco, Beecham and Webb (2006). These researchers wanted to identify which services provided by the key worker were more effective in improving the child's and family's outcomes. They sent questionnaires to 644 parents receiving services from key workers, only 205 (31.8%) questionnaires were returned. They recorded demographic information of the participating parents and how much interaction they had with key worker over a period of three months. The parents answered questionnaires that measured disability, impact of key worker on quality of life, processes of care, parental unmet needs, child unmet needs, and satisfaction with service. The mean age of the children was 8.1 years (SD= 4.72). This study was conducted in the United Kingdom and the racial/ethnic background of participants was 94.7% White, 3.7% South Asian, and 1.1% mixed race. The parents reported that the key worker facilitated communication among all professionals providing care for the child and ensured that necessary services were made available to them. Parents in this study reported lower levels of unmet needs and higher levels of satisfaction with services than those parents not receiving services from key workers. Most parents reported that having a key worker improved their access to services and their quality of life. They stated that the key worker provided information about the child's diagnosis and what services were necessary for the child. Furthermore, the key workers provided emotional support and advice, identified needs, coordinated services, and provided support in crisis. A limitation of this study was the low response rate (31.8%); perhaps parents overwhelmed with their burden could not find the time to answer the questionnaire.

Parents caring for CSHCN receive social support primarily from family members and friends, especially when the child is still young. As the child gets older, it is more difficult for the parents to find support from family and friends. Parents caring for children with more severe disabilities have more difficulties finding appropriate babysitting or respite care. Dissatisfaction with social support is associated with higher level of parent stress and decreases in well-being (Skok, Harvey, & Reddihough, 2006).

In the current health care environment, parents are expected to assume more responsibility in the care of their CSHCN and carry on tasks traditionally performed by HCP (Kirk, & Glendinning, 2004). Many parents of CSHCN, especially those with significant movement and cognitive disabilities, experience isolation and disruption in family life. Additional support would help improve the well-being of the entire family. This support could include assistance with care at home or at a designated site to give an opportunity for the family members to engage in activities conducive to a healthier family life (Cowen, 2002). Parents of CSHCN are responsible for the complex needs of their children and the challenge to meet those needs adds to the burden and stress already experienced by them. Professionals working with these parents must intervene to help lower their parenting stress.

Brown et al. (2011) conducted interviews and focus groups with parents of 23 children to explore their experience with full time daycare and residential care. The parents' race/ethnicity was not reported. The average child age was 12.7 years with a range of six to 19 years. The majority of the children were diagnosed with autism spectrum disorder (16), two with Asperger syndrome, three with Down syndrome, and three with psychiatric disorders including obsessive compulsive behavior. The majority of the children had moderate to severe speech impairment and challenging behaviors. Nineteen parents agreed to participate, 12 mothers and 7 fathers, with an age range of 30-50 years.

The parents noticed positive changes in the child's behavior and better communication after taking part of the full-time daycare and residential care. The researchers attributed these positive changes to an improvement in the quality of the time they spent together, with less anxiety, more relaxation, and more enjoyment (Brown, 2011). They also noticed improvement in family life and family interactions, including those with siblings, after their children with challenging behaviors had participated in the full-time daycare and/or residential care services. They experienced fewer restrictions and disruptions that affected their day-to-day family functioning and social interactions. In addition, they were able to sleep better at night, their work life became more stable, and they were able to spend more time with the siblings in activities at home or outside of the house (Brown, 2011). This study further illustrates the impact on family functioning for those parents caring for disabled children at home. These parents require significant support, perhaps in the form of respite care, to allow them to participate in their communities and to experience a more natural family environment.

The need for respite care evolves as the child develops and the demands for care change. Infants are expected to be dependent on their parents to have their needs met. However, as a child grows and is unable to reach the necessary milestones to become independent, the parent's burden of care increases proportionally. MacDonald and Callery (2004) conducted in-depth interviews with 19 mothers and seven fathers of children who required complex care residing in Northwest England. Children's ages ranged between eight and 16 years. They also interviewed 13 nurses and four social workers involved in respite care.

Parents described three different kinds of respite. The first type of respite care included the short breaks provided by extended family and friends; this type of respite consisted mainly of babysitting, looking after the child while the parents are out and meeting basic needs such as changing diaper and feeding. As the child grows older and bigger in size and perhaps their health care needs become more complex, the extended family members and friends are unable or reluctant to provide needed respite care. The second type of respite described by these parents consisted of periods of three to four hours provided by a respite agency (MacDonald, 2004). This type of respite would allow them to engage in recreational activities, shopping, or spending time with the siblings. The third type of respite was when the child was taken to a respite facility to stay overnight or up to a week to allow the parents to rest and replenish their energy in order to continue caring for their child (MacDonald, 2004). All the parents describe this type of respite as very important because it allowed them to spend time with the other children in the family, nurture the relationship with their partners, go away on vacation, and feel like a normal family.

As the child's care needs become more complex, it might be necessary for parents to receive respite care from trained professionals at home or at a designated facility (MacDonald, 2007). Understanding that the needs for respite care change as the child develops may help HCP assist these parents to anticipate the need for respite care during the child's transition from infancy to adulthood. The respite needs of parents caring for children who are technology dependent might be even more challenging and complex (MacDonald, 2004).

Kirk and Glendenning (2004) conducted in-depth interviews with 24 parents of technology-dependent children. The purpose of this study was to explore the experience of the parents caring for a technology-dependent child and their perception on how services could improve to better support their families. The parents were recruited from specialty hospitals in the north of England and children ages ranged from infant up to 18 years. These parents were expected to develop technical skills to carry on medical treatments at home. Parents caring for children requiring treatments such as suctioning airways, tube feedings, and adjusting medication dosages experienced increased levels of burden. Doing these procedures had a negative emotional dimension since some were painful or uncomfortable. Some parents believed that performing procedures traditionally done by HCP compromised their role as parents. They also stated that their sleep was often interrupted and their social activities were restricted. Additionally, parents reported loss of privacy when HCP came to the house to perform specialized procedures. Finally, parents of children with complex medical needs often express a lack of coordination and experience great challenges in communicating with multiple agencies and professionals. Consequently, having a designated key health care worker coordinate the delivery of services might help alleviate some of the burden they feel.

The constant demands of caring for a child that requires assistance with daily activities or that requires constant supervision will make it difficult for these parents to cultivate the relationships with their partners. Because of the increased demand of caregiving for a child with a disability, siblings in the family might not receive sufficient attention. These parents might also have difficulties leaving the house to participate in the workforce (Kirk, & Glendinning, 2004).

Reid et al. (2011) interviewed nine parents of adolescents or young adults (ages 17 to 22 years) diagnosed with cerebral palsy since birth. One of the objectives of this study was to explore interventions that could improve the care of children with cerebral palsy and better support the parents. Parents reported the need for support in helping them manage the increased demands of parenting and providing care for a child with cerebral palsy. They expressed the importance of taking time to strengthen their relationships with their spouses and to engage in self-care behaviors to stay healthy. They also mentioned the need to provide support for siblings, since they often do not receive individual attention and might miss out on certain experiences due to the adjustments made by the entire family to care for the child with cerebral palsy such as vacation time. They also identified the need for accurate information about diagnosis and functional deficits to better assess services and function as a better advocate for their children.

Transition periods become a significant challenge for these parents, i.e. when children transition from one level of care to another or from one educational institution to another. Help in facilitating communication among professionals and institutions would expedite the transition. Better communication among HCP would improve the quality of services and parents would not have to be solely responsible for encouraging the communication and exchange of information (Reid et al., 2011).

The day-to-day experience of these parents, such as shopping, getting ready in the morning, and taking care of the home, can also be affected. Simple activities might require an enormous effort by the entire family. Outings to a restaurant, grocery store, and/or amusement park might require extensive planning and strategy. Parents find themselves developing very specific routines to meet the needs of the CSHCN. The entire family could be engaged in following these routines, overriding the needs of the other members of the family. Often parents find that they do not spend any time with each other because all their time is invested in meeting the needs of the CSHCN and the other members of the family (McCann, 2012). Parents caring for children with disabilities report having difficulties carrying on normal family activities such as taking vacations.

Dependent Variables

Parenting Stress

Many factors can contribute to parenting stress of caring for a child with a disability and the parents' ability to cope with the challenges such as SES, family functioning, negative perception of social support, child "functional status" and severity of diagnosis. Early identification of parents at greater risk for high levels of parenting stress would allow HCP to implement measures to minimize the effects of stress (Trute, 2005).

The research literature supports the idea that parents caring for children with disabilities experience higher level of stress. Providing adequate interventions at home to support these parents can decrease their stress levels. Forde et al. (2004) conducted a study exploring how interventions aimed toward supporting parents in their homes can alleviate parenting stress. The sample consisted of 16 parents in Ireland, 15 mothers and one father. The intervention gave practical assistance to these parents to help alleviate burden of care, decrease social isolation, and provide respite. The parents were questioned using semi-structured interviews and quantitative data was collected using the PSI-SF before the interventions were implemented. The interventions were implemented for 12 months, attempting to meet the individual needs of each parent. Parents reported that interventions lowered their stress and improved their quality of life and family life. They also reported a reduction in social isolation. Although the sample in this study is very small, the study provides evidence that interventions geared to meet the individual needs of parents caring for children with disabilities can improve their overall well-being.

The way parents cope with the challenges of caring for a child with disabilities is highly individual. Many factors contribute to higher levels of stress and difficulties in coping. Severity of diagnosis combined with inadequate family support has a negative impact on the ability of parents to cope successfully. Glenn, Cunninghamm, Poole, Reeves, and Weindling (2009) conducted a study investigating the factors that contribute to stress among British mothers caring for children with cerebral palsy. The sample consisted of 80 children and their mothers, recruited from 11 child developmental centers in Northwest England. The children's mean age was 19.6 months (SD= 8.9). The mothers' mean age was 30.9 years (SD= 2). Approximately 93% of the children were Caucasian. The mothers answered a self-report questionnaire and a clinician visited the home to assess the child's functional status. The questionnaires measured family stress and needs, available support, and coping strategies. The family's ability to cope with stress was lower with higher severity of disability, lower family cohesion, and more child behavioral problems.

Cavallo, Feldman, Swaine, and Meshefedjaian (2009) conducted a study exploring the coping strategies of primarily non-Hispanic parents of children with physical disabilities, especially the relationship between the child's functional status and the parents’ coping strategies. The authors also wanted to describe how the mother’s education level, child’s age, and the family structure influenced the parent’s coping strategies. The sample consisted of 150 parents of children with physical disabilities referred to occupational/physical therapy from two pediatric Canadian hospitals. The children’s ages ranged from 18 to 116.7 months. Parental coping was measured using the Coping Health Inventory for Parents (CHIP). The Functional Independence Measure for Children (WeeFIM) was used to assess the children’s functional status. The participants also filled out a study questionnaire addressing socio-demographic information. Most parents thought that maintaining social support was a useful coping strategy. Parents of children with mild cognitive dysfunction had higher CHIP scores compared with parents of children with moderate to severe cognitive deficit indicating more effective coping skills. Also, parents of children younger than 24 months had higher scores on the CHIP subscale “understanding the medical situation”. Couples had higher scores on the CHIP subscale in relation to social support. The parents of children with greater physical dysfunction were more inclined to use the coping strategy of seeking a better understanding of the child’s medical condition through communication with HCP.

The development of effective coping skills can decrease stress on parents caring for a CSHCN. Churchill, Villarreal, Monaghan, Sharp, and Keickhefer (2010) conducted a study to describe and quantify coping skills and signs of depression in parents caring for CSHCN. The sample consisted of 129 parents with children ages 2 to 11 years participating in an educational class designed to teach them how to manage the children’s chronic condition. The majority of the parents were female (85%) and White (88%) with an average age 37 years. The researchers measured the parents' depressive symptoms with the CES-D and their coping skills with the Family Crisis Oriented Personal Evaluation Scales (F-COPES). They also assessed each child's condition, the parents' health care utilization pattern, and demographic characteristics. Compared with parents from the NS-CSHCN, this study's participants reported depressive symptoms more often, with 54% of parents having reported them. The number of depressive symptoms was associated with the severity of the child's condition. Higher coping scores were associated with lower depressive symptoms. Unemployed parents and single parents exhibited more symptoms of depression. The results of this study do not establish a causal relationship between the educational intervention and the parents coping strategies. Nevertheless, educational interventions designed to increase parental skills could be potentially beneficial and need to be investigated further.

Caring for a child with a disability can cause significant emotional stress affecting the entire family, including parents and siblings. It is important to understand caregiver burden and parenting stress because they can contribute to poor outcomes for the parent and for the child. Many factors can contribute to parenting stress including the child functional status, severity of the disability, family characteristics, such as SES, family functioning, and acculturation. The next section discusses the impact of the child characteristics (functional status and age), family context (family functioning, acculturation, and SES), and parenting stress on the physical and mental health of parents caring for children with disabilities.

Physical and Mental Health of Parents

Caring for a child with special needs has a negative impact on the physical and mental health of parents. Raina et al. (2005) examined the health and well-being of primarily non-Hispanic parents caring for CSHCN and found that the parents' physical and psychological health was negatively affected. The sample in this study consisted of 468 children with cerebral palsy and their parents. The mean age for children was 10.6 years (SD= 2.69) and for parents was 40.3 years (SD= 6.72). Ninety-five percent of the parents participating in this study were female, and they stated that their health was directly influenced by the children's behavior and caregiving demands. A high level of children's behavioral problems was associated with lower psychological (β= - .22) and physical health (β= -.18) among the parents. The parents' perceptions of lower caregiving demands were associated with better physical (β= .23) and psychological (β= .12) health. Similarly, higher family functioning was associated with better physical (β= .33) and psychological (β= .33) health of the parents.

Brehaut et al. (2004) compared the physical and psychological health of parents of children with cerebral palsy with parents in the general population. The sample in this study consisted of 2414 primary care givers of children with cerebral palsy, predominantly female (94.4%). The sample's racial or ethnic breakdown was not reported. This sample was recruited using stratified random sampling of children attending rehabilitation centers in Ontario, Canada. The data from this sample were compared with data from nationally representative samples obtained through the National Population Health Survey (n= 2441) and the National Longitudinal Study of Children and

Youth (n= 5549). The authors described the children according to ages and disability levels but did not provide any specific age ranges. They found that these parents had a higher incidence of emotional distress and physical problems, including back problems, migraine headaches, stomach/intestinal ulcers, asthma, arthritis, and musculoskeletal pain. They also had lower incomes and were less likely to work for pay than the rest of the population, indicating a potential financial burden. The interaction of the child's disability and the health outcomes of the parents must be better understood by the HCP working with these parents. This increase in awareness will help professionals provide more comprehensive and effective interventions to improve the health outcomes of the parents.

