IDENTIFICATION OF STRESS IN LATINO FAMILIES WHO HAVE YOUNG

EXCEPTIONAL CHILDREN

by

Jennifer M. Rosato

May, 2014

Director of Thesis: Dr. Linda Crane Mitchell

Major Department: Child Development and Family Relations

The Latino population in the US is growing and there are many stressors that can accompany life in a new country; much more so when a family has a child with special needs. The aim of the present study is to explore the experiences and stressors of Latino families in Eastern North Carolina who have young exceptional children. A sample of 10 parents completed modified, translated versions of a widely used stress index along with a questionnaire that specifically addressed experiences and challenges regarding adaptation to a new culture and parenting children with special needs. The stress index contained items from both parent and child characteristic domains. Parents ranked each item on a scale from strongly agree to strongly disagree, and answered translated, open-ended questions with the available assistance of a translator. Significant, positive correlations were observed between certain parent and child domains. Qualitative responses were also analyzed, with themes surfacing such as lack of information, changes in priorities, changes in family relationships, and a sense of being overwhelmed. Results of this study provide insight into the largely unexplored experiences of Latino families in the US who have children with special needs.

IDENTIFICATION OF STRESS IN LATINO FAMILIES WHO HAVE YOUNG

EXCEPTIONAL CHILDREN

A Thesis

Presented to the Faculty of the Department of Child Development and Family Relations

East Carolina University

In Partial Fulfillment of the Requirements for the Degree

Master of Science

by

Jennifer M. Rosato

May, 2014

IDENTIFICATION OF STRESS IN LATINO FAMILIES WHO HAVE YOUNG

EXCEPTIONAL CHILDREN

by

Jennifer M. Rosato

APPROVED BY:

DIRECTOR OF

THESIS: _____

Linda Crane Mitchell, PhD

COMMITTEE MEMBER: _____

Archana Hegde, PhD

COMMITTEE MEMBER: _____

Kristen Cuthrell, EdD

CHAIR OF THE DEPARTMENT

OF CHILD DEVELOPMENT AND

FAMILY RELATIONS: _____

Sharon Ballard, PhD

DEAN OF THE

GRADUATE SCHOOL: _____

Paul J. Gemperline, PhD

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

As the Latino population in the United States continues to grow at a rapid pace, more research is being conducted in order to better understand phenomena surrounding this populace. In this study, the term Latino will refer to "individuals whose origins may be traced to Spanish-speaking countries of Latin America" (Denney et al., 2007, p. 327). Also, the current study will focus on Latinos who have immigrated to the United States; therefore the terms Latino and immigrant may be used synonymously. Acculturation and the stress associated with it can play a large role in those individuals' abilities to adapt to and cope with a new environment. Acculturative stress and related obstacles such as language barriers, unfamiliarity with culture and policy, and fear of judgment, discrimination, or deportation can all have a significant effect on a family's ability to take advantage of available community resources. Parenting in general comes with its share of stressors; however, research has shown that this stress increases with the presence of disability or delay in one's child, and may increase even more with the addition of acculturation.

Acculturation refers to the adaptation that occurs for individuals within a new culture by means of interactions between that individual and his or her environment. These interactions can be social or psychological and can affect the individuals involved as well as the greater culture (Caplan, 2007). Factors such as language barriers, unfamiliarity with a new location, different or unknown cultural practices, and the pursuit of new schools and workplaces can all contribute to the stress that a family experiences in the acculturation process, regardless of the family's location or culture of origin. Research has indicated that the process of acculturation is lengthy, difficult, and highly variable, with many potential negative outcomes such as poverty (National Poverty Center, 2011), role confusion (Sy & Romero, 2008), psychological issues (Kataoka et

al., 2003), and an array of behavioral challenges (Martinez, 2006). Having an exceptional child, which for the purposes of this study will be defined as a child with disability or delay, and participating in available services is likely to add to the stress experienced by these families who are already attempting to adapt. Early intervention (EI) is a field that provides support, education, resources, and therapeutic services to families with young children who have disabilities (Sigel, 1972). EI programs allow families to become aware of their child's condition, create realistic expectations, and provide the tools and methods necessary to encourage optimal development (First & Palfrey, 1994). The earlier a developmental delay or disability can be identified, the greater the chances of the child fully benefitting from specialized interventions that are implemented (Guralnick, 2005). According to legislation, EI applies specifically to children from birth to three years of age; however, there are also early childhood services aimed at reaching children who are preschool and school aged (Bruder, 2010).

In 1986, amendments to the original special education law of 1975 (referred to as P.L. 99-457) were passed which mandated services for preschool-aged children with disabilities and also allowed individual states to receive funding for the development of service programs for children from birth to three (Bruder, 2010). In 1990, the original special education law (or PL 94-142) was reauthorized and renamed the Individuals with Disabilities Education Act (IDEA). Part C (services to children birth through 3 years of age) and Part B (services to children 3 through 21 years of age) mandate certain practices that remain consistent across the various EI programs, such as implementing services for infants and toddlers in their natural environments with the involvement of family members, utilizing methods that are appropriate for young children's attention spans and learning styles, and applying multiple different categories of milestones (Bruder, 2010; Dunst, 2000). In order to put these aspects of IDEA into practice,

individualized family service plans (IFSP) and individualized education plans (IEP) were created. As the name suggests, an IFSP is a more family oriented program for infants and toddlers, including home visits, training, and other family-centered care practices, while an IEP is based more upon the child's individual needs when he or she becomes of preschool age, but may include family-centered practices as well (Bruder, 2010).

In family service fields such as early intervention, it is imperative that professionals are sensitive to these issues and have a working knowledge of acculturation and related stressors in order to better understand and serve the Latino families with whom they come into contact. There are many published studies regarding acculturation effects on Latino individuals and families, as well as a growing number of studies addressing Latino parents who have children with disabilities or behavioral issues; however, there are few studies that have addressed the experiences and stress of Latino immigrant parents who have children with special needs and who have been involved with the early intervention process.

CHAPTER 2: REVIEW OF LITERATURE

Theoretical Background

According to White and Klein (2008), theory contributes to research and science as a whole by gathering and grouping literature, articulating ideas, providing guidance for the development and measurement of hypotheses, demonstrating the relationship between ideas, making sense of how phenomena operate, helping researchers make predictions, and providing answers to questions of why and how certain phenomena occur. Boss, Doherty, LaRossa, Schumm, and Steinmetz (1993) also highlight the importance of theories that focus specifically on feminist concepts such as ethnic minorities. As families' ethnic compositions are becoming more diverse and family dynamics are changing, the demographic percentages of the United States are following suit; and, as a result, it is important to both conduct and analyze research that seeks to better understand these diverse populations.

The use of theory is prevalent in this realm of research, which strengthens literature by helping readers to develop a framework or lens through which to view and understand the issues at hand. Many researchers who study acculturation and acculturative stress refer to the theory of stress and coping (Lazarus and Folkman, 1984). This is not surprising, as the theory covers a broad span of stress itself, appraisal of that stress, and associated methods of reacting to and dealing with that stress. The use of this theory provides readers with information that is essential in the understanding of stress and coping as concepts as well as how they relate to and affect one another. When conducting studies regarding a specific population's acculturation processes, including the theory of stress and coping provides a thorough, organized foundation to which readers can refer as they review data.

Another model mentioned in relevant literature is Berry's (1980) bidimensional model of acculturation; however, its undoubted relevance raises questions as to why it does not appear more frequently. Instead of assuming that the dominant culture of a new environment would affect an individual, the bidimensional model posits that the individual has more control over his or her circumstances. It explores the different ways that individuals can adjust, including combinations of different levels of adaptation to the new culture with levels of adaptation from the culture of origin. It seems that this can be easily related to theories of stress and coping, as stress can involve the environment's effects on the individual, while coping can involve the actions of the individual, either upon his or herself or upon his or her environment.

The commonly seen reference to Bronfenbrenner's (1979) work in different combinations of ecological theories was not unexpected. His use of microsystems, mesosystems, exosystems, and macrosystems relate very well to the topic of acculturative stress and coping, as well as to parenting an exceptional child (see Figure 1). Individuals and their families are typically the subjects studied within the field of research, which are basic microsystems. Schools and workplaces are often of interest, which bring mesosystems into the interaction. The exosystems are studied in circumstances such as analyzing the effects of a parent's career on other members of the family or the effects of a child's schooling or behavior problems on other members of the family. When studying acculturative stress or other immigration factors, all of these things fall under the macrosystem category of culture.

Figure 1. Ecological Theory Applied to Latino Families with Exceptional Children

Macrosystem
EI laws and
programming,
Immigration laws
and factors,
acculturation

Exosystem
EI services and
child behavior;
Parent careers
and ability to care
for children

Mesosystem
Schools,
workplaces,
EI Services

Microsystem
Child and
Family
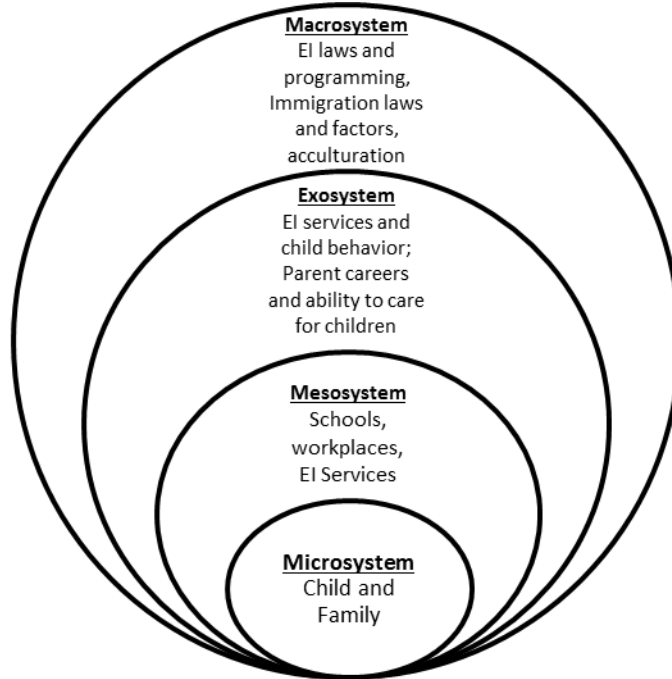
Note: Adapted from Bronfenbrenner (1979)

As the foundation of literature on the topics of acculturation and acculturative stress continues to grow, it is likely that the number of theories applied to these topics will grow as well. It is promising that researchers are already including well-established theories as well as newer models and frameworks when introducing concepts and analyzing data. With theoretical lenses in place, the reader is more prepared to consider any topic or study.

