EXPERIENCES OF PEDIATRIC PARENTING STRESS AND FAMILY SUPPORT FOR CAREGIVERS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS OR DEVELOPMENTAL DISABILITIES

by

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DISSERTATION ABSTRACT

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Title: Experiences of Pediatric Parenting Stress and Family Support for Caregivers of Children with Special Health Care Needs or Developmental Disabilities

Serving children with special health care needs (SHCN) or developmental disabilities (DD) and their families is an important public health issue (Healthy People, 2020). The prevalence of children with special health care needs or developmental disabilities is significant and increasing (Boyle et al., 2011). Caregivers of children with SHCN or DD and their families demand clinical and research attention given the potential range of health and well-being outcomes that are associated with their children's developmental or medical complexity. The purpose of this dissertation study was to use a quantitative descriptive research design to examine the experiences of pediatric parenting stress and family support for a sample of caregivers of children representing diverse special health care needs or developmental disabilities. Data were collected at four agencies that provide a range of services to children with SHCN or DD and their families. The data for 167 caregiver participants were used for the preliminary and main statistical analyses. Statistical analyses included Pearson product moment correlations, independent-samples *t*-tests, one-way analysis of variance (ANOVA) tests, internal consistency reliability analyses, and factor analyses. Present study findings revealed that (a) the Pediatric Inventory for Parents (PIP) and Family Support Scale (FSS) measures did not appear to be internally consistent for this study sample; (b) the existing PIP and

FSS factor structures did not fit the present study data well; (c) the present study sample had higher levels of pediatric parenting stress and lower levels of family support overall as compared to previous study samples of caregivers for children with chronic conditions; (d) the current study sample's experiences of pediatric parenting stress and family support differed significantly by several caregiver, child, and family correlates; and (e) the current study sample's levels of pediatric parenting stress and family support had a positive, significant association. Study findings emphasized the potential roles of stress and support in the caregiving experiences for children with SHCN or DD. Recommendations for further study of this caregiving population and their families are discussed.

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I would like to dedicate this dissertation study

to the caregiver participants and their families

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CHAPTER I

INTRODUCTION

Serving children with special health care needs or developmental disabilities and their families is an important public health issue (Healthy People, 2020). The prevalence of special health care needs (SHCN) and developmental disabilities (DD) in the United States is significant and reflects an increasing trend, affecting the lives of approximately 1 in 5 to 1 in 7 children between the ages of 0 to 18 years (Bethell, Read, Blumberg, & Newacheck, 2008; Boyle et al., 2011). Approximately 16.8 million caregivers provide informal, unpaid care to these children (National Alliance for Caregiving, 2009). SHCN and DD can have pervasive effects on children's developmental trajectories, including, among other factors, their body functions and structures, completion of daily living activities, and level of participation in key life contexts (O'Connor, Howell-Meurs, Kvalsvig, & Goldfeld, 2015- p. 15). To meet their complex needs, children with SHCN or DD and their families typically require access to more and specialized health-related and other support services across the lifespan that children without SHCN and DD and their families do not typically require such services (McPherson, Arango, & Fox, 1998; McPherson et al., 2004). In addition, a primary concern for these children and their families can include chronicity across the lifespan.

In families with children with SHCN or DD, the potential for negative health and well-being outcomes can be different from and higher than that of other families due to the increased stress level for both the caregivers as well as at the care recipients- their children with SHCN or DD (Cousino & Hazen, 2013). The stress associated with this multidimensional type of caregiving can extend beyond general parenting stress to

encompass additional types of stressors across various life domains (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2015). For example, caregivers' mental and physical health may be compromised as caregivers' experience secondary strains associated with care decisions, seeking and accessing resources, determining eligibility for services, advocating for their children and family, and other challenges, such as employment difficulty and financial burden (APA, 2010).