Most of the direct care of CSHCN is provided by mothers. Mothers caring for children with movement disorders often perform tasks such as transfers and handling activities multiple times each day, increasing the chances of sustaining musculoskeletal injuries, and consequently have a higher incidence of musculoskeletal problems (Tong et al., 2003). This problem becomes more relevant as the children grow and the parents age. Emotional distress has also been identified as a risk factor for musculoskeletal injuries such as lower back pain. Tong et al, (2002) conducted a study exploring the physical functioning of primarily non-Hispanic mothers of children with physical disabilities. Using a cross-sectional survey, they compared 90 mothers of children with a physical disability recruited from a pediatric rehabilitation center and 113 mothers of children with non-disabling conditions recruited from a pediatric endocrine clinic caring for children with diabetes, with mean ages of 37.4 years (SD= 7.6) and 41 years (SD=

6.16) respectively. The majority of the parents were mothers, 96% in the group caring for children with physical disabilities and 100% in the group caring for children with diabetes. The mean age of the children with physical disabilities was 114 months (S= 57.5); for the children with diabetes the mean age was 126.9 months (SD= 45.3). Parents of children with more severe physical disabilities showed significantly lower physical functioning and higher levels of pain. Lower scores on the Center for Epidemiologic Studies Depression Scale were related to parents' better physical functioning status.

A qualitative study conducted by Bourke-Taylor, Howie, and Law (2010) explored the impact of caring for school-aged children with cerebral palsy and autism on mothers. The children's ages ranged between eight and 14 years. One major source of stress reported by these mothers was the need to learn about the child's diagnosis and how the extent of the disability affects the proper care for their child. The mothers identified numerous additional responsibilities in caring for their children's multiple needs, including providing direct care, coordinating multiple medical appointments and services, as well as maintaining the household. In addition to these responsibilities, these mothers also had to deal with issues related to their partners, the child's siblings, changes in family functioning, and the extended family. All these overwhelming demands added to their emotional stress.

A study conducted by Eddy and Engel (2008) explored how specific diagnoses influence the functioning of parents caring for children with physical disabilities. Their sample consisted of 205 primarily non-Hispanic parents of children ages eight to 20 years of age with diagnoses including spinal cord injury, amputation, congenital limb deficiency, cerebral palsy, spina bifida, or neuromuscular disease. The majority of the parents were mothers, only 12% were fathers, with a mean age of 43 years. The participants completed a survey and a telephone interview about the child's health, functional status, quality of life, and use of health care services as well as demographic and descriptive data. The researchers also found that neuromuscular disorders tend to worsen over time, causing parents' anxiety to increase. Family outcomes were measured using the Child Health Questionnaire Parent Form 28. Parents of children with significant physical limitations such as congenital limb deficiency and amputation reported more interruption in family activities. Parents of children with conditions such as spina bifida, cerebral palsy, and other neuromuscular diseases had higher levels of anxiety.

Spratt, Saylor, and Macias (2007) conducted a study assessing parenting stress among four different groups of parents caring for children ages four through 12 years with different diagnoses and disabilities. Group 1 or Developmental-Behavioral Clinic (DBC) sample consisted of 46 boys and 11 girls; 60% White, 39% Black, and only 1% Hispanic. Their ages ranged from four years two months to 12 years six months with a mean age of eight years. These children exhibited behavioral disorders, learning disabilities, developmental delays, and motor problems as well as sensory and speech impairments. The researchers theorized that the parents caring for these children would experience greater levels of stress. Group 2 consisted of 70 children with an average age of 8.5 years (range eight to nine years), diagnosed with intra-ventricular hemorrhages (IVH); 70% had birth-weights under 1,500 grams. The majority of the children (64%)

were White, 33% were Black, and 3% were Hispanic. Group 3 consisted of 37 boys and 17 girls had an average age of 9.2 years (SD: 1.76); 33% were diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), 39% with Learning Disabilities (LD), and the remaining 28% had both ADHD and LD. The ethnic breakdown of this group was not reported. Group 4 consisted of 45 children four to 12 years old, diagnosed with Neural Tube Defects (NTD). In this group, 43% used a wheelchair for mobility at least part-time, 80% had a shunt at birth to treat hydrocephalus, and 48% were incontinent. The majority of these children (71%) were White, 27% Black, and 2% Hispanic.

Parental stress was measured using the PSI-SF, perceived resources was measured using the Family Resources Scale (FRS), and perceived social support was measured using the Family Support Scale (FSS). The children's development was measured using the Bayley Scales of Infant Development, the Stanford-Binet Intelligence Scale for Children, the Wechsler Intelligence Scale for Children-Third Edition or the Kaufman Brief Intelligence Test (S. Bain, & Jaspers, K. , 2010). The children's behavior was measured using Achenbach's Child Behavior Checklist (CBCL).

The DBC group showed a significant correlation between the children's externalizing behavior and parental stress ($r= .49$, $p< .001$). The IVH group showed a significant correlation of greater PSI-SF with lower FRS and higher children's externalizing behaviors. In the ADHD/LD group, the child's externalizing behavior correlated to PSI-SF. In the NTD group, greater PSI-SF was correlated with lower FSS, lower FRS, and higher children's externalizing behavior. In all four groups, a combination of children's greater externalizing behaviors as well as perception of inadequate resources and support accounted for higher parental stress. The percentage of Hispanic participants in this sample was very small. A more ethnically diverse sample would allow analyzing racial/ethnic differences.

Witt, Gottlieb, Hampton, and Litzelman (2009) conducted a study using data from the Medical Expenditure Panel Survey to explore the relationship of children's activity limitations with their parents' physical and mental health and the number of lost workdays. In this national survey of 18,827 parents caring for children ages newborn to 17 years, 15.6% of parents reported having a child with a functional limitation. Sixty percent of the parents were non-Hispanic White, 11.9% non-Hispanic Black, 16.1% Hispanic, and 5.9% were classified as "Other." The researchers defined children as having "activity limitation" if they were not able to do what most children their age could do. Not restricted to a specific diagnosis, this classification relates more to the child's independence in activities of daily living. They found that parents of children with activity limitations were more likely to report fair to poor physical and mental health than parents of children without activity limitations, which is more than twice the rate. Among parents with children with no limitations, only 7% reported fair/poor physical health, and 3.8% reported fair/poor mental health. Among parents with children with ongoing limitations, 17.1% reported fair/poor physical health and 11.8% reported fair/poor mental health. The percentage of parents who missed more than one day of work was almost twice as high (20.4%) for parents caring for children with ongoing activity limitations than those (10.8%) caring for children without limitations.

Blacher and McIntyre (2006) found an association between the presence of maladaptive behaviors and maternal well-being. The sample consisted of 282 parents of young adults, 132 Hispanic and 150 Anglo. The young adults' average age for the Hispanic sample was 20.4 years (SD= 2.3) and for the Anglo sample was 20.2 years (SD= 2.8). In the Hispanic sample, 37.9% of the children had mixed or undifferentiated intellectual disabilities, 26.5% had cerebral palsy, 27.3% had Down syndrome, and 8.3% had autism. In the Anglo sample, 42% had mixed or undifferentiated intellectual disabilities, 34.7% had cerebral palsy, 15.3% had Down syndrome, and 8% had autism. Mothers' ages ranged from 31 to 70 years, with a mean age of 49 (SD= 6.95). Home interviews were conducted in the preferred language of the parent. Besides demographic information, the researchers used the Vineland Adaptive Behavior Scales (VABS) to measure children's behavior, daily living skills, and communication. Maladaptive behaviors were measured using the Scales of Independent Behavior (SIB) and the Reiss Screen for Maladaptive Behavior. Family well-being was measured using the Family Impact Questionnaire (FIQ), the CES-D, and the Philadelphia Geriatric Center Morale Scale. They found that Down syndrome children showed the lowest level of maladaptive behaviors and children with autism displayed the highest. The mothers of children with autism reported more stress and depression compared to mothers of children with Down syndrome, who reported higher levels of emotional well-being. Parents caring for children with maladaptive behaviors tended to experience higher levels of stress and poorer outcomes in their emotional health compared with parents of children with other problems. Services and interventions designed to address these challenging behaviors will help safeguard the well-being of the entire family.

Children's disruptive or maladaptive behaviors are cited by many studies as a source of stress and a contributor to poor parental emotional health. Often, the children's maladaptive behaviors accompany neuromuscular disabilities, such as impaired ambulation, communication, and information processing. Caring for a child with neuromuscular deficits and maladaptive behaviors can be even more challenging (McGilloway et al., 2014)

A study conducted by Lach et al. (2005; 2009) compared four groups of parents. Data for this study were collected in the National Longitudinal Survey of Children and Youth in Canada (1994). The children ages ranged between four and 11 years. The majority (92.8%) of the primarily non-Hispanic parents participating in this study were female. Group 1 had children with both neurodevelopmental disorders and behavioral problems (n= 414); Group 2 had children with neurodevelopmental disorders only (n= 750); Group 3 had behavioral problems only (n= 1067); and in Group 4, children had either neurodevelopmental disorders or behavioral problems (n= 7236). The Health Utility Index was used to measure the children's health and the children's behavior was measured using the CBCL. The parents' health was measured by identifying the presence of a chronic condition, activity limitations, and self-rating. The parents' psychological health was measured using the CES-D and psychosocial adjustment was measured using the Family Assessment Device (FDA). The parents caring for children with both neurodevelopmental disorders and behavioral problems reported higher depression scores, more activity limitations, and more chronic conditions than all the other groups. Of the parents caring for children with a neurodevelopmental disorder and behavior problems, 54% rated their general health status as excellent or very good compared to 76% of parents caring for children without any problems. The other two groups were very similar; 68% of the parents caring for children with only neurodevelopmental disorders and 68% of the parents caring for a child with only behavior problems reported general health status as excellent or very good. Fifty-nine percent of the parents of children with both neurodevelopmental and behavior problems had at least one chronic condition; 21.3% reported having limitations in at least one domain of activity and experienced more depression. Among the parents of children without neurodevelopmental or behavior problems, 42% reported at least one chronic condition, 9% reported having limitations in at least one domain of activity and lower depression scores.

Macias, Saylor, Haire, and Bell (2007) examined differences in stresses experienced by primarily non-Hispanic mothers and fathers of children with neural tube defects (NTD). The sample consisted of 71 parents that included a mother and a father involved in the care of the child with NTD. The mean ages for fathers and mothers were 40 and 39, respectively. The ethnicities of children were 72% White, 27% Black, and 1% "Other". The majority (80%) of the children had a shunt and 54% had one or more shunt revisions. Parental stress was measured with the PSI-SF (Abidin, 1995). The Family Resource Scale (Dunst, 1984) was used to measure the parents' perceptions of the adequacy of available resources. The Family Support Scale (Dunst, 1984) was used to measure the parents' perception of social support. The Kaufman Brief Intelligence Test (K-BIT) (Bain & Jaspers, 2010) was used to measure cognitive development of the children. The CBCL (Achenback, 2000) was used to identify maladaptive behaviors. The Social Skills Rating System (Crosby, 2011) measured positive social skills and behavior problems. Variables related to the NTD were measured using the Medical Severity Index (MSI).

Fathers of children with more severe medical problems and mothers of older children showed higher level of stress. Both mothers and fathers of children with externalizing behaviors and poor social skills reported higher levels of stress. This study only included families with two involved parents. The emotional distress of single parents raising children with NTD or any other condition that results in physical and/or cognitive impairment might be very different (Macias, Saylor, Haire, & Bell, 2007).

The impact of pediatric traumatic brain injury on family functioning and parents' health is not well understood. Youngblut and Brooten (2008) conducted a study on the impact of pediatric traumatic brain injury on family functioning, mental health of the mother, and the relationship between the mother and the child 3 months after head injury. The sample consisted of 80 mothers of preschool children hospitalized with traumatic brain injury. Children with pre-existing chronic conditions or significant cognitive deficits were excluded from the study. Children with traumatic brain injury secondary to child abuse were also excluded from the study. Half (50%) of mothers were White, 30% were Black, 19% were Hispanic, and 1% Asian. The mothers' baseline mental health was measured at 24 to 48 hours after the admission of the child using the psychological well-being and psychological distress dimensions of the Mental Health Inventory (MHI). The relationship between the mother and the child was assessed using the three subscales of the PSI-SF (distress in parenting, dysfunction in the relationship and parents' perceptions of their child). Family functioning at three months post-injury was measured using the two subscales of the Family Adaptability and Cohesion Evaluation Scale (FACES II)**:** family cohesion and family adaptability (Olson, 2011). Social support was measured using the MSPSS (Zimet, 1988). The Parental Stressors Scale (PSS): Pediatric Intensive Care Unit (PICU) was used to assess the stress experienced by the mother during the child's hospitalization. The mothers' perception of the child's injury severity was recorded, and the objective severity of the child's injury was characterized with the Injury Severity Scale (ISS) as well as whether the child was admitted to a general care unit or to PICU.

The results of this study showed that the mothers that experienced greater psychological distress at three months post-discharge had not only experienced greater distress during the child's hospitalization but their children had also suffered more severe injuries. Having more children in the household had a negative effect of the mothers' psychological well-being. A dysfunction in mother-child relationship was related to the maternal baseline psychological distress and the perception of inadequate social support (Youngblut & Brooten, 2008).

Aitken et al. (2009) conducted a study describing the burden experienced by primarily non-Hispanic parents of children with traumatic brain injury during the first year after the injury. The initial sample consisted of 330 parents with a child who had been hospitalized with a traumatic brain injury between five and 15 years of age. The measure of caregiver burden was based on the distress experienced in relation to the child's physical and emotional health, behaviors, learning abilities, and attention. The researchers also explored how the child's condition affected the parents' ability to carry on everyday activities and their ability to work. The children's functional status was assessed using the Pediatric Quality of Life Inventory (PedsQL) (McCarthy, 2005). Family functioning was measured using the FAD. Parents were asked to rate their satisfaction with health care and educational services. Injury severity was assessed using the Abbreviated Injury Scale. Parents of children with more severe injuries reported more interruption in their daily activities and more dissatisfaction with health and educational services. Children's lower functional status measured with the PedsQL was related to greater parental distress and missing more workdays. The results of this study suggests that parents caring for children with more severe traumatic brain injury experience more emotional distress and more disruption in daily activities.

Summary

Many studies show that parents of children with disabilities report more health problems than parents caring for children with typical development. The health outcomes of Hispanics parents caring for children with disabilities has not been sufficiently investigated. The mothers usually assume the responsibility of providing direct care for CSHCN. Mothers shoulder multiple responsibilities including direct care, maintaining the home, and coordinating services. There is greater emphasis on the emotional distress caused by the burden of care. The effect on the physical health of parents has not being sufficiently explored. A few studies have investigated the incidence of musculoskeletal injuries due to performing direct care activities such as handling and lifting, primarily on mothers (Tong et al, 2003).