Early Intervention

Early intervention (EI) is an invaluable service to many families in the United States (US), consisting of mother-infant services, pediatric services, and developmental interventions (Denney, Itkonen, & Okamoto, 2007). In order to qualify for early intervention services, children must either have an identified medical diagnosis, significant two year delay in one area, or one and a half year delay in two areas (IDEA, 2004) as measured by standardized assessment. Over 25 years ago, roughly 10% of children in the US had some type of developmental delay or

disability (Drillien, Pickering, & Drummond, 1988). In 2010 and in the state of North Carolina alone, approximately 20,500 infants and toddlers were referred to the Infant-Toddler Program. Over 19,500 of these children were enrolled, which is roughly 5% of the total NC population of infants and toddlers. Latino children comprised 18% of those enrolled, with White children representing 52% and Black children representing 27% (NC Early Intervention Program, 2013). Due to the increasing prevalence of delays, the high number of referrals, the access to assessment, and the knowledge and expertise of EI professionals, it is of utmost importance that professionals are prepared to best understand and serve the families who are involved in these special services.

Delay has been said to be present when children have not met developmental milestones within an expected age-range that accounts for broad variation (Simeonsson, & Sharp, 1992). Providing the child with stimulation and education appropriate to his or her condition is essential and it is important to begin this process as early as possible, when the young child's nervous system is still impressionable. When parents are involved in EI services and begin to understand their children's conditions and needs, they can form realistic expectations and can provide appropriate support, equipment, and toys to the children's environments (First & Palfrey, 1994). EI can be just as helpful to the parents as to the child because, due to this regaining of control and knowledge, the parents can feel that they are genuinely helping their child and making a difference (Shonkoff & Hauser-Cram, 1987).

Stress in Families of Exceptional Children

A common topic within early intervention research is stress. Stress has been defined as a phenomenon that "occurs when an individual perceives that the demands of an external situation are beyond his or her perceived ability to cope with them" (Lazarus, 1966, p.9). Studies of stress

have shown that many negative results may come of it, including decreased immune function resulting in physical health problems, mood instability, and sleep complications (DeLongis, Folkman, & Lazarus, 1988). With this knowledge, it is of interest to know which circumstances, specifically within the realm of parenting and early intervention, are related or contribute to feelings of stress experienced by parents and families.

Parenting itself can affect the amount of stress experienced by an individual or family. Inverse correlations have been found between parental stress and positive parenting perceptions (Respler-Herman, Mowder, Yasik, Shamah, 2012), indicating that an individual's own views on and insights into parenting can have an effect on stress experienced. These parental stresses may only grow in families with exceptional children, due to added concerns and responsibilities. Families with children who require services for chronic illness may experience addition stress due to the fact that "stress can originate from the appraisal of uncertainty in illness as threatening and dangerous" (Moh & Magiati, 2012, p. 301; Santacroce, 2003). This uncertainty can likely be generalized to any situation of disability or delay to which one is unfamiliar. Parenting a child with a disability can be "a long-term and intense stressor that requires both short-term and long-term problem solving skills, and it is a very ambiguous stressor with issues such as the disorder's course and prognosis often unclear" (Weiss, 2002, p. 115).

Research has shown that stress levels tend to be higher for individuals who care for children with disabilities, and this can frequently be explained by challenges with communication and understanding (Johnston et al., 2003; Howe, 2006). While this finding refers to communication with the child, necessary communication with others about the disability can also contribute to stress. Moh and Magiati (2012) found that parental stress was positively correlated with the number of professionals with which the family had contact, and was

negatively correlated with the perceived collaboration with those professionals as well as the provision of information that was perceived to be helpful. Other common sources of stress within families of exceptional children are increased caregiver responsibility and extra expenses along with social aspects such as a lack of support (Plant & Sanders, 2007; Theule, Wiener, Rogers, & Marton, 2011). Mothers of children with autism have been found to more frequently report depressive symptoms, anxiety and somatic symptoms, and more distress related to burnout than their counterparts who were raising typically developing children or children with mental retardation (Weiss, 2002).

Regarding care-giving tasks, level of difficulty for the tasks and child behavior issues during the tasks have both been found to be high contributors to parental stress (Plant & Sanders, 2007). The severity of the child's disability and the parent's level of stress are also related (Plant & Sanders, 2007; Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005), which is likely in part to caregiver responsibilities. It is common for parents of children who have disabilities to report not getting enough sleep or poorer quality of sleep (Hedov, Anneren, & Wikblad, 2002; Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008; Meltzer, 2008), suggesting that the additional stressors of caring for children with disabilities can further affect the lifestyle and routines of parents (Gallagher, Phillips, & Carroll, 2010).

US Latino Population

According to 2010 census data, the Latino population in the United States has grown 43% since the year 2000, putting the count at approximately 50.5 million. This particular group now accounts for 16.3 of the total US population (Passel, Cohn, & Lopez, 2011). Between the years of 1990 and 2006, Latino students have accounted for 60% of public school growth in the US, resulting in about 10 million, or one in five, Latino students in the US public school system

(Fry & Gonzales, 2008). Fry and Gonzales (2008) also point out the projected growth in the number of Latino students to 28 million by the year 2050, in which case there would be more Latino students than non-Latino.

Acculturation

Acculturation is a topic that encompasses many facets of human development. Acculturation refers to "the process of social and psychological exchanges that take place when there are ongoing encounters between individuals of different cultures, with subsequent changes in either of both groups" (Caplan, 2007, p. 94). The term acculturative stress stems from the term acculturation, as these exchanges and encounters can evoke stress in the individuals involved. Factors such as language barriers, unfamiliarity with a new location, different or unknown cultural practices, and the pursuit of new schools and workplaces can all contribute to the acculturative stress that a family experiences in the process of becoming established, regardless of the family's location or culture of origin. Acculturative stress can also result from being a victim of discrimination (Gil, Vega, & Dimas, 1994).

When considering the population of Latino immigrants who are working, one factor of which to be aware is whether or not an individual's presence in the United States is documented. Research has shown that stressors for undocumented immigrants are more severe than for those of documented immigrants due to the increased likelihood of living alone and separated from family and of lower English proficiency (Arbona, et al., 2010). Also unique to undocumented individuals is the fear of deportation, which tends to be stronger in males than females (Arbona et al., 2010). It is worth noting that the sample used in the study conducted by Arbona and colleagues (2010) consisted of low-income and recent immigrants, making it likely that their stress levels could be higher due to financial struggle and unfamiliarity regardless of the status of

their documentation. Lack of US citizenship for parents is also a strong indicator of whether or not the children will have access to healthcare or health insurance (Huang, Yu, & Ledsky, 2006), both of which can be critical in families with special needs. Avoidance of the healthcare system for Latino immigrants may be due to language barriers, fear of deportation, and low levels of acculturation (Huang et al., 2006).

Separation from family and friends is a common theme in research conducted on the Latino immigrant population. Receiving social support has been found to be the most successful coping mechanism for Latino immigrants (Phinney & Haas, 2003), while results of other studies have indicated that separation from social networks can add to the stress experienced by immigrants, especially those who are undocumented (Hagan, Rodriguez, Capps, & Kabiri, 2003; Simich, 2006).

After looking specifically at the effects of acculturation on individuals and discussing certain theories as they pertain to families, one can assume that family units are affected as well. Smokowski, Rose, and Bacalloa (2008) examined acculturation in adolescents and in parents, and how levels of acculturation influenced different family factors such as cohesion, adaptability, and parent-adolescent conflict. The results indicated that individuals' involvement with their culture of origin along with biculturalism, which refers to being integrated into the new culture as well, were positively related to all three of the family-related dependent variables. Research by Miranda, Estrada, and Firpo-Jiminez (2000) also supports this notion, finding that Latino families who are bicultural demonstrate higher levels of commitment, help, and support, and therefore have lower levels of conflict. When families share a common goal of remembering their own heritage and culture while adapting to a culture that is new, it is likely to form a support system that is more cohesive in the way that it functions.

Acculturative stress has been found to be associated with depressive symptoms (Romero & Roberts, 2003), post-traumatic stress disorder (Kataoka et al., 2003), and other behavioral outcomes (Martinez, 2006). It has also been shown that many of these negative effects are similar across age groups within the Latino population (Crockett et al., 2007). In addition to the typical stressors present for Latino immigrants, having a child with delays or disabilities is sure to add to the amount of effort that parents must put forth in order for the family to thrive in a new environment. Factors contributing to acculturative stress may prevent families from accessing critical information about their children's disabilities and special needs, potentially putting children at greater risk for poor outcomes in the areas of health and development (Badr, 2001; Denney et al., 2007).With the population statistics now being as high as they are, there must be clear, easily accessible child and family services available to the families within the Latin American population who have children with disabilities.

Latinos' Experiences with Early Intervention

In order to know how to best serve a diverse population, it is important to understand a subject matter from another culture's perspective. Researchers have found that individuals from different ethnic and cultural groups have many differences regarding their beliefs about illness, disability, social support, and the use of certain professional practices and services (Bailey et al., 1999). These differences, especially between the professionals and families being served, can hinder the successful implementation of any treatment programs (Santos, Fowler, Corso, & Bruns, 2000). Early intervention professionals have attempted to broaden their cultural knowledge; however, data that specifically address the Latino population within the fields of pediatrics and EI are sparse (Walsh & Ross, 2003) and professionals have expressed reluctance to search for such data, as the process is time consuming and typically must be fit into the

workday (Lee, Ostrosky, Bennett, & Fowler, 2003). Because of this, challenges arise in finding a balance between using practices that are empirically validated and practices that are culturally relevant (Iglesias & Quinn, 1997).