One conceptualization of the unique stressors associated with caregiving for children with SHCN or DD is pediatric parenting stress (PPS), which is defined as the "stress associated with caring for a child with an illness" (Streisand, Braniecki, Tercyak, & Kazak, 2001, p. 151). Pediatric parenting stress (PPS) is conceptualized to span across four main life domains: communication, medical care, emotional distress/functioning, and role function (Streisand et al., 2001). PPS is correlated with negative health and well-being outcomes for caregivers, including (but not limited to) depression, anxiety, low self-efficacy, amongst other outcomes. Furthermore, higher levels of PPS are associated with child, caregiver, and family correlates, including resources (low-income caregivers and families), specific household structures (single parent households), and caregiver and child cultural and personal identities (younger parents and young children) (Barakat, Patterson, Tarazi, & Ely, 2007; Barakat et al., 2008; Cohen, Vowles, & Eccleston, 2010; Hilliard, Monaghan, Cogen, & Streisand, 2011; Odell, Sander, Denson, Baldassano, & Hommel, 2011; Preston et al., 2005; Storch et al., 2005; Streisand et al., 2001; Streisand, Tercyak, & Kazak, 2003; Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Taft, Ballou, & Keefer, 2012).

From a biopsychosocial, developmental, transactional, and ecological theoretical framework, the relationship context that informs the interactions between caregivers and their children with SHCN or DD (as the care recipients) is bidirectional and dynamic (Bronfenbrenner, 1979). With the scope of a family systems approach to examining child disability and health, caregivers' health and well-being affect the health and well-being of their children with SHCN or DD, and vice versa (American Psychological Association, 2010).

The health and well-being outcomes for the caregivers in families of children with SHCN or DD can be improved by way of psychosocial interventions, such as increasing caregivers' ability to effectively cope with multiple stressors. One form of coping is social support (Thoits, 1986). Social support can be conceptualized as either problem-focused and emotion-focused coping in nature. The buffering hypothesis proposes that social support can be particularly beneficial to health and well-being in the face of stress (Thoits, 1986) when social support is perceived as helpful and to match the demands of the stressful situation. As such, social support has emerged consistently as a protective factor for caregivers of children with SHCN or DD (Baum, 2004; Homer et al., 2008; Tak & McCubbin, 2002). Identifying the perceived stressors associated with caregiving and bolstering caregiver social support to mitigate the impact of such stressors is a promising area of research that may improve the functioning of caregivers of children with SHCN or DD and their families (Patterson, 1984; Rolland & Walsh, 2006; Saloviita, Itälinna, & Leinonen, 2005; Streisand et al., 2001).

The purpose of the present study was to use a quantitative descriptive research design to examine the experiences of pediatric parenting stress and family support for a

sample of caregivers of children with a broad range of special health care needs (SHCN) or developmental disabilities (DD). The study aims were to examine caregivers' reports about the occurrence of stressful caregiving-related events, the appraised difficulty of such stressors, as well as the perceived availability and helpfulness of family sources of support. It was anticipated that achieving the study aims would expand scholars and clinicians' understanding and knowledge about bolstering families' adaptation to the stress and support associated with caregiving for children with SHCN or DD. In sum, the overarching goal for the current study was to promote well-being and health in these families.

CHAPTER II

LITERATURE REVIEW

I conducted a literature review using the JSTOR and American Psychological Association's (APA) PsycNet search engines, which yielded the following results: 9 peer-reviewed articles for "pediatric parenting stress" and "family support", 157 peer-reviewed articles for "parenting stress", "family support", "special health care needs", or "developmental disabilities", 0 peer-reviewed articles for "parenting stress", "family support", "special health care needs", and "developmental disabilities", 57 peer-reviewed articles for "Pediatric Inventory for Parents", 12 peer-reviewed articles for "Pediatric Inventory for Parents" (with "Tests and Measures" specification), 104 peer-reviewed articles for "Family Support Scale" (with "Tests and Measures" specification), and, 64 peer-reviewed articles for "caregiving", "parenting stress", and "family support".