Some studies also found a correlation between the child's behavior and the emotional health of the parents (Spratt, 2007). Many parents experience anxiety about the future of their CSHCN. They feel uncertainty regarding how and by whom their child will be taken care of when they are no longer able to provide for their CSHCN (Dillenburger, 2011). HCP should have a better understanding of the needs of older parents caring for children with disabilities. A better understanding will facilitate the implementation of appropriate interventions to assist these parents in planning for the future.

Parents caring for CSHCN experience reduced employment when compared with parents of children without special health care needs. Parents of CSHCN who are employed often have to reduce their work hours and incur additional costs related to the care of their children. These additional financial difficulties are more evident with parents caring for children with more severe disabilities. Providing adequate insurance coverage and services through a medical home service model tend to reduce the financial difficulties experienced by these parents. Parents of CSHCN will benefit from child care services geared towards the children's needs and better support systems that would allow them to maintain employment (Kuhlthau, 2005; Looman, O'Conner-Von, Ferski, & Hildenbrand, 2009)

The day-to-day activities of these parents are directly affected by the increased number of hours caring for the CSHCN. These parents invest a great deal of time and energy coordinating services for their children. Simple outings can become difficult, especially for parents of children with severe disabilities. Often these children require special transportation, equipment, supplies, and medications to go out of the house. Potential architectural barriers at their destination site also have to be considered. These challenges can contribute to a sense of isolation experienced by some parents (Yantzi, 2006). Parents report that often they cannot find or afford appropriate respite services or that the service lacks the flexibility to meet their needs.

The ability to cope effectively is influenced by the severity of the child's disability, family cohesion, family functioning, social support, and parental education. Socioeconomic indicators such as income and access to health insurance also have an impact on how these parents cope. Parents tend to seek support from their friends and family members. Those who have children with more severe disabilities tend to also seek support from HCP. Some parents use passive behaviors to manage stress, such as watching television. Others use "me time" (time apart from the child) to do things, such as exercise, shop, and meet friends, as a strategy to manage their stress (Abbeduto, 2004).

Parents who find ways to cope effectively exhibit better emotional health with a lower incidence of depression (Churchill, 2010). Very little research has explored those family traits that contribute to family resilience. More research is needed to identify which family traits facilitate better family functioning in order to implement interventions that would enable more effective family coping. There is also a need to explore how the siblings of CSHCN are affected, especially children from racial/ethnic minorities and children from a lower SES. Racial/ethnic minorities are not adequately represented in many studies. Future research should focus on the impact of culture, immigration status, SES, and race and ethnicity factors on parents of CSHCN in order to develop more effective interventions.

CHAPTER III

METHODOLOGY

Research Design and Recruitment

This correlational study explores the effect of the degree of a child's characteristics (functional status and age) and family context (SES, parent acculturation, and social support) on parenting stress and, ultimately, on parent physical and mental health. A convenience sample of 50 Hispanic parents caring for children with disabilities was recruited through a Facebook page dedicated to this study and from agencies in South Florida providing services to children with disabilities and their families. Parent-signed informed consent for participating in this study was obtained in the parents' homes.

Setting

Parents were recruited from agencies in South Florida providing services to families caring for children with disabilities, these included: Parent-to-Parent of Miami; Miami-Dade County Public Schools; Pediatric Pulmonology Group of South Florida; Big Bear Academy, Inc. Prescribed Pediatric Extended Care Center (PPECC) and Pediatric Alternative Treatment, Care, Housing & Evaluation Services (PATCHES) PPECC. Also, an announcement was placed in the FIU announcement system (UNIVMAIL) with links to the Facebook page requesting parent's participation in the study. A description of each of these sources of study participants is included.

Parent to Parent of Miami is a resource center for parents of children with disabilities in Miami-Dade and Monroe counties. The center provides information, educational training, and support to families caring for children with disabilities or special health care needs. The center helps parents better understand their children's disabilities, educational needs, and assists with obtaining appropriate services for their children. Furthermore, it also facilitates more effective communication with school personnel and aids understanding of the Individuals with Disability Education Act. Their Community Parent Resource Center provides training and assistance to the families of over 39,000 children and youths with learning, physical, emotional, intellectual, and/or developmental disabilities and special health care needs in South Florida (http://www.ptopmiami.org).

Miami-Dade County Public Schools (MDCPS) is the fourth largest school district in the United States, comprised of 392 schools, 345,000 students, and over 40,000 employees. Located at the Southern end of the Florida peninsula, the school district stretches over 2,000 square miles of diverse and vibrant communities ranging from rural and suburban to urban cities and municipalities. MDC is a truly global community; district students speak 56 different languages and represent 160 countries.

MDCPS provides services to children with special needs through Homebound/Hospitalized Instructional Programs (HHIP), Community Based Programs (CBP), School Based Programs (SBP), and Alternative Telecommunications Programs (ATC). The HHIP provides certified teachers who can visit medically homebound students at home or in the hospital. Homebound students participate in teleclass from home via telephone, provided by teachers working from teleclass studios at the school. This program is available to any MDCPS student who meets eligibility criteria. In the CBP, students with severe disabilities who are also homebound receive instructional services in their home provided by caring teachers. The SBP provides services to students with severe disabilities who attend schools. The ATC provides services to students assigned there by the MDCPS Division of Alternative Education to participate in teleclass from home via telephone (http://www.dadeschools.net).

Pediatric Pulmonology Group of South Florida evaluates and treats all kinds of respiratory diseases in children, including asthma, chronic lung diseases, cystic fibrosis, pneumonia, and tuberculosis. This organization is strongly committed to a multidisciplinary medical approach to these complex disorders.

The Pediatric Pulmonology Program's Ventilation-Assisted Children Center (VACC) applies a similar multidisciplinary approach to the management of its tracheostomy-dependent, oxygen-dependent, and ventilator-dependent patients. Ventilation-assisted children rely on the developments of biomedical technology to sustain their lives; all have tracheostomies, while some require oxygen and others must be fed by gastrostomy tube.

Big Bear Academy, Inc. PPECC and PATCHES PPECC are alternative facilities that offer services to families of children with special needs. They specialize in the care for children ages 0-21 who need medical attention, therapy, and/or monitoring. Some of the services provided include: nursing, nutritional assessment, physical therapy, occupational therapy, respiratory therapy, speech therapy, special education, and recreation.

Sample

The sample consisted of 50 Hispanic parents of 50 children diagnosed with a disability leading to a low functional status living in South Florida. One parent from each family was used for data collection. The decision of which parent was going to participate was made based on willingness and availability. This convenience sample of 50 does not provide sufficient power to detect a medium effect size ($f^2 = .15$) in each of the three research aims. In order to have a power analysis for hypothesis testing with a significance level of 0.05 and 80% power, a one-tailed test was conducted with a sample of 50 subjects.

Inclusion Criteria

Criteria for children whose parents participated in the study included: 1) individuals age three to 21 years who 2) have a disability resulting in difficulties with mobility, activities of daily living (e.g. eating, dressing, toileting) and participating in age-appropriate activities, and 3) require the use of assistive devices, such as wheelchairs, walkers, canes, and/or external support, such as splints and/or orthotic devices. Criteria for parent included: 1) Hispanic mothers and fathers 18 years of age and older who 2) are able to speak English and/or Spanish and 3) are primarily responsible for the care of the child. “Parents” includes biological and adoptive parents, single and partnered parents, and grandparents. The parent and child must live in the same household.

Exclusion Criteria

Parents were excluded if they: 1) reside with another family member (other than the child with physical disabilities) who needs special care due to a physical or cognitive deficit, and/or 2) have a chronic health condition that could affect their physical and/or mental health that was diagnosed prior to the birth of the child with a physical deficit. Parents of children living full-time in a long-term care facility were also excluded.

Procedures

Subject Recruitment

The procedure to identify potentially eligible parents differed depending on the institution's policies and procedures. All letters, announcements, posters, and flyers were written by the researcher and contained a brief description of the study and contact information.

Upon approval from the FIU Institutional Review Board (IRB), the researcher opened a Facebook page for the study and placed an announcement in the FIU announcement system (UNIVMAIL) to assist with recruitment. The Facebook page and the UNIVMAIL announcement included the researcher's profile and contact information, as well as a description of the study with inclusion and exclusion criteria. There were two Facebook pages, one in English and one in Spanish. Parents were able to leave a message on the Facebook page and start written communications with the researcher.

After the FIU IRB's approval, Parent-to-Parent of Miami placed a brief announcement in their newsletter that was sent to their network of parents requesting participation in the study. The announcement in the newsletter was published for approximately six months. Only one mother responded to this announcement.

The MDCPS Research Review Committee (RRC) granted approval to recruit parents of children with disabilities attending MDCPS. The researcher submitted an Applicant Identification Form, a Research Review Form, a Research Proposal, a copy of the IRB approval letter from FIU, a copy the list of all the instruments, and consent forms used in the study. Once approval was obtained from MDCPS RRC, the researcher contacted the Department of Exceptional Education to identify those schools providing services to children with disabilities. The researcher contacted and visited all the MDCPS sites providing services to children with disabilities. Recruitment flyers were delivered to all of these schools, the school personnel sent the flyers home in the students' backpacks. Hundreds of flyers were sent to these parents. None of the parents responded to the recruitment flyers.

The staff of Pediatric Pulmonology Group of South Florida (PPGSF) identified potentially eligible parents and shared with them the recruitment flyers provided by the researcher. Three parents from PPGSF agreed to participate in the study. Multiple attempts to arrange appointments to conduct interviews were made.

The staff of PATCHES called all eligible parents at their facility to request their participation in the study. Recruitment flyers were also sent home in the children's backpacks. After multiple attempts the researcher was able to complete 10 interviews of parents recruited through PATCHES. Parents had to reschedule appointments multiple times due to time constraints and other numerous challenges.

The staff at Big Bear Academy also identified potentially eligible parents and referred them to the Facebook page dedicated to the study. Through the referral from Big Bear Academy, 13 parents contacted the researcher through the Facebook page. After multiple attempts including many cancellations and rescheduling appointments, 13 interviews were completed. One parent responded to the FIU announcement system (UNIVMAIL) and contacted the researcher through the Facebook page.

All other parents recruited, 22 in total, responded to the Facebook page directly. Most of them posted messages asking questions about the purpose of the study. It required multiple attempts by the researcher to contact these parents in order to arrange a phone conversation or a face-to-face meeting. It was extremely challenging to arrange face-to-face meetings. Most parents stated that it was very difficult to find the time to even have a phone conversation.

Potential participants contacted the researcher via phone, email, or Facebook for an initial communication where the researcher further described the study and addressed any questions or concerns. Upon parent agreement to participate, the researcher scheduled a face-to-face interview at a time and place convenient for the parent. The interviews were conducted in the language chosen by the parents. Parents who agreed to participate were asked to sign a consent form in English or Spanish. During the initial interview the purpose of the study, the duration of their participation, procedures, potential risks, benefits, and alternatives were discussed with the parents. The parents were given sufficient time to consider their participation. They were informed that they had the right to withdraw or opt out of the study at any time.

Collection of Data

Data collection consisted of a combination of questionnaires and demographic data provided by the parents participating in the study. The data collected included demographic information including age, marital status, racial/ethnic identity, educational attainment, occupation, and household income. For foreign-born parents, time in the U.S. and English proficiency were also recorded.

In addition, information about the child's age, gender, diagnosis, functional status, day-to-day health care needs, and level of assistance needed were also recorded. Data were collected on availability of formal and informal support systems. Formal support systems included health care services through governmental agencies and/or health insurance and support groups. Informal support systems included friends, church members, neighbors, and relatives. To help with enrollment, parents who completed the study's questionnaires received a $25 gift certificate.

The consent forms and instruments used were safeguarded by strict procedures to guarantee confidentiality. All data collected including contact information and consent forms were stored in separate locked files in a secure, locked room. In the locked filling cabinet, one drawer contained the completed questionnaires and the other drawer the consent forms. Only the researcher was able to access these documents. Electronic data were kept in a laptop computer exclusively used for this study. A backup copy of all data were saved in a USB drive with a built in AES 256-bit encryption. This USB drive was kept in the researcher's office in a locked drawer. The laptop computer was password protected and transported in a locked computer case. The data were stored at the researcher's office located at Mercy Hospital. All the instruments are available in Spanish and English, and the consent form was translated into Spanish by the researcher, who is bilingual. Furthermore, the researcher, who is fluent in Spanish, was available for any translation needs.

Instruments

The age, gender, and diagnosis of the children were recorded on the demographic form developed for this study based on the information reported by the parents. Each child's functional status was measured with the PEDI-CAT (Haley, 2010). The parents reported SES, including income and educational level, was recorded in the demographic form. The parents' acculturation was measured with the BAS for Hispanics. The parents' perception of social support was measured with MSPSS. The stress in the parent-child relationship was measured with the PSI-SF; parent physical health was measured with the SF-36 form; and parental mental health was measured with the CES-D.

Independent Variables

Child's Functional Status

The children's functional statuses were measured using the PEDI-CAT (Haley, 2010). This test is designed for use with children and youth who have physical and behavioral disabilities from birth through 21 years of age and do not required direct observation. Parents responded to the items during the interview. This test consists of four domains of function: Daily Activities, Mobility, Social/Cognitive Ability, and

Responsibility. This instrument is available in English and Spanish. The Daily Activities domain consists of 68 items in four content areas including: Getting Dressed, Keeping Clean, Home Tasks, and Eating and Mealtime. The Mobility domain consists of 75 items in five content areas including: Basic Movement and Transfers, Standing and Walking, Steps and Inclines, and Running and Playing. This domain also includes 22 items addressing mobility issues of children with mobility devices such as walking aids and wheelchairs. The Social Cognitive domain consists of 60 items in four content areas including: Interaction, Communication, Everyday Cognition, and Self-Management. The Responsibility domain consists of 51 items in four content areas including: Organization and Planning, Taking Care of Daily Needs, Health Management, and Staying Safe. The response scale for the first three domains is a four-point's difficulty scale with responses ranging from 1 "unable" to 4 "easy". The responsibility domain has a five-point scale with responses ranging from 1 "adult caregiver has full responsibility" to 5 "child takes full responsibility without any assistance". This clinical assessment tool was developed from the original PEDI test (Haley, 2010). The years of experience obtained by clinicians as well as their feedback and formal research were fundamental in the development of the PEDI-CAT. The instrument provides normative scores such as a T score and percentile based on the child's chronological age. The mean T score is 50, with T scores between 30 and 70 (two standard deviations) considered within normal limits (Haley, 2010).