While these services do not intentionally discriminate between different families and cultures, research has shown that some individuals have more difficulty accessing resources or participating in services regarding EI and other important health and family services (Salas, 2004; Denney et al., 2007). There is a lack of Latino or bilingual professionals in the early childhood field, as well as a lack of staff preparation and training for working with culturally diverse populations (Buysse, Castro, West, & Skinner, 2005). Buysse et al. (2005) found that Head Start showed the highest ratings of parental involvement, providing parents with opportunities to participate in making decisions about program policies and involving parents in child's education.

When addressing the needs of Latino parents who have children with disabilities, the need for information was the most commonly expressed need in the study conducted by Bailey and colleagues (1999), followed by family/social support and financial needs. Hughes et al. (2008) found that mothers were afraid for their children to go to school because of their lack of familiarity to and comfort with the school environment. Similarly, one father from the same study claimed that "teachers should write letters to the families to explain what is happening in the classroom" (p. 250). In response to attending Individualized Educational Plan (IEP) meetings which are designed to discuss the specific needs of a child with a disability or delay, one mother claimed that she does not like to attend the meetings because the educational staff "pretend to care about us, but they don't know us. They don't ask what we need or want. They always use those big words that I can't understand" (Salas, 2004, p. 188). Other mothers in Salas's study

(2004) also mentioned feeling embarrassed due to teachers' requests of English use only when speaking with parents. Some stated feeling disrespected in school meeting atmospheres by not having their time valued, by staff members' comments, by stares from other teachers and parents, and by a lack of inquiry regarding their needs. Salas advocates for educators' views on parental involvement to shift to a more diverse view that would better include families of different cultural backgrounds.

Language barriers have been shown to cause stress, frustration, and confusion specifically within neonatal intensive care units, with Spanish-speaking parents reporting that they received inadequate information regarding their infant's status and needs (Santarelli, Denney, Singer, & Singer, 2000; Denney et al., 2001; Denney et al., 2007). Within the need for information, information about services available to families of children with special needs was reported the most frequently, regardless of the ethnicity of the parents; though, Latino parents reported this specific need more than their American Indian and Euro-American counterparts (Sontag & Schacht, 1994; Denney et al., 2007). Researchers conducting a similar study found that Latino parents also reported more unmet needs than Euro-American parents regarding health conditions, rehabilitation therapy programs, information, and support (Gannotti, Kaplan, Handwerker, & Groce, 2004; Denney et al., 2007).

One of the main aspects of Latino culture that may be overlooked by professionals is their religious affiliations. In one sample of 250 Latino parents who have children with disabilities, over half of them perceived the presence of disability to be from God, whether it was considered to be a blessing or punishment. Only three percent of these parents believed that their child's disability was a punishment, with others adamantly claiming that this perception is outdated or more prevalent in other areas (Skinner, Rodriguez, & Bailey, 1999). Regardless of

whether the presence of disability was thought to be a positive or negative, understanding the beliefs of Latino parents will shed light on how they view their child's disability, how they cope, and which interventions will be most effective. At the very least, it would be beneficial to be aware of the fact that Latino families could possibly be suffering from this stigma within their own social support groups.

Poverty is not always a factor that first comes to mind when working with families through early intervention services; however, it seems to be a factor that affects Latino families in the United States. In 2010, 26.6% of Latinos in the United States were living in poverty (National Poverty Center, 2011). According to data collected in the National Early Intervention Longitudinal Study (NEILS), 48% of Latino families within Early Intervention programs are living in poverty (Scarborough et al., 2004). This discrepancy could be the result of more stress and financial strain within families who have children with disabilities as opposed to the general population. Latino students who were born outside of the US, which is about 35% of Latino students, are more likely to live in poverty than their US-born counterparts (Fry & Gonzales, 2008), suggesting that it takes a substantial amount of time for foreign individuals to adapt and become established in a new country and culture.

Stress has been found to be the largest indicator of cognitive and motor development in low-birth weight, Latino infants of low socioeconomic status, with maternal income, home environment, and maternal confidence explaining most of the variance in motor development (Badr, 2001). This finding is especially relevant in that recognizing stress is a key factor while still paying mind to others. The home environment could entail family dynamics, sanitation and safety, or amount of stimulation available to the infant, the latter two of which require the parent to be well informed of a child's special needs. Level of maternal confidence may determine how

much effort the mother puts toward caring for the child, including stimulation and healthy, loving interactions. Maternal confidence, or competence, is also a factor measured by the Parental Stress Index (PSI).

Parental Stress Index

The PSI was created based on the following three factors: "those inherent to the child, those inherent to the parent, and those related to the parent-child interaction" (Zaidman-Zait et al., 2010, p. 1269; Abidin, 1995). One of the most commonly used PSI forms in current research is the PSI short form (PSI-SF; Abidin, 1995), including 36 items addressing parental distress, parent-child dysfunctional interactions, and the parent's perception of the child's level of "difficulty" (Zaidman-Zait et al., 2010).

In a study of stress in mothers of children with intellectual disability, data collected from the PSI-SF showed a clear association between child behavior difficulties and parent stress, between greater levels of social support and lower levels of stress, and between mother's cognitive states and their parental stress (Hassall, Rose, & McDonald, 2005). The short form was also used in finding that ADHD characteristics in children was related to parent stress, as was being a single parent and lower levels of social support, with no relationship found between stress and parent age or parent education (Theule et al., 2007). Other researchers using the original PSI found that parents who have children with high functioning autism experience more parental stress than those who have typically developing children, attributing child factors such as hyperactivity, demandingness, and disturbed mood to this heightened level of stress (Rao & Beidel, 2009).

When applying the short form to families with exceptional children, however, Zaidman-Zait and colleagues (2010) found mixed results regarding the instrument's content validity.

16

While further analyses and studies must be conducted to confirm whether or not each item is appropriate, it may be useful to test other modified versions of the PSI in order to attain greater accuracy in measuring stress within families of exceptional children. The current study will contribute to literature that incorporates the various versions of the PSI, as the child characteristics of distractibility, demandingness, adaptability, and acceptability, and parent characteristics of competence, role restriction, and depression can be especially relevant to stress experienced by families of exceptional children. While these sets of characteristics, or domains, will be the main focus of analyses, additional domains (i.e. spousal factors) will be observed in order to address themes of past research, such as social support.

Purpose

The aim of this study is to analyze research that has been collected over the last five years at a local early intervention conference in order to gain a better understanding of the stress experienced by Latino parents who have young children with developmental delays, disabilities, or other special needs. The research study will focus on a convenience sample of 10 Latino parents who completed a modified version of the PSI (Parental Stress Index; Abidin, 1995) and responded to a questionnaire developed by the researcher. The qualitative data from the questionnaire from this same population was analyzed and compared to quantitative responses in order to provide detailed information about the experiences and stressors of these Latino families. While exploring this data, the following research questions are of interest:

1. What are demographic characteristics of Latino families and children within the current study's sample?

2. How do distractibility, demandingness, adaptability, and acceptability characteristics of children with special needs impact the competence, depression, and role restriction characteristics of parents?

3. a) What themes emerge from qualitative responses regarding Latino parents' experiences with their exceptional children?

   b) Do Latino parents emphasize acculturation factors that have commonly appeared in past research?

4) How do participants' quantitative responses relate to their qualitative responses?

CHAPTER 3: METHOD

Design

This was mixed-method design study, involving both a quantitative measure addressing different domains of parental stress and an open-ended questionnaire addressing more in-depth aspects of stress and daily challenges. Data were collected from a sample of Latino parents who have exceptional children in order to learn about their perceived stress and personal parenting experiences.

Instruments

The form given to participants was comprised of three sections. A short demographic form was included in order to collect sample characteristic details. The modified PSI (Mitchell, 2008) was used to obtain quantitative data as well as a questionnaire created by the researcher to obtain qualitative data.

Demographic information. A demographic questionnaire was created in 2009 to be distributed with the PSI forms to parent participants in the annual Early Intervention Conference. This questionnaire addresses gender, marital status, age range, race, highest education achieved, employment status, annual family income, number of children, whether or not at least one child has a disability or delay, the age of the child with disability or delay, the area of disability or delay, and current services received.

Modified PSI form. The original PSI, which consists of 120 total items, was shortened to 40 items (Appendix B) in order to provide parents with a simpler, less time-consuming survey. The 40 item PSI is also more concise for the purposes of the present study, addressing only certain child and parent characteristics that are especially relevant to families of exceptional children. This amended version of the PSI, created by an EI Specialist, was reviewed and revised

by a team of specialists who represented various agencies who provided services to families and who served on the annual EI conference planning committee. The questions included were not changed from their original wording. Domains seen as most relevant were chosen by the researchers, and questions within those domains were chosen to be included in this amended PSI. This modified form was also translated into Spanish by a bilingual specialist of a local school system who also served on the EI conference committee.

As in the original PSI, specific survey items are categorized within themes of both parent and child characteristics. Themes that were considered most relevant to the field of EI were of highest interest for data collection, and therefore included in the amended PSI. Included parent domains consisted of competence (5 items), depression (5 items), and role restriction (4 items), while included child domains consisted of distractibility (4 items), acceptability (5 items), adaptability (6 items), and demandingness (3 items). Various other items represent domains such as spousal factors and attachment.

Examples of questions within each domain are listed in Table 1. All items are Likert-type statements requiring participants to indicate the degree to which they agree on a 4 point scale including the following options: strongly disagree, disagree, agree, and strongly agree. Most of the items included in this form of the PSI are negatively worded, meaning that strong agreement with the items would indicate higher levels of stress or difficulty. Therefore, items that are positively worded, or those with which strong agreement would indicate less stress or difficulty, were reverse coded.