Dumas and Fragala-Pinkham (2012) conducted a study comparing the concurrent validity of the PEDI-CAT Mobility domain with the original PEDI Functional Skills

Mobility Scale and evaluated the item specific reliability in both tests. Parents of 35 children with neurodevelopmental disabilities completed the PEDI-CAT and the paper version of the PEDI. They described the strength of association between the two tests as good to excellent (r= .82). The intra-class correlation coefficient ranged from .34 to 1.00 and agreement ranged from 60% to 100%.

Dumas et al. (2012) examined the discriminant validity, test-retest reliability, and administration time of the PEDI-CAT. The sample consisted of 50 parents caring for a child with different types of disabilities and 52 parents of children without disabilities. They also completed a second test a month later with 11 parents of children with disabilities and 14 who have with children without disabilities to assess test-retest reliability. The discriminant validity of the PEDI-CAT is supported by significant differences on the four domains in the expected direction between parents with a child with disabilities and those with a child without disabilities. The mean time to complete the full PEDI-CAT was 12.66 minutes (SD= 4.47).

Child's Age

Demographic information for children whose parents participated in the study – including age, gender, and diagnosis – was collected using a form developed by the researcher for this study. The parents provided the age of the child at their last birthday on the demographic form. The child's use of adaptive equipment and hospitalizations was also recorded using this form.

Parental SES and Demographic Information

Available in Spanish and English, the parent's demographic form allowed the parent to record his or her age, race/ethnicity, SES (including income, occupation, and education level), time since arrival to the U.S., marital status, and the number of people living in the house. SES was measured by asking parents their highest grade and/or degree completed in school and the total combined family income for the household in the last 12 months. Time in the U.S. was defined as the time since arrival to the U.S. independent of their legal migratory status. The age of the parents at the time of arrival to the U.S. was also recorded.

Acculturation

Acculturation was measured using the BAS for Hispanics, available in English and Spanish. This instrument consists of 24 items, 12 for the Hispanic domain (Spanish) and 12 for the non-Hispanic domain (English). These items are divided in three subscales: Language Use Subscale, Linguistic Proficiency Subscale, and the Electronic Media Subscale. All item scores range from one to four. The response categories for items one to six and 19 to 24 (Language Use Subscale and Electronic Media Subscale) are: *almost always* (4), *often* (3), *almost never* (2), and *never* (1). The response categories for items seven through 18 (Linguistic Proficiency Subscale) are: *very well* (4), *well* (3), *poorly* (2), and *very poorly* (1). An average of each domain can be obtained. The administration time of this instrument is approximately 15 minutes. All the subscales show high internal consistency with alphas ranging from .65 to .97. The BAS is correlated with other acculturation scales such as the Short Acculturation Scale for

Hispanics. When compared with the Short Acculturation Scale for Hispanics, it had a correlation coefficient of .85 for the Language Use subscales, .82 for the Linguistic Proficiency subscales, and .67 for the Electronic Proficiency subscales (Marin, 1996). A total score was used in the analyses.

Social Support

Social support was measured using the MSPSS. This self-administered instrument measures the support from family, friends, and a significant others over the two weeks prior. It consists of 12 items rated from 1 = *very strongly disagree* to 7 = *very strongly agree*. The instrument is divided in three subscales: The Significant Other subscale (items 1, 2, 5, and 10), The Family subscale (3, 4, 8, and 11) and The Friends subscale (items 6, 7, 9, and 12). The sum of scores in each subscale is then divided by 4 to obtain a mean score for each subscale. The total scale score is the sum across all 12 items divided by 12. A mean total scale score ranging from 1 to 2.9 could be considered low support; a score from 3 to 5 could be considered moderate support; a score from 5.1 to 7 could be considered high support. Administration time is less than 10 minutes (Zimet, 1988).

The internal consistencies of the subscales and the total scale are very good (Cronbach's alphas= .85 to .91). The scales have demonstrated good test-retest reliability (r= .72 to .85). This scale was used by Skok et al. (2006) in a study of the influence of severity of disability, perceived stress, and perceived social support on the well-being of mothers caring for school age children with cerebral palsy. The results of this study showed a significant relationship between the mothers' well-being and MSPSS (r= .67, p<.001) and perceived stress (r=.59, p<.001). The MSPSS is available in English and Spanish (Solorzano, 1992). A total score was used in the analyses.

Dependent Variables

Parenting Stress

The stress experienced by those in their parenting role was measured using the PSI-SF (Abidin, 1995). This instrument consists of 36 items divided into three subscales: Parental Distress, items 1-12; Parent-Child Dysfunctional Interaction, items 13-24; and Difficult Child, items 25-36. Available in English and Spanish, this self-report instrument uses a five-point Likert scale: *strongly agree* (5), *agree* (4), *not sure* (3), *disagree* (2), and *strongly disagree* (1). The score for each subscale ranges from 12 through 60 and the total score ranges from 36-180; higher scores indicate higher levels of stress. Total scores of 90 or higher are considered clinically relevant. Also, a score of 33 or higher in the subscale Parental Distress and in the Parent Child-Dysfunctional Interaction subscales are also considered clinically relevant. In the Difficult Child subscale, a raw score of 27 or higher is too considered clinically relevant. The administration time of this short version of the instrument takes about ten minutes. The author reports internal consistency reliabilities (alphas) of .80 to .91 and test-retest reliabilities of .68 to .85 (Abidin, 1995).

Majnemer, Shevell, Law, Poulin, and Rosenbaum (2012) conducted a study exploring which factors contribute to the distress experienced by parents of children with cerebral palsy. The sample consisted of 87 school age children with cerebral palsy, with a mean age of 9.3 (SD= 2.1). The parents completed the PSI-SF and demographic, motor, cognitive, behavioral and functional characteristics of the children were also obtained. The instruments used to assess the children included: Gross Motor Function Measure, Leiter IQ, Strengths and Difficulties Questionnaire, and VABS. They found a relationship between the distress experienced by the parents and the child's motor deficits (r=0.30 to 0.48), cognitive abilities (r= - 0.29 to - 0.37), and behavioral difficulties (r= - .42 to -0.55).

Rose et al. (2005) conducted a study exploring the differences in the report of parents of burned children using the English and Spanish version of the PSI-SF. They compared the results of 148 PSI-SF in English and 142 in Spanish. The researchers concluded that the two versions were equivalent, but found differences in how parents from both groups cope and experience stress. They found that the Spanish speaking parents reported more distress.

Parents' Physical Health

The physical health of the parents was measured using the SF-36*,* available in English and Spanish*.* Designed to survey health status and quality of life, the SF-36 contains eight health subscales: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of physical or emotional problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions. The standard form of the instruments asks participants to reply according to how they have felt over the previous week. The items use Likert-type scales, some with five or six points and others with two or three points. The scores were transformed into a scale from zero (more disability) to 100 (less disability). For each domain (physical and mental health composite score) the mean is 50 and the standard deviation is 10 (Ware, 1992).

The SF-36 has been widely used and has had excellent psychometrics properties in previous studies (Gandek et al, 1998). Further psychometric evaluation of the SF-36 has produced two summary scores: The Mental Health Component Score and the Physical Health Component Score. The Cronbach's alphas for the various subscales of the SF-36 range from .67 to .94. Gandek et al. (1998) listed the results of 14 studies, combining the results of these studies showing the median alpha reliability for all scales exceeding 0.80, with the exception of the social functioning scale (0.76). There is considerable evidence for the validity of the SF-36 in a variety of patient populations with conditions such as asthma, cancer, cardiovascular disease, chronic obstructive pulmonary disease, diabetes, gastro-intestinal disease, migraine headache, HIV/aids, kidney disease, multiple sclerosis, musculoskeletal conditions, psychiatric diagnoses, surgical procedures, and trauma (McHorney, 1993; Ware, Kosinski, Keller, 1994). All scales were used for analysis except the General Mental Health Scale. This survey takes about ten minutes to complete.

Parents' Mental Health

The CES-D is available in English and Spanish and has a 20-item, self-report scale designed to measure depressive symptomatology in the general population (Radloff, 1977). Parents were asked to rate how often over the past week they experienced symptoms associated with depression, such as restless sleep, poor appetite, and feeling lonely. The response categories for items 1-3, 5-7, 13-15 are scored as follows: *rarely or none of the time* (less than one day) = 0, *some or little of the time* (1-2 days) = 1, *occasionally or a moderate amount of the time* (3-4 days) = 2, *most or all the time* (5-7 day) = 3. Items four, eight, 12 and 16 are reversed and scored as follows: *most or all of the time* (5-7 day) = 0, *occasionally or a moderate amount of time* (3-4 days) = 1, *some or a little of the time* (1-2 days) = 2, and *rarely or none of the time* (less than 1 day) = 3. The total score ranges from 0-60, where the total higher score indicates the presence of more depression symptomatology.

The CES-D has a criterion score (i.e. 16 or greater) to identify individuals at risk for clinical depression, with good sensitivity and specificity as well as high internal consistency (Lewinsohn, 1997). The CES-D has been used successfully across wide age ranges. It is sensitive to differences between parents caring for a CSHCN and parents caring for children without any special needs (Pinquart, 2003) as well as to changes in caregiver depressive symptoms after intervention (Pinquart, 2006). Although the CES-D has somewhat different factor structures across racial/ethnic groups, it can be used appropriately as one scale with diverse populations (Roth, 2008). The Cronbach’s alphas for parents caring for children with behavioral problems were .89 for mothers and .86 for fathers showing good internal consistency and reliability (Baker, 2005).

Ruiz-Grosso et al. (2012) conducted a study to validate and compare the psychometric properties of the Spanish versions of the CES-D and the Zung Self-Rating

Depression Scale (Zung, 1995). Both instruments were administered to 70 patients diagnosed with major depression and to 63 with other psychiatric disorders without major depression. The Cronbach's alphas for both instruments were 0.93 and 0.89, respectively. The sensitivity of the CES-D was 99.4%, specificity 96.7%, and it correctly classified 93.9%, supporting the Spanish's version's validity in detecting depression.

Data Management

In this study, the "case" is the family and contains parent and child data. Each family was assigned a study-generated ID number. A master logbook was used to keep track of the parents' information and the dates that the parents were contacted. This master logbook was kept in a locked cabinet located in the researcher's office.

Data analysis was conducted using PASW Statistics 18. Initial analyses included frequencies and descriptive statistics to examine ranges and distributions of the variables, identify outliers, and describe the sample. Data analysis for each research aim is described below.

Data Analysis

Research Aims

Aim 1: To explore the relationship of the child's characteristics (functional status and age) and family context (SES, parent acculturation, and social support) related to the parenting stress of Hispanic parents caring for children with disabilities.

Hypothesis 1: Parents caring for children with a low functional status requiring more direct care and assistance during daily activities will experience higher levels of parenting stress. Caring for these children as they get older becomes more challenging contributing to higher levels of parenting stress.

Hypothesis 2: Hispanic parents with low SES, low acculturation and poor perceived social support will experience higher levels of parenting stress.

Aim 2: To explore how the child's characteristics (functional status and age) and parenting stress are related to the physical and mental health of Hispanic parents caring for children with disabilities.

Hypothesis 1: Hispanic parents caring for children with a low functional status, older children and those experiencing higher levels of parenting stress will report poorer physical health.

Hypothesis 2: Hispanic parents caring for children with a low functional status, older children and those experiencing higher levels of parenting stress will report poorer mental health.

Aim 3: To explore how the child's characteristics and parenting stress are related to the physical and mental health of Hispanic parents when their SES, acculturation, and social support are controlled.

Hypothesis 1: Parents caring for older children, children with low functional status, low SES, low acculturation and low perceived social support will report poorer physical health.

Hypothesis 2: Parents caring for older children, children with low functional status, who have a low SES, low acculturation and low perceived social support will report poorer mental health.

To address research aim 1, 2 and 3, correlation analyses were conducted to address each research aim. For research aim 1, hypothesis 1, the parenting stress (PSI-SF), the child's age and the child's functional status (PEDI-CAT) were correlated. This correlation analysis was repeated for all the four individual domains of the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) and for all the subscales of the PSI-SF (Parental Distress, Parent Child Dysfunctional Interaction, Difficult Child) and Total Score. To address research aim 1, hypothesis 2, the parents' stress (PSI- SF), SES (Education and Income), parent acculturation (BAS English and Spanish domains), and perceived social support (MSPSS) were correlated. This correlation analysis was repeated to include all the subscales of the PSI-SF (Parental Distress, Parent Child Dysfunctional Interaction, and Difficult Child) and Total Score.

For research aim 2, hypothesis 1, the parents' physical health (SF=36 Mental Health), the child's age, the child's functional status (PEDI-CAT), and the parenting stress (PSI- SF) were correlated. This correlation analysis was repeated for all the four individual domains of the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) and for the subscales of the PSI-SF (Parental Distress, Parent Child Dysfunctional Interaction, Difficult Child) and Total Score. For research aim 2, hypothesis 2, the parents' mental health (SF-36- Mental Health), the child's age, child's functional status (PEDI-CAT), parenting stress (PSI- SF) were correlated. This correlation analysis was repeated for all the four individual domains of the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) and for all subscales of the PSI-SF subscales (Parental Distress, Parent Child Dysfunctional Interaction, Difficult Child) and Total Score. Parents' depression (CES-D) was also correlated with the child's age, child's functional status (PEDI-CAT), and parenting stress. This correlation analysis was repeated for all the four individual domains of the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) and the PSI-SF subscales (Parental Distress, Parent Child Dysfunctional Interaction, Difficult Child) and Total Score.

For research aim 3, hypothesis 1, the parents' physical health (SF-36), the child's age, the child's functional status (PEDI-CAT), perceived social support (MSPSS), parents' SES, (income and education), parent acculturation (BAS English and Spanish domains), and parenting stress (PSI-SF) were correlated. This correlation analysis was repeated for all the four individual domains of the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) and the PSI-SF subscales (PSI- Parental Distress, Parent Child Dysfunctional Interaction, Difficult Child) and Total Score. For research aim 3, hypothesis 2, the parents' mental health (SF-36), the child's age, child's functional status (PEDI-CAT), perceived social support (MSPSS), parents' SES (income and education), parent acculturation (BAS), and parenting stress (PSI-SF) were correlated. This last correlation was repeated with the same variables with parent depression (CES) replacing mental health (SF-36). These correlations were repeated for all four domains of the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) and all the subscales of the PSI-SF subscales (Parental Distress, Parent Child Dysfunctional Interaction, and Difficult Child) and Total Score.