Table 1

Modified PSI Items Included in Each Domain

Domain	Modified PSI Item
Competence	
	When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.
	I can't make decisions without help.
	I feel that I am successful most of the time when I try to get my child to do or not to do something.
Depression	
	When I think about the kind of parent I am, I often feel bad or guilty about myself.
	When my child misbehaves or fusses too much, I feel responsible, as if I didn't do something right.
	After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.
Role Restriction	
	Most of my life is spent doing things for my child.
	I feel trapped by my responsibilities as a parent.
	I often feel that my child's needs control my life.
Distractibility	
	My child squirms and kicks a great deal when being dressed or bathed.
	My child appears disorganized and is easily distracted.
	My child will often stay occupied with a toy for more than ten minutes.
Acceptability	
	My child doesn't seem to learn as quickly as most children.
	My child does a few things which bother me a great deal.
	My child does not like to be cuddled or touched very much.
Adaptability	
	My child gets upset easily over the smallest things.
	It takes a long time and it is very hard for my child to get used to new things.
	My child doesn't seem comfortable when meeting strangers.
Demandingness	
	My child seems to cry or fuss more often than most children.
	My child has had more health problems than I expected.
	My child seems to be much harder to care for than most.

Questions addressing parents' perceived levels of support were grouped into a separate variable in order to determine the relationship between social support and other parental characteristics. This social support variable consisted of items such as "I feel alone and without

friends" and "Since having my child, my spouse (or male/female friend) has not given me as much help and support as I expected."

    Reliability. Cronbach's alpha levels (Cronbach, 1951) for the chosen domains were observed from the original PSI calculations (Abidin, 1995) and compared to the levels found for the new modified version in order to determine whether or not the new selection of items maintained internal consistency, or reliability, comparable to that of the original. Table 2 shows this comparison. While some alpha levels seem lower than what is acceptable, this is likely due to the number of items within each domain, as it is common to find low alpha levels for scales with less than ten items (Pallant, 2010). Under these circumstances, the mean inter-item correlations can also be useful, with an optimal range for each domain's mean being between 0.2 and 0.4 (Briggs & Cheek, 1986; Pallant, 2010).

Table 2

Alpha Levels for Each PSI Domain

Domain	Original PSI	Modified PSI
Child Domain		
Adaptability	0.76 (11 items)	0.77 (6 items)
Acceptability	0.79 (7 items)	0.70 (5 items)
Demandingness	0.73 (9 items)	0.60 (3 items)
Distractibility	0.82 (9 items)	0.49 (4 items)
Parent Domain		
Depression	0.84 (9 items)	0.81 (5 items)
Role Restriction	0.79 (7 items)	0.55 (4 items)
Competence	0.83 (13 items)	0.45 (5 items)

    It was shown in the reliability outputs that, in some cases, a scale's alpha level would increase if a specific item within the scale was removed. The alpha level for distractibility would have increased to 0.63 without the item "My child will often stay occupied with a toy for more than ten minutes." The alpha level for role restriction would have increased to 0.64 without the item "Most of my life is spent doing things for my child." In both of these cases, researchers felt

that the items mentioned were valuable to their respective domains, and therefore should not be removed for the sake of a higher alpha level. The other two domains with lower alphas, competence and demandingness, did not have increased alpha levels upon the removal of any item. The mean inter-item correlations for each domain fell between 0.2 and 0.4 with the exceptions of competence (.15) and depression (.48), with both not deviating from the ideal range by more than one tenth.

Questionnaire. A questionnaire containing seven open-ended items was also distributed to participants. The aim of utilizing this form was to acquire greater depth of responses regarding participants' experiences with parental stress and acculturation. Questions address length of time in the US, family dynamics, daily challenges in caring for the exceptional child, changes to which the family has had to adjust, and challenges in adapting to a new culture. The questionnaire can be found in Appendix D.

Sample

Parent characteristics. Because such a specific population was needed to collect this data, random sampling was not feasible. The sample for this study was a convenience sample (N=10) of parents who were recruited by a bilingual specialist through a local public school system. All who agreed to participate were female. These mothers were all of Latin American descent and had moved to the United States. Six were married, three indicated being in a long-term relationship, and one did not specify a marital status. Three indicated being 23-26 years of age, one was 27-30, one was 31-34, and five were 35 or older. Four mothers did not complete high school, five mothers reported their highest level of education being high school graduate or equivalent, and one reported receiving a Bachelor's degree. One mother was employed full-time, eight were unemployed, and one did not specify. Three mothers identified a yearly family

income of $10,000 to $20,000, four identified $20,000 to $30,000, 1 identified $30,000 to $50,000, and two did not specify.

Child characteristics. Regarding the children of participating mothers, the average age was 4.6 years, with ages ranging from two to eight. While the gender of the children with disabilities was not addressed on the demographic questionnaire, qualitative responses indicated that eight of the ten children were male, with the remaining two not indicating. All children had some degree of delay or disability (see Figure 2) that the mother open-endedly specified: three with autism, one with Downs Syndrome, one with developmental delay, one with speech impairment, one with hearing impairment, one with impairments of vision, hearing, and communication, and one not specified. All children had siblings, with five children having one sibling, two children having two siblings, one child having three siblings, one child having four siblings, and one child having five siblings.

Figure 2. Child Disabilities and Delays Represented

Not specified
11%

Autism
34%

Speech, Vision,
or Hearing
Impairment
33%

Down's
Syndrome
11%

Developmental
Delay
11%
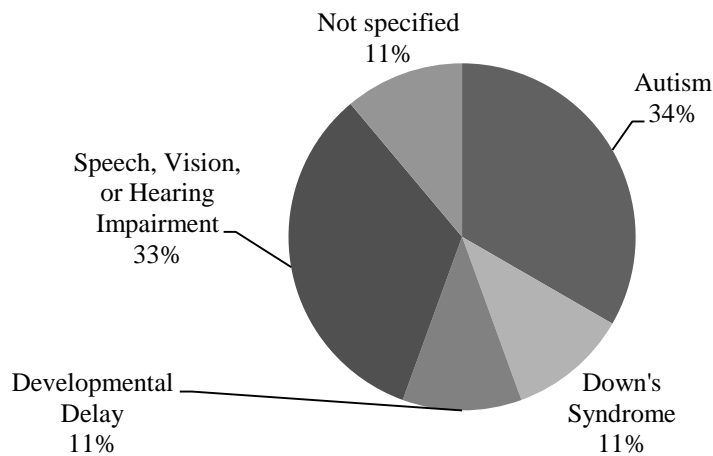
Procedure

The amended version of the PSI used in this study has been used to collect data at an annual EI conference in Eastern North Carolina over the five year period between the years 2008 and 2013. Data were collected at the conference each year with the exception of 2011, due to two

conferences in 2010. Completing this form was optional and anonymous for conference attendees. Completed surveys were labeled with an ID number and the year of the conference attended in order to protect participants' identities. No compensation was given to those who participated. While the Latino portion of this large, unpublished data pool will be referred to, the focus will be on the forms and qualitative responses of the sample of 10 from 2013.

For the 2013 conference, open-ended questions were developed by the first author, reviewed by and edited with the input of an expert in the field of EI, and translated by the same specialist who translated the PSI form. Approval was obtained for these questions, along with the amended PSI, to be distributed to Latino parents in order to gain qualitative data regarding their unique stressors and experiences while still being able to compare quantitative responses to those of the larger data pool. Due to limited Latino parent attendance at the 2013 conference, the bilingual specialist offered participation in our study to parents from a local school system by passing out survey packets to be completed if desired. This translator was available to each parent who wished to complete the questions, providing assistance with explanations of items and with writing responses, as well as with translating responses back to English before returning forms to the researchers.

CHAPTER 4: RESULTS

Plan for Analysis

Correlations between domains were conducted on the modified PSI data using SPSS in order to determine relationships between the different modified PSI domains. Pearson product-moment correlation coefficients were calculated to note the strength and direction of the relationships (Pallant, 2010). In addition, qualitative responses were analyzed for comments containing either themes which were commonly found in past literature, or content relevant to the PSI domains. Qualitative responses were coded (Strauss & Corbin, 1990) in order to find themes within the data as well as alignment between questionnaire responses and PSI domains.

The coding process used was similar to the constant comparative method proposed by Glaser and Strauss (1967). The constant comparative method included reading answers to the questions numerous times and grouping answers thematically across various responses acquired from the participants. First, themes were generated from the responses of the participants in the study. Second, common themes across the participants were identified.

In order to provide a foundation for the current study's correlational results, the comparisons between domains within the large pool of Latino participant data collected over the course of EI conferences since 2008 (n=22) is shown in Table 3. Latino families comprised about 28% of this larger sample. Considering the current study's small sample of amended PSI data, current results were compared to the results from the large data pool in order to assess the similarity between the two sets.

Table 3

Correlations Between Modified PSI Child and Parent Domains in Large Data Pool

		CDis	CDem	CAd	CAc	PC	PRR	PD
CDis	Correlation	1	.613[**]	.329	.626[**]	.436[*]	.201	.151
	N	22	22	18	20	21	22	21
CDem	Correlation	.613[**]	1	.719[**]	.714[**]	.455[*]	.154	.132
	N	22	22	18	20	21	22	21
CAd	Correlation	.329	.719[**]	1	.673[**]	.149	-.326	-.330
	N	18	18	18	17	18	18	17
CAc	Correlation	.626[**]	.714[**]	.673[**]	1	.376	.356	.312
	N	20	20	17	20	19	20	19
PC	Correlation	.436[*]	.455[*]	.149	.376	1	.210	.472[*]
	N	21	21	18	19	21	21	20
PRR	Correlation	.201	.154	-.326	.356	.210	1	.773[**]
	N	22	22	18	20	21	22	21
PD	Correlation	.151	.132	-.330	.312	.472[*]	.773[**]	1
	N	21	21	17	19	20	21	21

Note: CDis=Child Distractibility; CDem=Child Demandingness; CAd=Child Adaptability; CAc=Child
Acceptability; PC=Parent Competence; PRR=Parent Role Restriction; PD=Parent Depression
**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Correlations

Table 4 represents the relationships between the domains included in the modified PSI.

Specifically of interest were the relationships between child domains and parent domains. There

was a moderate association between child distractibility characteristics and parents' feelings of

role restriction ($r = 0.67$, $p=.07$), though the relationship is not quite statistically significant.

Child demandingness was found to be significantly associated with all parent domains. The

strongest relationship of the three was found between child demandingness and parental role

restriction ($r=.97$, $p<.001$). Child adaptability was significantly correlated to both parental

competence ($r=.88$, $p<.01$) and parental role restriction ($r=.89$, $p<.01$). Child adaptability also

was found to be significantly associated with parental competence (r=.75, p<.05) and parental

role restriction ($r=.87$, $p=.01$). Significant relationships were also observed between certain

parent domains. Parent competence was significantly correlated with role restriction ($r=.85$,

$p<.01$), as was parental depression ($r=.76$, $p<.05$).

Table 4

Correlations Between Modified PSI Parent and Child Domains

		CDis	CDem	CAd	CAc	PC	PRR	PD
CDis	Correlation	1	.681[*]	.352	.446	.403	.668	.506
	N	10	10	8	9	10	8	9
CDem	Correlation	.681[*]	1	.868[**]	.850[**]	.729[*]	.966[**]	.697[*]
	N	10	10	8	9	10	8	9
CAd	Correlation	.352	.868[**]	1	.965[**]	.879[**]	.892[**]	.539
	N	8	8	8	7	8	7	7
CAc	Correlation	.446	.850[**]	.965[**]	1	.745[*]	.870[*]	.566
	N	9	9	7	9	9	7	8
PC	Correlation	.403	.729[*]	.879[**]	.745[*]	1	.852[**]	.615
	N	10	10	8	9	10	8	9
PRR	Correlation	.668	.966[**]	.892[**]	.870[*]	.852[**]	1	.759[*]
	N	8	8	7	7	8	8	7
PD	Correlation	.506	.697[*]	.539	.566	.615	.759[*]	1
	N	9	9	7	8	9	7	9

Note: CDis=Child Distractibility; CDem=Child Demandingness; CAd= Child Adaptability; CAc=Child
Acceptability; PC=Parent Competence; PRR=Parent Role Restriction; PD=Parent Depression
*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

Comparison to large data pool. Due to the greater sample size of the large data pool,

some correlations were much weaker than in the current study but still attained statistical

significance. This seemed to be the case for many of the comparisons between parent and child

domains. An example of this is the relationship between child demandingness and parental

competence. In the current study, this correlation was moderate in strength and significant

($r=0.73$, $p<.05$); while, in the large data pool, significance was attained with a much weaker

correlation ($r=0.46$, $p<.05$). Correlations between child demandingness and all parent domains

were significant for the current study but not all relationships between these variables were significant in the large data pool.

Correlations between child distractibility and demandingness were significant in both the current study's sample ($r=.68$, $p<.05$) and in the larger data pool ($r=.61$, $p<.01$). Parent role restriction and parent depression were also significantly and positively correlated in both the current study ($r=.76$, $p<.05$) and in the larger data pool ($r=.77$, $p<.01$).

Questionnaire Responses

Qualitative responses to the open ended questions were compiled according to themes that align to the parent and child characteristics represented in the amended PSI. Responses that related to each domain are shown in Table 5. The domains included in the amended PSI were clearly represented in participants' qualitative responses. The domain of distractibility was the least represented among responses, indicating that other concerns may take precedence over their child's distracted behaviors.

Table 5
Qualitative Responses and Respective PSI Domains

Parent Characteristics
    Competence   "Need help knowing how to deal with child's behavior"
                                         "I don't know what to do"
                                         "I need help to know how to educate him"
                                         "[challenges include] teaching him and helping him in his development and speech"
                                         "Managing my son's bad behavior, his aggression to others, and communication since he doesn't speak; These are some challenges which are very difficult for me to manage."
                                         "I did not understand what he wanted."
    Role Restriction   "[challenges include] not sleeping, not caring for myself…"
                                           "We can't go to the movies, visit friends, or attend social events."
                                           "He wants my full attention. He does not want his siblings to come near me, not even his Dad."
    Depression   "[challenges include] crying when I don't know how to respond to him screaming."

	"Nobody helps me."
	"I feel depressed and tired."
Child Characteristics	
Distractibility	"I try to make sure he behaves in other places. We take turns, my husband and I."
Demandingness	"He needs a lot of attention, patience, and love."
	"The biggest change for me is always adjusting to his needs, his extreme supervision, and his care."
Acceptability	"It has been difficult to accept him as he is. He fights with his siblings and sometimes with his stepdad. I'm used to it now but I have to try and keep order"
	"He is intelligent but has not reached the level of other children yet."
	"He fights with the other children sometimes but he's like any other child."
	"He is making very little progress."
Adaptability	"Family can't play well with him because of his [autistic] characteristics"
	"I have gotten used to his therapies and what he needs."
	"For a short time everything is good, then he doesn't want to share his toys and the problems start. Sometimes with his dad, he is aggressive"
	"[challenges include] learning sign language"
	"[relationship with family is] a little difficult because they don't understand him"
Acculturation	
	"[challenges include] the society, adapting, and cutting off some friendships"
	"In my case, [challenges include] the English language because I can't help him."
	"A difficulty is that I don't speak English"
	"Yes, everything was different, the language"

Themes. Themes emerged from the qualitative responses within each of the PSI domains. Within the competence domain, a lack of information, lack of education, and feelings of incompetence were expressed. This is seen in comments such as "I don't know what to do" and "I need help to know how to educate him." Regarding behavior specifically, mothers express needing help "knowing how to deal with child's behavior" as well as claiming that a very difficult challenge consists of managing "bad behavior, his aggression to others, and communication since he doesn't speak." This same theme also arose within the depression

domain, in that a mother confesses that she copes by "crying when I don't know how to respond to him screaming." This statement also hints at a sense of being overwhelmed, which is further supported within the depression domain by comments such as "nobody helps me" and "I feel depressed and tired."

Themes such as the neglect of self or a change in priorities can be seen in the domain of role restriction, and also could relate to depression considering their similarity to a sense of being overwhelmed. One mother expresses "not sleeping, not caring for myself," while others claim that social outings are no longer possible or that the child "wants my full attention," disliking when other family members are near. This seems to be closely related to the domain of demandingness, which also consists of comments regarding extra attention for the child and greater adjustment to the child's care and supervision. The domain of acceptability shows a different side of these themes, largely demonstrating how parents have learned to accept the new lifestyle and the needs of their children. One mother states "It has been difficult to accept him as he is. He fights with his siblings and sometimes with his stepdad. I'm used to it now but I have to try and keep order."

The adaptability domain contains themes of family relationship complications and personal development, expanding on the family's acceptance and demonstrating how it has adapted accordingly. Some comments had a positive tone, such as a mother who expressed having learned sign language to communicate with her child, and a mother who claims that she has "gotten used to his therapies and what he needs." Other comments indicate the hardship that comes with the adaptation process, like the mother who stated that family relationships are more difficult due to members who "don't understand him." One mother claims that "for a short time

everything is good, then he doesn't want to share his toys and the problems start. Sometimes with his dad, he is aggressive."

Comparison of themes to PSI responses. Themes found in qualitative responses were compared to related correlational results in order to assess congruency between the two result sets. Qualitative responses regarding competence relate largely to the demandingness of the child and the child's needs. This parallels the correlational results as there is a significant, positive relationship between parental competence and child demandingness ($r=.73$, $p<.05$). Correlations also match the responses relating to role restriction that hint at depression ($r=.76$, $p<.05$) and demandingness ($r=.97$, $p<.001$), as the relationship between role restriction and both of the latter variables are significant. Responses under the domain of depression seem to be associated with a lack of adaptation and competence. This is not, however, congruent with quantitative measures as neither adaptation ($r=.54$, p$>.05$) nor competence ($r=.62$, p$>.05$) are significantly associated with depression.

Social Support

The variable created to address social support within the modified PSI was used to analyze quantitative associations between perceived level of social support and other characteristics. An item addressing social support on the questionnaire was also analyzed.

Quantitative. Correlations between the social support domain and parent characteristics were analyzed in order to determine any association between perceived feelings of support and other parental characteristics. This analysis showed a significant, positive relationship only between social support and parental competence ($r=.71$, $p<.05$). The other relationships were positive in direction and moderate in strength but did not approach significance. These relationships are shown in Table 6.

Table 6

Correlations Between Perceived Social Support and PSI Parent Domains

		SS	PC	PRR	PD
SS	Correlation	1	.707[*]	.527	.467
	N	10	10	8	9
PC	Correlation	.707[*]	1	.852[**]	.615
	N	10	10	8	9
PRR	Correlation	.527	.852[**]	1	.759[*]
	N	8	8	8	7
PD	Correlation	.467	.615	.759[*]	1
	N	9	9	7	9

Note: SS=Social Support; PC=Parent Competence; PRR=Parent Role Restriction;
PD=Parent Depression.
*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

Qualitative. Qualitative responses from this study support the well-established importance of social support. Surprisingly, with the exception of few, respondents indicated strong support systems. One respondent stated, "Sometimes I leave the children with my sister, and my aunt helps with my autistic child." This family support can be helpful in a number of ways, providing parents with the opportunity to rest, engage in self-care, care for other family members, or work. Another respondent emphasized the help of her husband: "I try to make sure [my child] behaves in other places. We take turns, my husband and I." One respondent reported the help of both her husband and her child's school; help from the latter of which is not frequently noted in literature for Latino immigrant families. Only one respondent very obviously indicated the lack of a support system regarding her child with special needs, stating "Nobody helps me."

CHAPTER 5: DISCUSSION

Based on the results found in the current study, this section aims to further discuss the findings as well as possible causes for any significant relationships. This discussion will include the sections of results in respective order. Comparisons to past research and implications for future research will also be included in order to determine how the current study's results can fit into current literature and influence future studies.