Hierarchical Multiple Regression

This type of regression allows building several regression models by adding variables that will be added in a fixed order of entry to control the effects of covariates and to test the predictive effects of independent variables. Hierarchical multiple regression provides a way to identify if variables explain a statistically significant amount of variance in the dependent variable (Petrocelli, 2003).

To address research aim 1and hypothesis 1, parenting stress was entered as the dependent variable, the child functional level or score on the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility) were entered as the primary variable. The score for each of the PEDI-CAT domains was tested separately. The child's age was entered in the independent box or control variable. To address research aim 1 and hypothesis 2, parenting stress was entered as the dependent variable and acculturation (BAS Spanish domain) was entered as primary variable. The parents' perceptions of social support (MSPSS), income, and education were entered as control variables.

To address research aim 2 and hypothesis 1, the parents' physical health (SF-36 Physical Health) was entered as the dependent variable. The child's functional status (PEDI-CAT) and age were entered as primary variables and the PSI-Parental Distress subscale was entered as the control variable. This hierarchical multiple regression was repeated with each of the four PEDI-CAT domains. To address research aim 2 and hypothesis 2, the parents' mental health (SF-36 Mental Health) was entered as the dependent variable. The child functional status (PEDI-CAT) and age were entered as primary variables and the PSI- Parental Distress was entered as a control variable. This analysis was repeated using parental depression (CES-) as the dependent variable. These hierarchical multiple regressions were repeated with the scores for each of the four PEDI-CAT domains for each one of the regression analyses.

To address research aim 3 and hypothesis 1, the parents' physical health (SF-36 Physical Health) was entered as the dependent variable. The child's functional status (PEDI-CAT) and age were entered as the primary variables. The parents' acculturation (BAS-Spanish Domain), education level, and income were entered in the independent variable box and PSI- Parental Distress and MSPSS in a different box, as control variables. These regressions were conducted for all four PEDI-CAT domains.

To address research aim 3 and hypothesis 2, the parents' mental health (SF-36 Mental Health) was entered as the dependent variable. The child's functional status (PEDI-CAT) and age were entered as primary variables, and the parent's acculturation (BAS- Spanish Domain) and age were entered as the primary variables. As control variables, the parents' acculturation (BAS-Spanish Domain), education level, and income were entered in the independent box and PSI- Parental Distress and MSPSS were entered in a different box. These regressions were conducted for all four PEDI-CAT domains with CES-D as dependent variable.

Human Subjects Considerations

Participants in the study are Hispanic parents (mothers and fathers) of children with physical disabilities. The Hispanic parents were asked to respond to a set of instruments about themselves and their child. The level of physical and cognitive deficits was obtained through parent report.

The data obtained from the study includes personal health information such as demographic information and child diagnosis. Following strict procedures to guarantee confidentiality will safeguard this information. All data collected, contact information, and consent forms were stored in separate locked files in a secure, locked room. Only the researcher was able to access the data, consent forms, and contact information.

The only foreseeable risk for the subjects is a breach of confidentiality. The researcher treated these parents in the most compassionate, sensitive, and professional manner. The researcher and the dissertation committee chair completed the online CITI basic course for research with human subjects and the Health Information Privacy and Security as required by FIU IRB.

CHAPTER IV

RESULTS

The purpose of this correlational study of Hispanic parents caring for children with disabilities is to investigate the association of the child's functional status and age and parent family context (SES, parent acculturation, and perceived social support) on parenting stress and, ultimately, on the parents' physical and mental health. Descriptive statistics were used to determine characteristics of study parents and their children; correlation analysis and hierarchical multiple regression analysis were used to address each research aim.

Sample

The sample consisted of 50 Hispanic parents each caring for a child with a disability. The sample included 45 biological mothers, four biological fathers, and one grandmother. The parents' ages ranged from 21 to 62 years of age ($\bar{x}$= 40.5, SD= 10.9), the largest group having 18 participants, or 36% of the total sample, was between 41 and 50 years of age. The ethnic background distribution included 23 parents from Cuba, 12 from Mexico, 11 from Puerto Rico, three from Nicaragua, and one from the Dominican Republic. Fifty eight percent (*n*= 29) of the parents had a high school education or less.

The majority (60%, n= 30) of the parents reported that they lived in households with an income of $25,000 or less. Furthermore, the majority (74%, n=37) were married or living with a partner. Almost half of the parents (46%, n= 23) reported being unemployed, 28% reported working full-time and 22% worked part-time. When asked how the child's care affected their employment, 48% stated that they had to stop working. Another 30% reported that they often take-time off from work to meet their child's health care needs. Refer to Table 1 below for a complete account of the parents' demographics.

Table 1. Parents Demographics

Demographic Variable	**N= 50**	**Percentage**
Relationship with child		
Biological Mothers	45	90
Biological Fathers	4	8
Grandmother	1	2
Age: Range 21-62		
21-30	10	20
31-40	13	26
41-50	18	36
51-62	9	18
Ethnic Background		
Cuba	23	46
Mexico	12	24
Puerto Rico	11	22
Nicaragua	3	6
Dominican Republic	1	2
Education Level		
Less than High School	10	20
Completed High School	19	38
Associate or Bachelor Degree	18	36
Masters or Doctorate	3	6
Income		
Less than $25,000	30	60
$26,000-$50,000	14	28
50,000 or higher	6	12
Marital Status		
Married or living with partner	37	74
Living without a partner	13	26
Employment		
Employed Full Time	14	28
Employed Part Time	11	22
Unemployed	23	46
Back in school	2	4

The majority of the parents described themselves as religious. The parents' religious affiliations were as follows: 58% Catholic, 34% Protestant, and 8% other. When asked to described how important religion was for them on a scale of one to 10, 64% answered seven or higher. When asked how they pay for their own health care and medical expenses, 44% responded with public insurance, 32% self-pay or pay out of pocket, and 24% had private insurance. The most common medical condition reported by these parents was back and neck pain, sore muscles, and high blood pressure. For more details on the parents' medical history, see table 2 below.

Table 2. Parents Medical History

Diagnosis	N= 50	Percentage
Back and/or neck pain	30	60
Sore muscles	24	48
High Blood Pressure	14	28
Arthritis	8	16
Mental Health Issues	8	16
Heart Disease	6	12
Diabetes	5	10
Chest Pain	5	10
Asthma	2	4
Kidney Disease	2	4
Liver Disease	1	2

The age for children of Hispanic parents who participated in the study ranged from three to 21 years with the average age at 12 (SD= 6.5), see Table 3 below. Sixty percent of the children were male and 40% female. The large majority (n= 43) of the children had a diagnosis of cerebral palsy. Reported disability diagnoses included four children with traumatic brain injury, one child with spina bifida, one child with muscular dystrophy, and one child with global developmental delay. One child used canes to ambulate, 18 used a wheelchair in the community, and three used braces and splints. When asked to compare the general health of their children with other children of the same age on a scale of one to 10, 42% (N=21) reported a score of six or less. The majority (n= 47, 94%) of the parents reported that they used public insurance to pay for their child's medical expenses. Refer to Table 3 for the demographic data of the children in the study.

Table 3. Children Demographics

Demographic Variable	N= 50	Percentage
Age: Range 3-21		
3-6	16	32
7-12	9	18
13-21	25	50
Gender		
Male	30	60
Female	20	40
Diagnosis		
Cerebral Palsy	43	86
Traumatic Brain Injury	4	8
Spina Bifida	1	2
Muscular Dystrophy	1	2
Developmental Delay	1	2

Parent Acculturation

The majority (78%, n=39) of the parents in the sample reported that they have lived in the U.S. for more than ten years. The instrument used to measure acculturation was the BAS. An average of 2.5 can be used as the cut off score to indicate higher or lower adherence to each domain (Marin, 1996). A score higher than 2.5 indicates a higher level of acculturation.

Close to half of the sample or 48% (n= 24) scored less than 2.5 in the non-Hispanic domain (English), indicating lower adherence; 52% (n= 26) scored more than 2.5 indicating higher adherence to the non-Hispanic domain. The majority of the parents (90%, n= 45) scored higher than 2.5 indicating adherence to the Hispanic domain (Spanish). Only 10% (n= 5) scored less than 2.5 indicating low adherence to the Hispanic domain. This indicates that most parents, although potentially bilingual, show a tendency to prefer Spanish to English. Refer to Table 4 on page 103.

Perceived Social Support

Parents' perceived social support was measured using the MSPSS. The parents in this study scored an average of 3.4 (moderate support) in the Significant Other subscale, 3 (moderate support) in the Family subscale, and 2.9 (low support) in the Friends subscale (Zimet, 1988). See Table 4 on page 103.

Functional Status of Children

The functional status of children was measured using the PEDI-CAT. Most children in this sample had a T score below 20 in all four domains: the Daily Activities domain (*n*= 41, 82%), the Mobility domain (*n*=43, 86%), the Social/Cognitive domain (*n*= 44, 88%), and the Responsibility domain (*n*=41, 72%). The majority of these children show a low functional status. The normative data provided by this instrument considers scores within normal limit T scores between 30 and 70, two standard deviations of the mean 50. This results indicate that this is a very homogeneous sample with a very little variance. See Table 4 on page 103.

Parent Depression Scale

The CES-D was used in this study to measure depression of the parents. The CES-D provides a criterion score for clinical depression of 16 or greater, identifying individuals at risk for clinical depression (Lewinsohn, 1997). The majority of these parents were not at risk for clinical depression. Approximately two thirds of the parents (n= 34, 68%) scored less than 16 and 32% (n= 16) scored higher than 16. Refer to Table 4 on page 103.

Parenting Stress

Parenting stress was measured using the PSI-SF. Total scores of 90 or higher are considered clinically relevant. In this sample, 34 parents or 68% scored more than 33 ($\bar{x}$= 34.3, SD= 8.4) in the Parent Distress (PD) subscale; only six parents scored higher than 33 ($\bar{x}$= 27.4, SD= 5.4) in the Parent Child-Dysfunctional Interaction subscale; and in the Difficult Child subscale, 41 parents scored higher than 27 ($\bar{x}$= 30.3, SD= 8.2). The Total Score of the PSI-SF shows 36 parents (64%) scored 90 or higher ($\bar{x}$= 92, SD= 17.7). These scores are considered clinically relevant (Abidin, 1995). These results indicate that the majority of these parents report parenting stress. Refer to Table 4 on the next page.

Physical and Mental Health

The parents' physical and mental health was measured using the SF-36 Short form. In this sample only 14 parents or 28% scored below the mean in the physical health domain. The mean score for the physical health domain was 53.2. In the mental health domain, 29 parents or 58% scored below the mean. The mean score in the mental health domain for this sample was 48.2. See Table 4 below.

Table 4: Scores by Variable/Instrument

Variable	Instrument	Score	
Acculturation	BAS	< 2.5	> *2.5*
	Non-Hispanic Domain	*n*= 24	*n*= 5
	Hispanic Domain	*n*= 26	*n*= 45
Perceived Social Support	MSPSS Subscales:		
	Significant Other	3.4	
	Family	3	
	Friends	2.9	
Children Functional Status	PEDI-CAT Domains:	T score < 20	
	Daily Activities	*n*= 41, 82%	
	Mobility	*n*= 43, 86%	
	Social/cognitive	*n*= 44, 88%	
	Responsibility	*n*= 41, 72%	
Depression	CES-D	< 16	> 16
		n= 34	*n*= 16
Parenting Stress	PSI-SF Subscales:		
	Parental Distress	$\bar{x}$= 34.3, *SD*= 8.4	
	P-C Dysfunctional Interaction	$\bar{x}$= 27.4, SD= 5.4	
	Difficult Child	$\bar{x}$= 30.3, SD= 8.2	
	Total Score	$\bar{x}$= 92, SD= 17.7	
Physical Health	SF-36 SF	$\bar{x}$= 53.3, *SD*= 7	
Mental Health	SF-36 SF	$\bar{x}$= 48.2, *SD*= 8.5	

Correlational Analysis

Aim 1: To explore the relationship of the child's characteristics (functional status and age) and family context (SES, parent acculturation, and social support) related to the parenting stress of Hispanic parents caring for children with disabilities.

Hypothesis 1: Parents caring for children with a low functional status requiring more direct care and assistance during daily activities will experience higher levels of parenting stress. Caring for these children as they get older becomes more challenging contributing to higher levels of parenting stress.

All three subscales of the PSI- SF (Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child) and Total Score were correlated with the child's age. There was no statistically significant correlation between the child's age and parenting stress. There was no statistically significant correlation between parenting stress and the PEDI-CAT (Daily Activities, Mobility, Social/Cognitive, and Responsibility). All subscales of the PEDI-CAT were tested individually. There was a statically negative significant correlation between the child's age and the PEDI-CAT Daily Activities subscale ($r (48) = -.291, p< 0.05$). There was also a statistically significant negative correlation between the child's age and the PEDI-CAT Mobility subscale ($r (48) = -.427$, $p < 0.01$).

Hypothesis 2: Hispanic parents with low SES, low acculturation, and poor perceived social support will experience higher levels of parenting stress.

There was a statistically significant correlation between the parents' household income and the parents' education level ($r (48) = .497, p< 0.0.1$). There was also a negative statistically significant correlation between MSPSS and PSI-Parental Distress ($r (48) =.-491, p< 0.01$) and with the PSI-Total Score ($r (48) = -.345, p<.05$). Household income shows a statistically positive correlation with BAS-English domain ($r (48) = .408$, $p< 0.01$) and negative correlation with the BAS Spanish domain ($r (48) = -.302, p<.05$).

The BAS Spanish domain shows a positive correlation with the PSI Parental Distress (r (48) = .306, p< .05). Parents' education level was negatively correlated to the PSI Parental Distress (r (48) = -.437, p < .01).

Aim 2: How are the child's characteristics (functional status and age) and parenting stress related to the physical and mental health of Hispanic parents caring for children with disabilities?

Hypothesis 1: Hispanic parents caring for children with a low functional status, older children, and those experiencing higher levels of parenting stress will report poorer physical health.

The parents' physical health had no statistically significant correlation with the child's age, child's functional status (PEDI-CAT), or parenting stress (PSI-SF). All the subscales of the PEDI-CAT and PSI were tested individually.

Hypothesis 2: Hispanic parents caring for children with a low functional status, older children, and those experiencing higher levels of parenting stress will report poorer mental health.

There were not statistically significant correlations between the child's age, functional status (PEDI-CAT), parenting stress (PSI-SF), and parents' mental health (SF-36 and CES-D). The parents' mental health score (SF-36- Mental Health) shows a negative correlation with the PSI Total score (r (48) = -.443, p < 0.01) and with the PSI Parental Distress subscale (r (48) = -.472, p < 0.01). Parental depression (CES-D) was correlated with the PSI Total Score (r (48) = .324, p < .05) and with the PSI Parental Distress (r (48) = .501, p < .01).

Aim 3: To explore how the child's characteristics and parenting stress are related to the physical and mental health of Hispanic parents when their SES, acculturation, and social support are controlled.

Hypothesis 1: Parents caring for older children and/or children who have low functional status, low SES, low acculturation, and low perceived social support will report poorer physical health.

The parents SF-36 Physical Health score had a positive correlation with the MSPSS score (r (48) = .335, p < .05). The MSPSS had a negative correlation with the PSI Parental Distress score (r (48) = -.491, p < .01) and with the PSI Total Score (r (48) = -.345, p < .05). The parents' education level was negatively correlated with the PEDI-CAT Daily Activities (r (48) = -.404, p < .001), the PEDI-CAT Mobility (r (48) = -.368, p< .01), and with the PEDI-CAT Social/Cognitive (r (48) = - .322, p< .05). Household income had a negative correlation with the PEDI-CAT Daily Activities score (r (48) = -.330, p < .05).

Hypothesis 2: Parents caring for older children and/or children with low functional status who have a low SES, low acculturation, and low perceived social support will report poorer mental health.

There was no statistically significant correlation between the child's age, the child's functional status (PEDI-CAT) and parenting stress or the parents' mental health

(SF-36 Mental Health and CES-D). Also, there was no statistically significant correlation between the parents' income and education on parenting stress and mental health. There was a positive correlation between the PSI Parental Distress and the BAS Spanish scores (r (48) = .306, p <.05). The score on the MSPSS was correlated with the parents' score on the SF-36 Mental Health (r (48) = .444, p < .05) and with the CES-D (r (48) = .541, p < .01).

A correlation analysis was conducted exploring the relationship of years lived in US and all the study variables. Years lived in the US had a statistically significant positive correlation with the BAS English domain (r (48) = .614, p < .01) and house household income (r (48) = .385, p < .01). Years lived in the US had a statistically significant negative correlation with the PSI Parental Distress score (r (48) = - .325, p < .05) and with BAS Spanish domain (r (48) = - .647, p < .01).

Hierarchical Multiple Regression

For the results for the research aim 1and hypothesis 1, multiple regressions were not statistically significant. The model included the PSI- Parental Distress as the independent variables. The PEDI-CAT scores and the child's age were the independent variables. The analysis was repeated with all four domains of the PEDI-CAT separately.

The results for the research aim 1and hypothesis 2 show a statically significant model. The PSI- Parental Distress was used as the dependent variable and parent education level, income, and acculturation as independent variables. The results showed that perceived social support (MSPSS), household income, and parental education level explained 37.6% of the variance ($R^2 = .378$, $F (3, 46) = 9.22$, $p < .000$). When parent acculturation (BAS) was added to parental education, household income, and perceived social support, the predictors combined explained 46.5% of the variance ($R^{2 =} .465$, $F (4, 45) = 9.77$, $p < .000$).

The results of research aim 2 and hypothesis 1 multiple regressions were not statistically significant. The parental physical health (SF-36 Physical Health) was the dependent variable. The independent variables child's age and functional status (PEDI-CAT) were entered first and then the PSI- Parental Distress was entered second. This multiple regression was repeated for all four domains of the PEDI-CAT.

For research aim 2 and hypothesis 2, the parental metal health (SF-36 Mental Health) was the dependent variable. The independent variables entered first were the child's age and functional status and then the PSI- Parental Distress was entered second. The results of the first model were not statistically significant. When the PSI was added to the regression with the PEDI-CAT Daily Activity domain, the results of the regression explained 26.3% of the variance ($R^2 = .263$, $F (3, 46) = 5.46$, $p < .003$). For the regression with the PEDI-CAT Mobility domain the results explained 25.7 % of the variance ($R^2 = .257$, $F (3, 46) = 5.32$, $p < .000$). For the regression with the PEDI-CAT Social/Cognitive domain, the results explained 27.1% of the variance ($R^2 = .271$, $F (3, 46) = 5.70$, p, .002). For the regression with the Parent Responsibility domain, the results explained 26.8% of the variance ($R^2 = .268$, $F (3, 46) = 5.60$, p, .002).

Parent depression (CES-D) was entered as a dependent variables with the same predictor of independent variables as in the previous analysis. The results show that the regression with the child's age and functional status were not statistically significant. When the PSI- Parental Distress was added to the model with the PEDI-CAT Daily Activities domain, the results explained 25.9 of the variance ($R^2 = .259$, $F(3, 46) = 5.365$, $p < .003$). For the model with the PEDI-CAT Mobility domain the results explained 26% of the variance ($R^2 = .260$, $F(3, 46) = 5.379$, $p < .003$). For the model with the PEDI-CAT Social/Cognitive domain, the results explained 25.9% of the variance ($R^2 = .259$, $F(3, 46) = 5.361$, $p < .003$). For the model with the PEDI-CAT Responsibility domain, the results explained 27.3% of the variance ($R^2 = .273$, $F(3, 46) = 5.745$, $p < .002$).

To address research aim 3 and hypothesis 1, a regression was conducted with the SF-36 Physical Health as the dependent variable. The child's functional status and age were entered first. The parent acculturation, parent education level, and household income was added second and finally the PSI- Parental distress was added. The results were not statistically significant. The regression analysis was repeated for all four domains of the PEDI-CAT.

To address research aim 3 and hypothesis 2, the parental mental health (SF-36) was the dependent variable. The child's age and functional status were entered first. Parent acculturation (BAS), parent education level, and household income were introduced second and finally the PSI- Parental Distress and perceived social support (MSPSS) were introduced. The results of the regression were statistically significant when the PSI- Parental support and perceived parental support (MSPSS) were introduced. The results model with the PEDI-CAT Daily Activities the explained 37.5% of the variance ($R^2 = .373$, $F(7, 42) = 3.605$, $p < .004$). The results of the model with the PEDI-

CAT Mobility domain explained 37.6% of the variance ($R^2 = .376$, $F (7, 42) = 3.609$, $p < .001$). The model with the PEDI-CAT Social/Cognitive domain explained 37.2% of the variance ($R^2 = .372$, $F (7, 42) = 3.559$, $p < .004$). The results of the fourth model with the PEDI-CAT Responsibility domain explained 37.3% of the variance ($R^2 = .373$, $F (7, 42) = 3.57$, $p < .004$).

Parental depression (CES-D) was used as the dependent variable with the same independent variables of the previous regression analysis. Again, the results were statistically significant only when the parents perceived social support (MSPSS) and the PSI- Parental Distress are entered. For the model with the PEDI-CAT Daily Activities domain, the results explained 42.7% of the variance ($R^2 = .427$, $F (7, 42) = 4.479$, $p < .001$). For the model with the PEDI-CAT Mobility, the results explained 41.8% of the variance ($R^2 = .418$, $F (7, 42) = 4.303$, $p < .001$). For the model with the PEDI-CAT Social/Cognitive domain, the results explained 41.9% of the variance ($R^2 = .419$, $F (7, 42) = 4.32$, $p < .001$). The results of the final model with the PEDI-CAT Responsibility domain explained 44.1% of the variance ($R^2 = .441$, $F (7, 42) = 4.370$, $p < .001$).

A stepwise multiple regression was conducted to address any potential issues of multicollinearity and to identify which independent variables were better predictors for the dependent variables. For research aim 1, the best predictor variables for the parental distress were the perceived social support (MSPSS) and parent education level ($R^2 = .450$, $F (2, 49) = 12.531$, $p < .001$). For research aim 2, the best predictor variable for mental health was parental distress ($R^2 = .223$, $F (2, 49) = 13.742$, $p < .001$). Also for research aim 2 the best predictor for depression (CES-D) was parental distress ($R^2 = .251$, F (2,

49) = 16.052, $p < .00$). For research aim 3, the best predictor variable for physical health (SF-36- Physical Health) was perceived social support ($R^2 = .112$, F (2, 49) = 6.074, $p < .01$). The best predictor variable for mental health (SF-36 Mental Health) was parental distress and parent education level ($R^2 = .299$, F (2, 49) = 10.003, $p < .000$). The best predictor variables for parent depression (CES-D) were parental distress and perceived social support ($R^2 = .365$, F (2, 49) = 13.526, $p < .000$).

Conclusion

The majority of this sample were mothers (90%) who had an education level of high school or less (58%), live in a household with an income of less than $25,000 (60%), and are married or live with a partner (74%). Approximately half of the parents scored low in the BAS English, indicating lower English proficiency.

One third of the parents scored 16 or above in the CES-DS; a score of 16 is considered a cut-off score for clinical depression. These parents reported moderate perceived social support from significant others and close family members, and low support from friends. The majority of the parents (64%) scored higher than 90 (cut-off score) in the PSI- Total Score. Out of the three domains of the PSI, these parents scored higher (above cut-off score) in the PSI Parental Distress domain (68%) and in the PSI-Difficult Child domain (82%). Only 28% of the parents scored below the mean in the SF-36 Physical Health Survey and 58% in the SF-36 Mental Health Survey.

The majority of the children had a diagnosis of cerebral palsy and half (*n*= 25) were older than 13 years of age. The most common adaptive equipment reported was a wheelchair, with 18 children in need of one. All children scored below a T score of 20 in the PEDI-CAT in all domains: Daily Activities, Mobility, Social/Cognitive, and Responsibility. The mean T score of the population is 50, and two standard deviations is considered within normal limits.

There was a positive correlation between income and education with the BAS English domain. There was a negative correlation between the BAS Spanish domain and household income. The PSI Parental Distress had a positive correlation with the BAS Spanish domain and the CES-DS. The SF-36 Physical Health and Mental Health domains have a positive correlation with the parents' perceived social support (MSPSS). The PSI (Parental Distress and Total Score) had a negative correlation with the MSPSS, SF-36 Mental Health Survey, educational achievement of the parents, and how long the parents have lived in the U.S. There is a negative correlation between the CES-DS and the MSPSS as well as the SF-36 Physical Health Domain. The parent score in the BAS Spanish domain had a negative correlation with the household income.

The exploratory hierarchical multiple regression identified parental education, acculturation, and perceived social support as predictors of parenting stress (PSI- Parental Distress). Household income, child's age and child's functional status were not identified as predictors of parenting stress (PSI Parental Distress). Parental distress and perceived social support were predictors of parental physical health (SF-36 Physical Health), parental mental (SF-36 Mental Health), and parental depression (CES-D).

Chapter V

DISCUSSION

Demographic Characteristics

This study of Hispanic parents caring for children with disabilities focused on the effects of the degree of the child's functional status, child's age, family context (SES, parent acculturation, and social support) on parenting stress and ultimately, on the parents' physical and mental health. Despite the fact that Hispanics are the largest minority in the U.S. (Bureau, 2015), there is very little research focused on the impact of caring for a child with a disability on Hispanic parents (Walsh, 2003). Members of different racial/ethnic groups cope with chronic diseases and disabilities differently. The cultural constructs of *familism* and *allocentrism* might influence how Hispanic parents cope with chronic disease and disabilities and can also influence their interactions with health care professionals (Rodriguez et al., 2007).

The sample in this study consisted primarily of mothers (90%); most of the fathers in these sample declined to participate. The literature shows that fathers are extremely underrepresented in family-based research. Increasing the participation of fathers in family research is very important; their participation will help researchers have a better understanding of their contribution in the well-being and health outcomes of all members of the family (Davison, 2017). Fathers' participation should be emphasized in future research by developing strategies targeted specifically toward their involvement. Improving the participation of fathers in research might be more challenging with working class fathers, racial/ethnic minorities, and low SES (Doyle, Weller, Daniel, Mayfield, & Goldston, 2016).

The parents in this study considered themselves religious, and the most common denomination among them was Catholic. The literature shows that religion plays an important role in the health beliefs and coping strategies used by Hispanics. Professionals working with Hispanic parents should be aware of the impact of religious beliefs and cultural constructs in order to implement interventions meeting the specific needs of these parents (Jurkowski et al., 2010; Salkas, Magaña, Marques, & Mirza, 2016).

More than half of these parents had an education level of high school or less and lived in low-income households. Studies with Hispanic parents have demonstrated a correlation between SES and increased parenting stress and perception of poor social support (Devine et al., 2012; Porterfield, & McBride, 2007). The literature also supports the importance of SES and parents' satisfaction with health care services. Parents with a lower SES report more dissatisfaction with health care services and more unmet health care needs (Fulda, Lykens, Bae, & Singh, 2009; Javier, Huffman, Mendoza, & Wise, 2010). The interaction between SES and cultural constructs and how this interaction influences access to and satisfaction with health care services needs further exploration.

Half of the parents worked either part-time (22%) or full-time (28%) and most of them stated that they had to stop working or to take time off from work to be able to meet the healthcare needs of their children. These findings are similar to other studies showing that parents caring for children with disabilities have difficulties sustaining full-time employment because of the additional caregiving demands (DeRigne, 2010; Looman et al., 2009; Loprest, 2004; Porterfield, & DeRigne, 2011). The parents in this sample show a significant unemployment level (48%), contributing to the low household income and the use of public funding to pay for healthcare services.

Studies have shown that, among parents caring for children with disabilities, the risk of having to reduce work hours or to stop working decreases when they receive family-centered care, better coordination of services, and consistent source of care (DeRigne, 2010). Helping these parents keep their current employment or reentering the workforce can improve their SES. Furthermore, unemployment can have a negative impact in the mental health of these parents. Studies have shown that employment status contributes to negative mental health outcomes among parents caring for children with disabilities (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010).

The majority of the parents reported having back and/or neck pain and painful muscles. These results are similar to findings of other studies exploring the impact on the parents' physical health, especially when caring for children with movement disorders. Parents caring for children with motor and sensory deficits secondary to diagnosis such as cerebral palsy are at higher risk of sustaining musculoskeletal injuries. These parents are involved in constant lifting, transferring, carrying, and pushing when assisting their children in activities of daily living. As the children get older, the physical burden on these parents intensifies, increasing the probability of sustaining a musculoskeletal injury (Tong et al., 2002; Tong et al., 2003; Tonga & Düger, 2008). Interventions geared to decrease musculoskeletal injuries among parents caring for children with movement disorders has not been adequately explored. Interventions – such as teaching better body mechanics, the use of lifting equipment, and physical conditioning – might help parents taking care of children with disabilities, resulting in the reduction of self-care deficit and the risks of sustaining a musculoskeletal injury. The success of these interventions needs further examination in order to implement effective measures to decrease the incidence of musculoskeletal injuries.