Correlations

The strong correlation between child distractibility characteristics and parental role restriction indicates that parents may be spending more of their time trying to occupy children with short attention spans. Role restriction, in turn, was associated with higher levels of parental depression, which may signify burnout. This is only one of the many examples of how indirect relationships may exist. Though child distractibility and parental depression were not significantly correlated, distractibility was significantly associated with role restriction, and role restriction significantly associated with depression. This also indicates that parents may sometimes focus on their own characteristics before those of their children; indeed, significant positive correlations between parental domains suggest that one parental domain may have higher scores due to another parental domain, and not necessarily due to a child characteristic.

The significant correlation between child demandingness and both parental role restriction and parental depression support previous findings that parent stressors such as exhaustion can affect positive parent perceptions (Respler-Herman et al., 2012). As child distractibility and child demandingness are moderately correlated ($r=.68$, $p<.05$), it is not surprising that both are positively related to parental role restriction. The strongest correlation of any two domains in the current study was found between child demandingness and parental role

restriction. Whether considering very short attention spans or greater needs due to disability or delay, parents will likely be spending more of their time providing care for these children than those who have children who are typically developing.

Considering child demandingness and parental role restriction are strongly related, and also considering that parental role restriction and parental depression are strongly related, it could be expected that child demandingness correlates with parental depression, as is indicated in this study. Parents who are not providing care to themselves or to other important individuals in their lives may not only feel restricted, but experience depressive symptoms due to this lack of involvement.

Two child domains which are very strongly related are child adaptability and child acceptability. This relationship suggests that as children and parents adapt to the child's special needs, there is a greater level of acceptance, or vice versa. Correlations of particular interest are between these two child domains and the parent domain of competence. These strong, positive associations may indicate that parents gain feelings of capability after reaching a level of adaptation and acceptance; or, inversely, parents may already feel competent in the care of their child, and therefore are more readily able to adapt and accept. Adaptability and acceptability are also related to role restriction which suggests that efforts to adapt and accept may consume a great deal of parents' time and energy. While there is some similarity in how child domains relate to parental role restriction and depression, this is not the case with adaptability and acceptability. This further supports the aforementioned notion that parental depression may be the result of other parental factors and not necessarily due to the processes of adaptation and acceptance.

Questionnaire Responses

Themes relating to parental competence involved a lack of information and education regarding caregiving tasks, as well as general feelings of incompetence. Finding a lack of information to be of concern is consistent with past studies of Latino families who have children with special needs (Bailey et al., 1999; Hughes et al., 2008). Assuming that information about and education related to caregiving tasks would assist families in adapting to their children's special needs, the significant, positive association between adaptability and competence found for the sample supports these qualitative responses. Within the domain of parental role restriction, changing priorities and neglect of self both appeared as themes, which also relate to the adaptation process that a family experiences. With role restriction and adaptability being highly and positively correlated, this supports qualitative responses as well.

Finding similar themes within the domains of parental competence, role restriction, and depression also support the correlational results that these domains are related. As the demandingness domain included comments regarding the great need for attention and patience as well as adjusting to extreme care and supervision, it is not surprising that demandingness showed significant, positive relationships with all parent domains in addition to presenting similarities in qualitative data.

Comparison of themes to PSI responses. Similarities between qualitative and quantitative responses certainly have implications but require careful consideration. Domains within the modified PSI were frequently found as themes within the qualitative responses. Finding parallels between the two sets of data provides a source of support for the validity of the modified PSI in that participants' written responses match their item scores. On the other hand, discrepancies must be carefully considered as well. As previously mentioned, the relationship

between two variables may be impacted by lurking variables and other relationships; therefore, the correlation may not truly depict the complexity of the association. For example, one would expect that lack of perceived competence and adaptability would contribute to an individual's feelings of depression. There may be factors which compensate for feelings of incompetence and inability to adapt that prevent an individual from feeling depressed. Also, the small sample size must be remembered, as a larger and more generalizable sample may offer different results.

Acculturative Stress

There was less of a response regarding acculturation challenges than expected. Only four out of the ten respondents indicated on their questionnaires having faced difficulties while adapting to the new culture. However, those who did identify difficulties relating to the acculturation process mentioned topics that are prevalent in literature. The most commonly mentioned issue was the language barrier, followed by changes in social dynamics and an overall different culture or environment. These results can be linked back to previous studies that address additional stress due to lack of English proficiency (Arbonna et al., 2010; Salas, 2004).

Social Support

While it seems that most participants had a support system to some degree, there was still a positive and significant relationship between social support and competence. This supports the notion established in past research that suggests social support is important to parents' ability to learn and to possess feelings of capability (Phinney & Haas, 2003; Hagan, Rodriguez, Capps, & Kabiri, 2003; Simich, 2006).

The growth of the Latino population in the United States may be contributing to the amount of social support experienced by Latino individuals. As awareness is raised for this population and resources are given within school systems, Latino parents of children with

37

disabilities may feel less isolated. Also, within the current study's sample, there were no families who had lived in the United States for less than five years, which can imply that families have had more time to become settled and create new support systems.

Theoretical Application

The theory of stress and coping (Lazarus & Folkman, 1984) is seen throughout the mothers' differing qualitative responses. Variables such as education, income, access to resources, and family support, among others, all contribute to the family's appraisal of stress. The level of perceived ability or inability to cope with the stress of having an exceptional child is dependent on that appraisal and may fluctuate throughout the coping process as the family grows and adapts.

Much of this study's results relate to Bronfenbrenner's (1979) microsystem of the individual or family unit. Early intervention services, whether in-home or through school systems, represent a key aspect of the mesosystem for these families. The amount of parent and child education as a result of EI services can greatly impact how a family is able to adapt, which approaches the exosystem, and the macrosystem is represented by the further development of services, research, and general culture due to these interactions.

Conclusion and Implications

The results of this study demonstrate the different interactions between child and parent characteristics in families of exceptional children. It seems that parent characteristics of role restriction, depression, and competence are inter-related, as are many of the child characteristics included within the PSI. These characteristics are not independent of one another and the implications of one should be considered on the others. As shown in the qualitative responses, despite the continued progression in the field of early intervention, Latino families are still

expressing a lack of knowledge and of resources to help them with their child's care. Mothers of Latino exceptional children seem to largely be the primary caregivers; however, paternal education may benefit the family in terms of increasing maternal perceived social support and lessening perceived role restriction due to shared understanding and responsibilities. Some families seem to remain unaware of how to interact with the exceptional child, or how to encourage other siblings and family members how to appropriately interact with the exceptional child.

Limitations and Future Research

The use of quantitative measures in research of Latino families with exceptional children is rarely seen and, therefore, these results can be built upon in order to better understand the relationships between these characteristics. Due to the small sample of this study, the use of quantitative measures is also a limitation. With such a specific population, it proves difficult to build a sample that can be generalized to the population. Convenience samples over random samples are not uncommon in literature; although, as the Latino population in the US continues to grow, it may become easier to obtain a large, random sample for future research. This sample also consisted of families who had access to a school system with a bilingual specialist. This fact alone may have impacted their perceived levels of social support and lessened their levels of acculturative stress in regard to parenting.

The newness of the modified version of the PSI may also be a limitation. This version has not yet been widely used; however, past research suggests that widely used forms are not perfect (Zaidman-Zait et al., 2010), which can justify the testing of newer forms. The field of early intervention is ever progressing, especially in regards to the Latino population. It is only fitting that research continue to grow and develop accordingly.

REFERENCES

Abidin, R. R. (1995). *Parenting Stress Index* (3rd edn). Odessa, FL: Psychological Assessment Resource.

Arbona, C., Olvera, N., Rodriguez, N., Hagan, J., Linares, A., & Wiesner, M. (2010). Acculturative stress among documented and undocumented Latino immigrants in the United States. *Latino Journal of Behavioral Sciences, 32*(3), 362-384.

Badr, L. K. (2001). Quantitative and qualitative predictors of development for low birth weight infants of Latino background. *Applied nursing research*, *14*(3), 125-135.

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A., (2005). Stress levels and adaptability in parents of toddlers with and without Autism Spectrum Disorders. *Research and Practice for Persons with Severe Disabilities, 30*(4), pp 194-204.

Bayley, N. (1969). *Bayley scales of infant development.* New York, NY: The Psychological Corporation.

Bayley, N. (1970). Development of mental abilities. In A. Gottfried (Ed.), *Home environment and early cognitive development* (pp. 235-269). New York, NY: Academic Press.

Bailey, D., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M., Rodriquez, P., …& Skinner, M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104*(5), 437-451.

Berry, J. W. (1980). Acculturation as varieties of adaptation. In A. M. Padilla (Ed.), Acculturation: Theory, models, and some new findings (pp. 9-25). Boulder, CO: Westview.

Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R., & Steinmetz, S. K. (1993). *Sourcebook of family theories and methods: A contextual approach*. NY: Plenum Press.

Briggs, S. R. & Cheek, J. M. (1986). The role of factor analysis in the development and

    evaluation of personality scales. *Journal of Personality, 54,* 106-148.

Bronfenbrenner, U. (1979). The ecology of human development. Cambridge, MA: Harvard

    University Press.

Bruder, M. B. (2010). Early childhood intervention: A promise to children and families for their

    future. *Exceptional Children, 76*(3), 339-355.

Buysse, V., Castro, D. C., West, T., & Skinner, M. (2005). Addressing the needs of Latino

    children: A national survey of state administrators of early childhood programs. *Early*

    Childhood Research Quarterly, 20, 146-163.

Caplan, S. (2007). Latinos, acculturation, and acculturative stress: A dimensional concept

    analysis. *Policy, Politics, & Nursing Practice, 8*(2), 93-106.

Crane Mitchell, L. (2008). Modified Parental Stress Index. *Unpublished Manuscript, East*

    Carolina University, Greenville.

Crockett, L. J., Iturbide, M. I., Torres Stone, R. A., McGinley, M., Raffaelli, M., & Carlo, G.

    (2007). Acculturative stress, social support, and coping: Relations to psychological

    adjustment among Mexican American college students. *Cultural Diversity and Ethnic*

    Minority Psychology, 13(4), 347-355.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*,

    16(3), 297-334.

DeLongis, A., Folkman, S., & Lazarus, R. S. (1988). The impact of daily stress on health and

    mood: psychological and social resources as mediators. *Journal of Personality and Social*

    Psychology, 54(3), 486-495.

Denney, M., Itkonen, T., & Okamoto, Y. (2007). Early intervention systems of care for Latino families and their young children with special needs. *Infants & Young Children, 30*(4), 326-335.

Denney, M. K., Singer, G. H. S., Singer, J., Okamoto, Y., Brenner, M. E., & Fredeen, R. M. (2001). Mexican immigrant families' beliefs and goals for their infants in the neonatal intensive care unit. *Journal of the Association for Persons with Severe Handicaps, 26*(3), 148-157.

Drillien, C. M., Pickering, R. M., & Drummond, M. B. (1988). Predictive value of screening for different areas of development. *Developmental Medicine & Child Neurology*, *30*(3), 294-305.

Dunst, C. J. (2000). Revisiting "Rethinking early intervention." *Topics in Early Childhood Special Education, 20,* 95-104.

First, L. R. & Palfrey, J. S. (1994). The infant or young child with developmental delay. *The New England Journal of Medicine, 330*(7), 478-483.

Fry, R. & Gonzales, F. (2008). One-in-five and growing fast: A profile of Latino public school students. *Pew Latino Center*. www.pewLatino.org

Gallagher, S., Phillips, A. C., & Carroll, D. (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Pediatric Psychology, 35*, 728-737.

Gannotti, M. E., Kaplan, L. C., Handwerker, W. P., & Groce, N. E. (2004). Cultural influences on health care use: Differences in perceived unmet needs and expectations of providers by Latino and Euro-American parents of children with special health care needs. *Developmental and Behavioral Pediatrics, 25*(3), 156-165.

Gil, A. G., Vega, W. A., & Dimas, J. M. (1994). Acculturative stress and personal adjustment among Hispanic adolescent boys. *Journal of Community Psychology*, *22*(1), 43-54.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* New Brunswick, NJ: Aldine.

Guralnick, M. J. (2005). An overview of the developmental systems model for early intervention. In M. J. Guralnick (Ed.), *The developmental systems approach to early intervention* (pp. 3-28). Baltimore, MD: Paul H. Brookes.

Hagan, J., Rodriguez, N., Capps, R., & Kabiri, N. (2003). The effects of recent welfare and immigration reforms on immigrants' access to health care. *International Migration Review, 37*(2), 444-463.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418.

Hedov, G., Anneren, G., & Wikblad, K. (2002). Swedish parents of children with Down's syndrome: Parental stress and sense of coherence in relation to employment rate and time spent in child care. *Scandavian Journal of Caring Sciences, 16*, 424-430.

Howe, D. (2006). Disabled children, parent-child interaction and attachment. *Child and Family Social Work, 11,* 95-106.

Huang, Z. J., Yu, S. M., & Ledsky, R. (2006). Health status an health service access and use among children in U.S. immigrant families. *American Journal of Public Health, 96*(4), 634-640.

Hughes, M. T., Valle-Riestra, D. M., Arguelles, M. E. (2008). The voices of Latino families raising children with special needs. *Journal of Latinos and Education, 7*(3), 241-257.

Iglesias, A., & Quinn, R. (1997). Culture as a context for early intervention. In *Contexts of early intervention: Systems and settings.* Baltimore, MD: Brookes.

Individuals with Disabilities Education Act of 2004 (IDEA). P.L. 108-446.

Johnston, C., Hessl, D., Blasey, C., Eliez, S., Erba, H., Dyer-Friedman, J. et al. (2003). Factors associated with parenting stress in mothers of children with Fragile X Syndrome. *Journal of Developmental and Behavioral Pediatrics, 24,* 267-275.

Kataoka, S. H., Stein, B. D., Jaycox, L. H., Wong, M., Escudero, P., Tu, W., ... & Fink, A. (2003). A school-based mental health program for traumatized Latino immigrant children. *Journal of the American Academy of Child & Adolescent Psychiatry, 42*(3), 311-318.

Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York, NY: McGraw-Hill.

Lazarus, R. S. (2000). Toward better research on stress and coping. *American Psychologist, 55*, 665-673.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.

Lee, H., Ostrosky, M., Bennett, T., & Fowler, S. (2003). Perspectives of early intervention professionals about culturally-appropriate practices. *Journal of Early Intervention, 25*(4), 281-295.

Lopez-Wagner, M. C., Hoffman, C. D., Sweeney, D. P., Hodge, D., & Gilliam, J. E. (2008). Sleep problems of parents of typically developing children and parents of children with autism. *Journal of Genetic Psychology, 169*, 245-259.

Martinez Jr., C. R. (2006). Effects of differential family acculturation on Latino adolescent substance use. *Family Relations, 55*(3), 306-317.

Meltzer, L. J. (2008). Brief report: Sleep in parents of children with autism spectrum disorders. *Journal of Pediatric Psychology, 33*, 380-386.

Miranda, A., Estrada, D., & Firpo-Jimenez, M. (2000). Differences in family cohesion, adaptability, and environment among Latino families in dissimilar stages of acculturation. *Family Journal, 8*, 341-350.

Moh, T. A., Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 6*, 293-303.

National Poverty Center. (2011). Poverty in the United States frequently asked questions. website: http://www.npc.umich.edu/poverty/#4

NC early intervention program. (2013, November 15). Retrieved from NC Early Intervention Program At-A-Glance website:
http://www.beearly.nc.gov/data/files/pdf/EIatAGlance2010.pdf

Pallant, J. (2011). *SPSS survival manual* (4th ed.). New York: Open University Press.

Passel, J. S., Cohn, D., & Lopez, M. H. (2011). Latinos account for more than half of nation's growth in past decade. *Pew Latino Center,* http://pewLatino.org/files/reports/140.pdf.

Phinney, J. S., & Haas, K. (2003). The process of coping among ethnic minority first-generation college freshmen: A narrative approach. *The Journal of Social Psychology, 143*(6), 707-726.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*(2), 109-124.

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on

    parental stress, sibling adjustment, and family functioning. *Behavior Modification, 33*(4),

    437-451.

Respler-Herman, M., Mowder, B. A., Yasik, A. E., & Shamah, R. (2012). Parenting beliefs,

    parental stress, and social support relationships. *Journal of Child and Family Studies*,

    21(2), 190-198.

Romero, A. J., & Roberts, R. E. (2003). Stress within a bicultural context for adolescents of

    Mexican descent. *Cultural Diversity and Ethnic Minority Psychology, 9*(2), 171.

Salas, L. (2004). Individualized educational plan (IEP) meetings and Mexican American parents:

    Let's talk about it. *Journal of Latinos and Education, 3*(3), 181-192.

Santacroce, S. J. (2003). Parental uncertainty and posttraumatic stress in serious childhood

    illness. *Journal of Nursing Scholarship, 35*(1), 45-51.

Santarelli, G. E., Denney, M. K., Singer, J., & Singer, G. H. S. (2000). "With my eyes I was

    telling her no": The experiences of fifteen Latino families in a NICU. *Unpublished*

    manuscript, University of California, Santa Barbara.

Santos, R., Fowler, S, Corso, R., & Bruns, D. (2000). Acceptance, acknowledgment, and

    adaptability: Selecting culturally and linguistically appropriate early childhood materials.

    Teaching Exceptional Children, 32(3), 14-22.

Scarborough, A. A., Spiker, D., Mallik, S., Hebbeler, K. M., Bailey Jr., D. B., Simeonsson, R. J.

    (2004). A national look at children and families entering early intervention. *Exceptional*

    Children, 70(4), 469-483.

Shonkoff, J. P., & Hauser-Cram, P. (1987). Early intervention for disabled infants and their

    families: a quantitative analysis. *Pediatrics*, *80*(5), 650-658.

Sigel, I. (1972). Developmental theory: Its place, the relevance in early intervention programs. *Young Children, 27,* 364-372.

Simeonsson, & Sharp. (1992). Developmental delays. In *Primary pediatric care* (pp. 867-870). St. Louis, MO: Mosby-Year.

Simich, L. (2006). Hidden meanings of health security: Migration experiences and systemic barriers to mental well-being among non-status migrants in Canada. *International Journal of Migration, Health and Social Care, 2*(3/4), 16-27.

Smokowski, P. R., Rose, R., & Bacallao, M. L. (2008). Acculturation and Latino family processes: How cultural involvement, biculturalism, and acculturation gaps influence family dynamics. *Family Relations, 57*(3), 295-308.

Sontag, J. C., & Schacht, R. (1994). An ethnic comparison of parent participation and information needs in early intervention. *Exceptional Children, 60*(5), 422-433.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Thousand Oaks, CA: Sage.

Sy, S. R., & Romero, J. (2008). Family responsibilities among Latina college students from immigrant families. *Journal of Latino Higher Education, 7*(3), 212-227.

Theule, J., Wiener, J., Rogers, M. A., & Marton, I. (2011). Predicting parenting stress in families of children with ADHD: Parent and contextual factors. *Journal of Child and Family Studies, 20,* 640-647.

Walsh, C., & Ross, L. (2003). Are minority children under- or overrepresented in pediatric research? *Pediatrics, 112*(4), 890-895.

Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical

    children, children with autism, and children with mental retardation. *Autism, 6*(1), 115-

    130.

White, J. M. & Klein, D. M. (2008) *Family theories*. (3rd Ed). Thousand Oaks, CA: Sage

    Publications.

Zaidman-Zait, A., Mirenda, P., Zumbo, B. D., Wellington, S., Dua, V., & Kalynchuk, K. (2010).

    An item response theory analysis of the Parenting Stress Index-Short Form with parents

    of children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry,*

    51(11), 1269-1277.