Parent Acculturation

Acculturation is a complex multidimensional process, and as such is very challenging to measure or quantify. The process of acculturation leads to changes in behaviors and values in one group when exposed to a continuous interaction with a different culture (Cuellar, 1980). The construct most commonly used to measure acculturation among Hispanics is language preference or proficiency. Most instruments used to measure acculturation are language-based questionnaires (Mills, Malcarne, Fox, & Robins Sadler, 2014). The acculturation measurement used in this study provided a score for the Hispanic domain (Spanish) and one for the non-Hispanic domain (English). This instrument measures the language preference and proficiency for verbal communication as well as for the use of electronic media (Marin, 1996).

The majority of the parents in this study obtained a higher score in the Hispanic domain indicating a level of comfort and preference for the use of Spanish in verbal communication and with electronic media. Slightly more than half of the parents scored higher than the cutoff score in the non-Hispanic domain indicating that they were bilingual and were comfortable using English in verbal communication and with electronic media. The majority of the parents in this sample considered themselves bilingual; even though, they preferred Spanish and most of the interviews were conducted in Spanish. Language preference or proficiency can have a negative impact in the ability of Hispanic parents to seek and access health care services (Wolff & Ellis, 2009). Minority parents report higher levels of dissatisfaction with health care services compared with non-Hispanic White parents. Minority parents often report that health care professionals do not spend enough time with them and lack sensitivity to their cultural values (Magaña, Parish, & Son, 2015). Furthermore, Hispanic parents with lower English proficiency report that their services are not well coordinated and comprehensive (Decamp, Choi, & Davis, 2011). Professionals working with Hispanic parents should bring about interventions that are more effective addressing the cultural constructs prevalent among Hispanics. By having a better understanding of the cultural constructs of *familism* and *allocentrism*, health care professionals could understand the importance of including the entire family in the plan of care. Researchers must explore how the inclusion of these cultural constructs in the care of these parents improves the effectiveness of therapeutic interventions.

Parents with lower English proficiency reported higher parenting distress, lower education level, and lower income. Parents with lower English proficiency, lower income, and lower education level are at higher risk to experience higher burden of care. Studies have shown Hispanic parents having difficulties accessing health care services (Sharib et al., 2014). Decreased access to health care and poorer health outcomes among Hispanics have been associated to language proficiency, immigrant status, and SES.

Avila and Bramlett (2013) conducted a study exploring the effect of language proficiency and immigrant status on the health care disparities among Hispanic children. They found that nonimmigrant Hispanic parents with better English proficiency had more access to care and better health outcomes.

The results of this sample show a correlation between years lived in the U.S. with English proficiency and household income. Those parents who arrived to the U.S. more recently, with lower acculturation, and lower income showed higher level of parenting stress. These results accentuate the need for early identification of parents' with lower acculturation in order to implement measures improving access to and satisfaction with health care services. Better access and increased satisfaction with health care services can decrease parenting stress.

Perceived Social Support

The parents in this sample reported moderate support from significant others and family members and low support from friends. This finding confirms the importance of the cultural constructs of *familism* and *allocentrism* among Hispanics. The constructs of *familism* and *allocentrism* create the expectation of loyalty and devotion from all family members. Family members are expected to be the major source of emotional support and solidarity (Rodriguez et al., 2007). Furthermore, the cultural construct of a*llocentrism* stresses the well-being of the family as a whole with less emphasis on the needs of the individual (Gallo, 2009). The findings in this study demonstrated the importance of improving awareness among health care workers about prevalent cultural constructs among Hispanics that emphasize the family as the primary source of social support.

Understanding the significance of the family system in the Hispanic culture will facilitate the implementation of more culturally relevant and effective interventions.

The parents in this sample reporting higher perceived social support showed better physical and mental health, and those reporting lower perceived social support showed higher level of parenting stress and depression. These findings support the need to implement interventions geared to minimize parenting stress and depression through adequate/enhanced social support. Interventions designed to improved health outcomes should include all members of the family system. Parents should receive the necessary and relevant information about the child's disability and the services available in the community. These parents ought to receive additional support during transition periods to make important health care decisions that affect their child and the entire family. Finally, these parents can also benefit from legal support, financial support, educational support, transportation, psychosocial support, and respite care (Cantwell, Muldoon, & Gallagher, 2014; Tétreault et al., 2014).

Parents caring for children with disabilities experience family life disruption and social isolation, especially those caring for children with severe disabilities. Respite care services can help alleviate the burden experienced by these parents (Brown, 2011; Doig, McLennan, & Urichuk, 2009). Hispanic parents might feel particularly reluctant to use respite care because of the aforementioned constructs of *familism* and *allocentrism*. They might feel that it is their sole responsibility to care for their own child and that they should not relinquish the care of their child to outsiders. Studies with adult Hispanic caregivers of elderly parents show that they tend to use less respite care and spend more caregiving hours per week compared with other ethnic groups (Miyawaki & Miyawaki, 2016). These findings suggest that cultural constructs emphasizing responsibility and devotion to the family could influence how Hispanics use health care services.

Very few studies have explored how cultural constructs moderate Hispanic parents' perceptions and expectations of social support and its effect on their physical and mental health. The few studies exploring Hispanic parents' perceptions of social support have shown that they tend to report lower levels of social support and parenting satisfaction and higher levels of parenting stress (Devine et al., 2012). This study validates the need to provide adequate social support to parents caring for children with disabilities in order to reduce any negative effects on their physical and mental health. The findings of this study indicate that Hispanic parents receive social support primarily from family members. These results can help service providers design interventions geared to all members of the family in order to improve their coping skills and make the family a more effective and resilient support system.

Children's' Functional Status

The children in this sample show a very low functional status in all areas measured by the PEDI-CAT. This instrument measures the child's functional status in four areas: Daily Activities, Mobility, Social/Cognitive, and Responsibility. The Responsibility subscale measures the ability of the child to function independently. Parents of children requiring more assistance with all activities of daily living reported higher scores in the CES-DS and in the PSI difficult child subscale.

The aforementioned results are consistent with literature. Parents caring for children with a severe physical disability and self-care deficit tend to report more back and neck pain secondary to the amount of physical assistance required by their children. These parents experience a negative impact on their physical health due to the physical demands of caring for children with a severe disability. These physical demands increase as the child grows and becomes more difficult to handle during activities of daily living. The literature shows that parents caring for severely disabled children report disrupted sleep, financial burden, difficulties taking family vacations, maintaining employment, keeping a healthy marital relationship, and maintaining social interactions (Davis, 2010; Devine et al., 2012; Schertz, Karni-Visel, Tamir, Genizi, & Roth, 2016). Caring for these children becomes more challenging as the children get older, and the parents often feel anxious about the future (Burkhard, 2013). Future research studies ought to explore how caring for children with severe disabilities affect the physical health of the parents and determine which interventions will help these parents reach better health outcomes.

Parenting Stress

The parents in this study scored high in the parent stress and difficult child subscales. Parents who scored higher in the Hispanic domain of the acculturation scale reported higher parenting stress. Consistently, parents that had lived longer in the U.S. and had a higher education level reported lower parenting stress scores. These parents also reported a high score in the difficult child subscale. This high score might be associated with the specific challenges of caring for a child with a disability and low functional status.

The scores in the Parent-Child Dysfunctional Interaction sub-scale were not statistically significant. This subscale measures if the child meets the parents' expectations. It also measures the level of satisfaction of the interactions with the child. Parents that feel disappointed with the interaction with their child feel rejected from their child and score high in this subscale (Abidin, 1995). Motherhood and devotion are highly valued in the Hispanic culture. The literature reports that there is a tendency among Hispanic parents to accept high levels of care dependency of a child with a disability. This ability to endure high levels of caregiving demands is considered as a desirable parental attribute (Castillo, 2010). The scores in this study supports previous findings that Hispanic parents are reluctant to report a negative interaction with their disabled child. This reluctance to report negative interactions with their children might prevent HCP' ability to implement interventions to facilitate more fulfilling parent-child interactions.

The parents in this sample showed a positive correlation between parenting stress and symptoms of depression. Additionally, the high parenting stress correlated with a low perception of social support and poorer physical and mental health. These findings are similar to other studies exploring the impact of parenting stress on the parents' physical and mental health. Regretfully, very few studies have explored the experience of Hispanic parents caring for children with disabilities (Johnson, Frenn, Feetham, & Simpson, 2011; Miodrag, Burke, Tanner-Smith, & Hodapp, 2015). The role of cultural constructs and SES requires further exploration. Future researchers must explore the impact of SES versus cultural constructs by studying Hispanic parents of diverse SES.

Depression

Approximately one third of the parents in this sample scored 16 or greater in the CES-DS. A score of 16 or higher identifies individuals at risk for clinical depression (Lewinsohn, 1997). Parents that scored higher in the depression scale also scored higher levels of parenting stress. Furthermore, these same parents with higher scores in the depression scale also show lower levels of perceived social support and poorer self-reported physical and mental health. These findings are consistent with other studies exploring the impact of caring for a child with a disability and the parents' mental health. Studies have shown an association between parents' depression, severity of the child's disability, perception of low social support, availability of respite care, and poverty (Griffith et al., 2011; Tonga & Düger, 2008).

Parents caring for children with disabilities often report high levels of anxiety and depression. Nurses and other professionals involved in the care of these parents need to be more aware of the impact of caring for a child with a disability on the mental health of the parents. The interventions strategies that can better help parents cope more successfully need further investigation (Oers et al., 2014). Moreover, the ways cultural constructs modulate the parents' ability to cope with their care giving burden need further exploration. Few studies have explored the experience of immigrant parents with low acculturation. Most studies conducted with Hispanic parents and their experience with the health care system have actually concentrated on the parents SES and not on cultural constructs and acculturation (Knapp, Madden, Marcu, Sloyer, & Shenkman, 2011; Young & Rabiner, 2015). Cultural constructs must be included in the development of interventions intended to improve mental health and alleviate parenting stress. Understanding the cultural constructs of *allocentrism* and *familism* will help professionals implement interventions in harmony with the collectivistic tendencies of the Hispanic culture.

Physical and Mental Health

In this sample, only 14 parents scored below the mean in the physical health domain and more than half scored below the mean in the mental health domain. Parents scoring higher in perceived social support scored higher in self-reported physical and mental health. Self-reported mental and physical health were lower among those parents who reported higher levels of parenting stress and depression. These findings uphold prior studies, showing that parents caring for children with disabilities tend to report poorer physical and mental health and higher levels of parenting stress and depression (Chambers & Chambers, 2015; Oelofsen & Richardson, 2006).

Research Aim 1

The results of this study demonstrate that parents who have lower acculturation, lower educational achievement, and lower perceived social support experience higher levels of parenting stress. Studies examining the experience of immigrant parents also reveal that parents with lower acculturation experience more parenting challenges (Decamp et al., 2011; Doig et al., 2009; Yu & Singh, 2012). Lower acculturation and language proficiency can also lead to difficulties navigating the health care system, decreasing access to health services and adding to parenting stress. A study conducted by

Becerra, Androff, Messing, Castillo, and Cimino (2015) exploring the perception of Hispanics regarding health care services found that those patients with lower acculturation reported more difficulties navigating the health care system and more dissatisfaction with health care services.

Hispanics in the U.S. experience significant health care discrepancies due language barriers, lack of insurance coverage, and legal status (Decamp et al., 2011; Lucke, Martinez, Mendez, & Arévalo-Flechas, 2013). All members of the health care team should address these health care disparities, implementing interventions geared to the unique needs of Hispanic parents caring for children with disabilities, particularly those parents with lower language proficiency. In the future, researchers should explore which culturally appropriate interventions are more effective in order to improve the health outcomes of these parents and their children.

Research Aim 2

The results of this study clearly indicate that parents experiencing higher levels of parenting stress are at higher risk to have poorer mental health. Likewise, high parenting stress was a predictor of parent depression. These findings validate previous studies examining the physical and mental health of parents caring for children with disabilities. Higher parenting stress due to increased burden of care leads to poorer physical and mental health outcomes (Cantwell et al., 2014; Gallagher & Hannigan, 2014; Murphy, 2006). Professionals working with these parents need to be more aware of the potential negative physical and mental health outcomes in order to facilitate early identification and initiation of appropriate interventions. Psychosocial interventions designed to address the specific needs of these parents could minimize the negative effect on their physical and mental health. Researchers should explore which psychosocial interventions are more effective meeting the specific needs of parents belonging to minority groups.

Research Aim 3

The results of this study provide evidence that parents with a lower education level and those experiencing higher parenting stress report poorer mental health. Moreover, these parents also reported lower perceived social support, had more symptoms of depression, and poorer physical health.

Parents of children with disabilities are more likely to report a higher incidence of chronic conditions, activity limitations, poor general health, and symptoms of depression (Brehaut, 2004). Other studies have shown that parents caring for children who have severe motor deficits with activity limitations report poorer physical and mental health outcomes. Many of these parents reported difficulties sleeping, chronic pain, and symptoms of depression (Kuhlthau, 2005; Mörelius, 2014). Having a better understanding of how SES and cultural constructs influence the parents' perception of caregiving burden can help HCP implement more effective interventions.

Limitations of the Study

The small sample size is one of the most significant limitations of this study. Recruiting parents for this study was extremely time consuming and challenging. The parents often had privacy concerns and many were simply reluctant to speak openly about their experiences with a stranger. In the majority of the families, the fathers refused to participate. A significant number of parents stated that it was extraordinarily difficult arranging time to complete the questionnaires due to the many tasks they had to perform every day. Moreover, some local institutions refused to participate in the recruitment process due to privacy issues and legal concerns.

An additional limitation of this study was the use of convenience sampling. This sampling method can potentially introduce systematic biases. Another potential limitation of the sampling method is that the sample obtained might not be representative of the entire population, minimizing the possibility of making accurate generalizations applicable to the intended population (Acharya As, 2013) .

All the questionnaires used to collect data in this study were self-reports. There is a potential for participants to report inaccurate or untruthful responses. Hispanic parents often seem reluctant to verbalize any negative comments about their children, especially CSHCN. Cultural constructs such as *familism* and *allocentrism* and the high value placed on motherhood might influence how Hispanic parents respond to questions about their children and the challenges of caring for them (Haley, 2010; Rodriguez, Donovick, & Crowley, 2009; Rodriguez et al., 2007).

Multiple studies have shown that the PEDI-CAT poses good psychometric characteristics; it has been used in different types of populations and it seems to be very useful in the clinical setting (Dumas, Fragala-Pinkham, Rosen, Lombard, & Farrell, 2015; Haley, 2010). However, in this study, the results of the PEDI-CAT did not provide sufficient differentiation among these low functioning children. Most of the children in this sample were extremely low functioning and were all classified in the same category. The majority of the children scored below the fifth percentile in all four domains tested by this instrument, indicating that this sample was homogenous with very little variance in their functional status. The use of a different instrument designed specifically for children with severe disabilities could assist future research studies adequately measure the child's functional status.

Conceptual Framework

The conceptual framework of this study proposed that parenting stress was modulated by the child's age, child's functional status, SES, acculturation, and perceived social support. The Hispanic parents is this study did not report higher levels of parenting stress related to the child's functional status and age. This finding is different from other studies that indicate that parents caring for children with severe disabilities tend to experience higher levels of parenting stress (Dellinger & McKerr, 2011; Knox, 2008, Polissano et al., 2009; Chiarrello, 2010). It is possible that the parents in this study did not feel comfortable reporting negatively about their children due to the cultural construct of *allocentrism, familism*, and the high value placed on motherhood. These constructs predispose Hispanic parents to accept and adjust to higher levels of care giving burden (Castillo, 2010; Gallo, 2009; Rodriguez, 2013).

Parents that indicated low perceived social support, lower SES, and lower acculturation reported higher levels of parenting stress. Parents in this study specified that they received social support predominantly from family members and significant others. They did not rely on social support from friends or institutions. This finding supports the importance of the cultural construct of *familism*. Years lived in the U.S., higher acculturation and higher education were negatively correlated with parenting stress. Although income was correlated to parental acculturation and education, it did not show a statistically significant correlation with parenting stress

This conceptual framework also theorized that the child's characteristics (functional status and age) and parenting stress would have a negative impact in the parents' physical and emotional health. In this sample, the child's functional status and age did not seem to have an important modulating influence on the parents' physical and mental health. Many studies report a negative impact on the physical and mental health of parents caring for children with disabilities (Raina et al., 2005; Brehaut et al., Aitken, 2009). The majority of the children in this sample were low functioning with very little variance and highly homogenous. Perhaps a sample with more variance could very illustrate the relationship between functional status and parents' well-being. In this study, those parents reporting higher levels of parenting stress reported poorer mental health and higher levels of depression. This finding is consistent with finding reported in the literature (Cavallo et al., 2009; Churchill et al., 2010; Trute, 2005).

In this study, parents with low SES, low acculturation, and low perceived social support reported poorer mental health and more depression. The findings are consistent with the findings of studies exploring the impact of SES and the well-being of parents caring for children with disabilities (DeRigne & Porterfield, 2010; Porterfield & McBride, 2011). The only variable positively correlated with parents' physical health in this sample was their perceived social support. Parents that reported higher levels of social support indicated better self-reported physical health.

Implications for Nursing

Parents caring for children with movement disorders, requiring assistance with bed mobility, transfers activities, toileting, bathing, and with ambulation are at higher risk of sustaining a musculoskeletal injury (Tong et al, 2003; Tong et al., 2002; Tonga & Düger, 2008). These parents can benefit from training programs teaching them proper body mechanics to decrease the potential for musculoskeletal injuries. They can also benefit from training programs demonstrating how to properly use special equipment to assist during activities of daily living that require lifting or carrying. Studies exploring the use of equipment to assist during lifting reported that, initially, parents offer some resistance. However, after receiving training and making some modifications in their homes, they are more willing to use the equipment. The introduction of a lifting device such as a hoist has a positive impact in the quality of life of the parents and their children (Nicholson, 1999; Shepherd, Stewart, & Murchland, 2007).

There is a need to develop support systems to assist parents with coordinating, planning, implementing, and delivering services for their children. Parents caring for children with disabilities have the additional task of becoming the service coordinator and liaison among the different member of the health care team. This added responsibility increases the burden of care experienced by them, potentially contributing to negative health outcomes. Studies exploring the impact of interventions meant to support parents as they coordinate services and facilitate communication have shown that they can reduce parenting stress and improve health outcomes (Crettenden, Wright, & Beilby, 2014).

The literature also shows that implementing interventions to assist parents with coordinating services and improving communication among members of the health care team increases access to and satisfaction with health care services, alleviating some of the burden of care experienced by these parents (Miller, 2014). Parents of children with disabilities experience high levels of anxiety anticipating what is going to happen to their child when they become older and are no longer able to care for their child. Parents often experience lack of coordination among different agencies during transition periods. They express multiple unmet needs such as employment, future living arrangements, further education, and assistance with daily activities. Older parents might experience failing health, financial pressures, and a constant worry about the future (Dillenburger, 2011). These parents can benefit from services aimed toward providing information and counseling regarding the transition process and assistance with services coordination among the different agencies involved. These types of interventions can reduce the anxiety and stress experienced concerning the future of their children (Clarke et al., 2011).

The information needs of these parents are complex and they evolve over time. The information needs at the time of diagnosis are not the same as what is needed during a period of transition such as a change in the level of care or as children get older. These parents have to be able to understand what services are needed and available in their communities to support their child’s well-being (Palissano, 2009). Parents often report the need for accurate information that includes realistic expectations given in a positive and compassionate manner. The literature supports the need to tailor the information given to the specific needs of each family (Andrews, 2009). Accurate information given in a compassionate manner can help parents better cope with the child's diagnosis and plan for the future (Palissano, 2009).

The literature also shows that financial difficulties increase proportionately with the severity of the child's diagnosis. Increased severity in the child's condition correlates with more out-of-pocket expenses and more difficulties for the parents to sustain full-time employment (Kuhlthau, 2005). Parents caring for children with severe functional impairments experience more financial challenges and time constraints. Children with more severe conditions require more health care services; consequently, their parents have to coordinate the delivery of multiple health care services (Bumbalo, 2005). Therefore, these parents have difficulties maintaining full-time employment, leading to negative financial consequences and perhaps less employer supported health insurance (Heck, 2000; Lindly, Chavez, & Zuckerman, 2016; Witt et al., 2009).

In this sample, a significant number of the parents are unemployed or only work part-time. Almost half of the parents stated that they had to stop working and approximately one third had to take time off from work to meet the health care needs of their children. These parents could benefit from interventions geared to help them stay in the workforce, e.g. adequate and affordable respite care. Bourke-Taylor, Howie, and Law (2011) conducted a study exploring the obstacles encountered by mothers of children with disabilities who participate in the workforce and how their employment status influenced their health. They found that mothers who worked reported better quality of life and health outcomes compared with mothers who did not work. Their findings strongly support the need to improve services to increase these parents' employment status.

Studies suggest that parents caring for children with disabilities who belong to minority racial/ethnic groups are more likely to have inadequate insurance coverage. Lacking appropriate insurance deprives these parents of the necessary support and services causing them to have more out-of-pocket expenses and financial hardship than parents with better insurance coverage (Yu et al, 2004).

Finally, teaching relevant cultural constructs that impact how patients relate to health care workers and make health care decisions should be emphasized in nursing curricula and training programs. This is particularly important for nurses and other professionals providing services to culturally diverse populations (Amendola, 2011; Parés-Avila, Sobralske, & Katz, 2011). Studies show that when Hispanic patients receive services delivered by culturally competent professionals, their satisfaction with health care services improve (Castro & Ruiz, 2009; Hamilton, Lerner, Presson, & Klitzner, 2013; Lucke et al., 2013).

Future Research

The way cultural constructs influence the parents' attitudes towards interactions with and expectations of HCP needs further exploration. Moreover, how culture influences the health care decisions of Hispanic parents regarding their own health has not been sufficiently investigated. Cultural constructs, such as *familism* and *allocentrism,* could influence how Hispanic parents interact with HCP (Campos, Ullman, Aguilera, & Dunkel Schetter, 2014; Koerner & Shirai, 2012). These cultural constructs could modulate how Hispanic parents cope with the challenges of caring for a child with a disability. Furthermore, the ways in which culturally sensitive interventions could facilitate better health outcomes among parents that belong to minority racial/ethnic groups has not being sufficiently explored (Bayles & Katerndahl, 2009; Calzada, 2010; Domenech Rodriguez, 2009).

The incidence and severity of musculoskeletal injuries among parents caring for children with disabilities needs further examination. The risk of sustaining an injury increases as the child grows, and activities such as transfers and lifting become more physically demanding for the parents (Smith, Seltzer, & Greenberg, 2012; Soares et al., 2012; Tonga & Düger, 2008). Few studies have explored the impact of caring for a child with a severe disability and/or complex health care needs and the development of musculoskeletal injuries among the parents.

The kind of social support services that will be more effective at preventing negative health outcomes requires further exploration. Parents caring for children with disabilities might require a variety of social support services, such as information support, help with decision making, legal assistance, financial assistance, help with leisure and social activities, and respite care. Hispanic parents tend to rely less on respite care services and prefer to care for their family members by themselves compared with other groups (Miyawaki & Miyawaki, 2016). HCP need to understand which cultural values specific to Hispanics influence their caregiving patterns and acceptance of different kinds of social support.

Summary

Parents belonging to minority racial/ethnic groups are at higher risk of experiencing burden of care, more financial difficulties, less access to health care services, and poor health outcomes (Reid, 2011;Yu et al., 2004). More research is needed to improve the understanding of the impact of caring for a child with a disability on Hispanic parents and what kind of interventions can produce better health outcomes. This study and the literature posit that the burden experienced by these parents contributes to poor health. Providing assistance in the form of respite care, especially as the child gets older, could help lessen the severity of the burden of care experienced by these parents (MacDonald, 2007).

The majority of the parents in the sample were mothers living in low-income households with an education level of high school or less. They reported having difficulties sustaining full-time employment due to the caregiving demands. The findings of this study are consistent with previous studies showing parents caring for children with disabilities having low participation in the workforce (Bourke-Taylor et al., 2011; Loprest, 2004).

The most common medical problems reported by the parents in this study were high blood pressure and back and neck pain, as well as sore muscles. These findings are similar to other studies reporting that parents caring for children with movement disorders have a higher risk for musculoskeletal injuries. The risk of sustaining an injury increases as the child grows and activities such as transfers and lifting become more physically demanding (Düger, 2003; Tong et al., 2003). There is a need for further research to identify which specific variables increase the potential of sustaining a musculoskeletal injury among these parents. Future research can also identify which interventions are more effective in decreasing the potential for musculoskeletal injuries.

The parents in this study, although longtime residents of the U.S., showed a preference for Spanish and scored higher in the Hispanic domain. This is a significant finding because many studies show a connection between low English proficiency and dissatisfaction with health care services (Avila & Bramlett, 2013; Decamp et al., 2011; Parés-Avila et al., 2011; Sharib et al., 2014; Wolff & Ellis, 2009). These parents reported higher perceived social support from family members and significant others and lower perceived social support from friends. These findings confirm how the cultural constructs of *familism* and *allocentrism* shape Hispanic parents' expectations of social support (Gallo, 2009; Rodriguez et al., 2007).

The results of this study corroborate that those parents with low acculturation experience higher levels of parenting stress. On the other hand, parents reporting higher education level and longer residency in the U.S. exhibited lower levels of parenting stress. In this study, parents who experienced higher levels of parenting stress were more prone to report symptoms of depression. Parents who perceived low social support and higher levels of parenting stress were more likely to report more negative physical and mental health outcomes. These findings are consistent with the results of recent studies exploring the effects of parenting stress on the health of parents caring for children with disabilities (Almasri, 2011; Dillenburger, 2011; Eisenhower, 2005; Spratt, 2007). Conversely, parents who reported high levels of perceived social support reported better physical and mental health outcomes. These findings validate previous studies showing a strong correlation between perceived social support and health outcomes (Cantwell et al., 2014; S. Tétreault et al., 2014). Parents caring for children with disabilities can benefit from interventions, helping them improve their ability to cope with parenting stress. This study reaffirmed the importance of the family as the prevalent source of social support for Hispanic parents. Professionals working with these parents must implement interventions to improve family functioning and social support. Improved family functioning and perceived social support can have a positive impact on the physical and emotional health of these parents (Becerra et al., 2015; Brown, 2011; Devine et al., 2012; Doig et al., 2009).

The parents in this study with lower acculturation and lower educational achievement also reported lower perceived social support and higher level of parenting stress. This is consistent with the findings of various studies exploring the experience of immigrant parents with lower acculturation (Becerra et al., 2015; Decamp et al., 2011; Doig et al., 2009; Lucke et al., 2013;Yu & Singh, 2012). Parenting stress was the best predictor of depression as well as physical and mental health. These findings are similar to the findings of studies examining the physical and mental health of parents caring for children with disabilities (Cantwell et al., 2014; Gallagher & Hannigan, 2014). Parenting stress and low education level were good predictors of poor mental health; other studies have shown similar results (Kuhlthau, 2005; Lach, 2009; Mörelius, 2014).

The main limitations of this study included the small sample size, the use of the convenience sampling method, and the use of self-report questionnaires. Finally, the instrument used to measure the children's functional status did not offer sufficient differentiation.

This study highlighted the need to implement interventions to decrease the risk for musculoskeletal injuries on parents caring for children with movement disorders. Similar findings have been reported in the literature (Miller, 2014; Shepherd et al., 2007; H. Tonga et al, 2003; Tonga & Düger, 2008). In addition to helping these parents develop better support systems, they need assistance coordinating, planning, implementing, and delivering services for their children. This kind of assistance would promote more effective interventions to better serve the children and alleviate some of the burden of care experienced by these parents (Crettenden et al., 2014; Miller, 2014; Andrews, 2009; Palissano, 2009).

The parents in this study live in low income household and show low workforce participation. This is consistent with other studies reporting that parents caring for children with disabilities have difficulties maintaining employment (Heck, 2000; Lindly et al., 2016; Witt et al., 2009). These parents can benefit from interventions helping them enter or stay in the workforce. Higher participation in the workforce will improve the SES of these parents and can also have a positive effect on the parents' health outcomes (Bourke-Taylor et al., 2011). Parents in this study had inadequate insurance coverage;

this is consistent with the findings of eminent studies with minority racial/ethnic groups (Yu et al., 2004; Yu & Singh, 2012). This study supports the need to develop educational and training programs to teach health care professionals the cultural constructs relevant to minority groups. These training programs will improve the delivery of health care services and increase patient satisfaction as well as health outcomes (Amendola, 2011; Castro & Ruiz, 2009; Hamilton et al., 2013; Lucke et al., 2013; Parés-Avila et al., 2011).

Future research ought to continue exploring the impact of cultural constructs on parents' attitudes, expectation, decision-making, and priorities. Cultural constructs, such as *familism* and *allocentrism,* prevalent in the Hispanic community, should be investigated further (Campos et al., 2014; Koerner & Shirai, 2012). The incidence and severity of musculoskeletal injuries among parents caring for children with movement disorders should be explored further along with which interventions will be more effective in their prevention (Smith et al., 2012; Soares et al., 2012; Tonga & Düger, 2008). Finally, future research should investigate which social support interventions will better serve Hispanic parents caring for children with disabilities.

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