APPENDIX A: IRB AMENDMENT

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/irb**

Notification of Amendment Approval

From: Social/Behavioral IRB

To: Linda Mitchell

Date: 10/2/2013

Re: Ame1_UMCIRB 11-0158
        UMCIRB 11-0158
        [IMPORTED] Addressing the Support and Training Needs of Families in Early
        Intervention: Identifying Parent Stress

Your Amendment was reviewed and approved using expedited review on10/2/2013. It was the
determination of the UMCIRB Chairperson (or designee) that this revision does not impact the
overall risk/benefit ratio of the study and is appropriate for the population and procedures
proposed.

Please note that any further changes to this approved research may not be initiated without
UMCIRB review except when necessary to eliminate an apparent immediate hazard to the
participant. All unanticipated problems involving risks to participants and others must be
promptly reported to the UMCIRB. A continuing or final review must be submitted to the
UMCIRB prior to the date of study expiration.The investigator must adhere to all reporting
requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be
used to consent participants (consent documents with the IRB approval date stamp are found
under the Documents tab in the study workspace).

The approval includes the following items:

Document	Description
questions for research study.docx(0.01)	Surveys and Questionnaires

 The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: MODIFIED PARENTAL STRESS INDEX - ENGLISH

Rating Scale: SA =Strongly Agree   A=Agree   D=Disagree   SD=Strongly Disagree

1. My child is so active that it exhausts me.	SA	A	D	SD
2. My child appears disorganized and is easily distracted.	SA	A	D	SD
3. My child will often stay occupied with a toy for more than ten minutes.	SA	A	D	SD
4. My child squirms and kicks a great deal when being dressed or bathed.	SA	A	D	SD
5. My child seems to cry or fuss more often than most children.	SA	A	D	SD
6. My child doesn't seem to learn as quickly as most children.	SA	A	D	SD
7. When playing, my child doesn't often giggle or laugh.	SA	A	D	SD
8. My child looks a little different than I expected and it bothers me at times.	SA	A	D	SD
9. My child does a few things which bother me a great deal.	SA	A	D	SD
10. My child is not able to do as much as I expected.	SA	A	D	SD
11. My child does not like to be cuddled or touched very much.	SA	A	D	SD
12. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.	SA	A	D	SD
13. Being a parent is harder than I thought it would be.	SA	A	D	SD
14. Leaving my child with a babysitter is usually a problem.	SA	A	D	SD
15. My child gets upset easily over the smallest thing.	SA	A	D	SD
16. My child easily notices and overreacts to loud sounds and bright lights.	SA	A	D	SD
17. It takes a long time and it is very hard for my child to get used to new things.	SA	A	D	SD
18. My child doesn't seem comfortable when meeting strangers.	SA	A	D	SD
19. My child has had more health problems than I expected.	SA	A	D	SD
20. My child seems to be much harder to care for than most.	SA	A	D	SD
21. I can't make decisions without help.	SA	A	D	SD
22. I enjoy being a parent.	SA	A	D	SD
23. I feel that I am successful most of the time when I try to get my child to do or not do something.	SA	A	D	SD
24. It takes a long time for parents to develop close, warm feelings for their child.	SA	A	D	SD

25. Sometimes my child does things to bother me just to be mean.   SA   A   D   SD

26. When I was young, I never felt comfortable holding or taking care of children.   SA   A   D   SD

27. Most of my life is spent doing things for my child.   SA   A   D   SD

28. I feel trapped by my responsibilities as a parent.   SA   A   D   SD

29. I often feel that my child's needs control my life.   SA   A   D   SD

30. It is hard to find a place in our home where I can go to be by myself.   SA   A   D   SD

31. When I think about the kind of parent I am, I often feel guilty or bad about myself.   SA   A   D   SD

32. When my child misbehaves or fusses too much, I feel responsible, as if I didn't do something right.   SA   A   D   SD

33. I often feel guilty about the way I feel toward my child.   SA   A   D   SD

34. I wind up feeling guilty when I get angry at my child and this bothers me.   SA   A   D   SD

35. After my child has been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.   SA   A   D   SD

36. Since having my child, my spouse (or male/female friend) has not given me as much help and support as I expected.   SA   A   D   SD

37. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).   SA   A   D   SD

38. Having children has been much more expensive than I had expected.   SA   A   D   SD

39. I feel alone and without friends.   SA   A   D   SD

40. Physically, I feel good most of the time.   SA   A   D   SD

Índice Modificado del Estrés de los Padres

Marque lo que corresponde: FA = Fuertemente de acuerdo   A = En acuerdo
D = En desacuerdo   D = Fuertemente en desacuerdo

1. Mi hijo/a es tan activo/a que me agota.	FA	A	D	FD
2. Mi hijo/a aparece desorganizado/a y se distrae fácilmente.	FA	A	D	FD
3. A menudo, mi hijo/a se mantiene ocupado/a con un juguete para más de 10 minutos.	FA	A	D	FD
4. Mi hijo/a se retuerce y patea mucho cuando se lo/la viste.	FA	A	D	FD
5. Mi hijo/a parece hacer más escándalos o llora más que otros niños.	FA	A	D	FD
6. Mi hijo/a no parece aprender a la misma velocidad que otros niños.	FA	A	D	FD
7. Cuando juega, mi hijo/a no se ríe.	FA	A	D	FD
8. Mi hijo/a tiene un aspecto distinto a lo que esperaba y eso me molesta a veces.	FA	A	D	FD
9. Mi hijo/a hace algunas cosas que me molestan mucho.	FA	A	D	FD
10. Mi hijo/a no puede hacer tantas cosas como esperaba.	FA	A	D	FD
11. A mi hijo/a no le gusta que lo toquen ni que lo abrazan.	FA	A	D	FD
12. Cuando llegó mi hijo/a del hospital, estaba insegura de mi capacidad de ser padre.	FA	A	D	FD

13. Ser padre es más difícil de lo que pensaba.	FA	A	D	FD
14. Dejar a mi hijo/a con una cuidadora resulta ser problemático a veces.	FA	A	D	SD
15. Mi hijo/a se molesta fácilmente por muy poca cosa.	FA	A	D	FD
16. Mi hijo/a se fija fácilmente y reacciona a sonidos fuertes y a luces brillantes.	FA	A	D	FD
17. Le toma mucho tiempo a mi hijo/a y le cuesta acostumbrarse a cosas nuevas.	FA	A	D	FD
18. Mi hijo/a no parece cómodo/a cuando conoce a gente nueva.	FA	A	D	FD
19. Mi hijo/a ha tenido más problemas de salud de lo que esperaba.	FA	A	D	FD
20. Me parece que mi hijo/a exige más cuidado que otros niños.	FA	A	D	FD
21. No puedo tomar decisiones sin ayuda.	FA	A	D	FD
22. Disfruto ser padre.	FA	A	D	FD
23. Siento que casi siempre tengo éxito cuando quiero que mi hijo/a haga o no haga algo.	FA	A	D	FD
24. Toma mucho tiempo para que un padre desarrolle sentimientos de cariño para un niño.	FA	A	D	FD
25. A veces mi hijo/a hace cosas para molestarme y ser malo/a.	FA	A	D	FD
26. Cuando era joven, nunca me sentí cómodo agarrando o cuidando niños.	FA	A	D	FD
27. Paso la mayor parte de mi vida haciendo cosas para mi hijo/a.	FA	A	D	FD
28. Me siento atrapado por mis responsabilidades como padre.	FA	A	D	FD
29. Con frecuencia, siento que las necesidades de mi hijo/a controlan mí vida.	FA	A	D	FD
30. Es difícil encontrar un lugar en mi casa donde puedo estar solo.	FA	A	D	FD
31. Cuando pienso en el tipo de padre que soy, a menudo me siento culpable o mal conmigo.	FA	A	D	FD
32. Cuando mi hijo/a se comporta mal y se pone fastidioso/a, me siento responsable, como si no hubiera hecho algo bien.	FA	A	D	FD
33. Con frecuencia, me siento culpable por los sentimientos que tengo por mi hijo/a.	FA	A	D	FD
34. Termino por sentirme culpable cuando me enojo con mi hijo/a y eso me hace sentir mal.	FA	A	D	FD
35. Después de que mi hijo/a había estado en la casa por más de un mes me sentí más triste y deprimido que lo que había esperado.	FA	A	D	FD
36. Desde que he tenido mi hijo/a, mi esposo/a (amigo/a) no me ha aportado la ayuda que esperaba.	FA	A	D	FD
37. El haber tenido un/a niño/a ha causado más problemas de lo que esperaba en mi relación con mi esposo/a (amigo/a).	FA	A	D	FD
38. El haber tenido niños ha sido mucho más caro de lo que esperaba.	FA	A	D	FD
39. Me siento solo y sin amigos.	FA	A	D	FD
40. Físicamente, me siento bien la mayor parte del tiempo.	FA	A	D	FD

53

APPENDIX D: QUESTIONNAIRE - ENGLISH

1. How long have you lived in the United States?

2. Have you experienced any difficulties adjusting to the new culture?

3. What changes have you had to make to your daily life due to your child's special needs? What effect do these changes have on the family?

4. How would you describe your social support system?

5. How would you describe the relationship between your child and other family members?

6. What services does your child receive from early intervention? Has your child benefitted from these services?

7. What are some challenges that you have faced with your child's special needs and how have you adapted to or dealt with these challenges?

APPENDIX E: QUESTIONNAIRE – SPANISH

1) ¿Desde hace cuanto tiempo vive usted en los Estados Unidos?

2) ¿Ha tenido usted algunas dificultades acomodándose a la nueva cultura?

3) ¿Cuáles son los cambios que usted ha tenido en su vida diaria debido a las necesidades especiales de su niño/a?

¿Cómo han afectado estos cambios a su familia?

4) ¿Cóme explicaría usted su sistema de apoyo social?

5) ¿Cómo explicaría usted la relación entre su niño/a y los otros miembros de la familia?

6) ¿Cuáles son los servicios que su niño/a recibe de la intervención temprana? Ha beneficiado su niño/a de estos servicios?

7) ¿Cuáles son algunos de los retos que usted ha tenido que enfrentar con las necesidades especiales de su niño/a y cómo se ha adaptado usted a estos retos?