Definitions for the Study

Scholars have proposed various definitions and conceptualizations for the following key terms: caregiving, special health care needs, developmental disabilities, as well as patient- and family-centered care. An overview of these terms and concepts is provided in the following section.

Caregiving. Caregiving has been defined as being "a person who provides paid or unpaid assistance and support to another person who, for reasons of illness, disability, and/or age, cannot independently perform the usual activities of daily living" (Bruhn & Rebach, 2014, p. 5). Caregiving can vary according to several factors, including (but not limited to) paid or unpaid care, amount of care required (e.g., assistance required with activities of daily living), and level of care provided (e.g., hours of caregiving provided

per day) (American Psychological Association, 2016). Caregiving may be informal, unpaid care (e.g. care provided by family members, friends) or formal, paid care (e.g., care provided by healthcare and other professionals) (National Alliance for Caregiving, 2009).

It is estimated that approximately 16.8 million caregivers (which represents approximately 1 in 7 caregivers in the United States) provide care to a child between ages 0 to 18 years with either SHCN or DD (Bruhn & Rebach, 2014; National Alliance for Caregiving, 2009). Caregivers are considered to be at-risk due to the increased likelihood that they will experience physical and mental health difficulties because of their caregiving experience (National Alliance for Caregiving, 2009). For example, caregivers' mental and physical health may be compromised as they experience secondary strains associated with care decisions, seeking and accessing resources, determining eligibility for services, advocating for their children and family, and other challenges, such as employment difficulty and financial burden (APA, 2010). It is important to state, however, that caregiving experiences can also provide opportunities for growth and meaning-making, including expanding caregivers' sense of purpose, life roles, and identity (APA, 2010; Bray et al., 2017; Folkman & Moskowitz, 2000, 2004, 2007). It has been further proposed that the experience of SHCN or DD provide the opportunity for post-traumatic growth (Barakat, Alderfer, & Kazak, 2005). The potential stress and benefits associated with caregiving for children with SHCN or DD (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991) highlight the multidimensionality of this particular experience.

Special health care needs. The Maternal and Child Health Bureau (MCHB), which is part of the Health Resources and Service Administration within the United States Department of Health and Human Services, provided the following definition of children with special health care needs (SHCN):

> "those who have, or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson, Arango, & Fox, 1998, p. 138).

The definition of children with SHCN was expanded as follows to include functional limitations:

> "children who have a chronic physical, developmental, behavioral, or emotional condition and have functional limitation or require health and health-related services beyond those of other children." (McPherson et al., 2004, p. 1541)

Special health care needs (SHCN) can include (but are not limited to) the following conditions: learning disability; attention deficit or attention deficit hyperactivity disorder; depression; anxiety problems; behavioral or conduct problems; autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder; any developmental delay; intellectual disability and mental retardation; cerebral palsy; stuttering, stammering, or other speech problems; Tourette syndrome; asthma; diabetes; epilepsy or seizure disorder; hearing problems; vision problems that cannot be corrected with glasses or contact lenses; bone, joint, or muscle problems; and, brain injury or concussion (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2012).

Per the MCHB's definitions of children with SHCN, functional limitations can accompany SHCN and are common (McPherson et al., 1998, 2004). In the National Survey of Children with Special Health Care Needs (NS-CSHCN) 2009/10,

approximately half of children with SHCN had functional limitations that significantly impacted their engagement or participation in major life activities. Functional limitations can span one or more of the following four areas of development: physical, learning, language, or behavior. Examples of functional limitations include (but are not limited to) the following: breathing or other respiratory problems; feeding problems; chronic physical pain, including headaches; vision problems, hearing problems; self-care; comprehension problems; attention problems; communication problems; behavior problems; and interpersonal difficulties with peers (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2012). As a result of such limitations, a child's engagement or participation can be affected for major life activities, which include (but are not limited to) self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (Centers for Disease Control and Prevention, 2011).

The prevalence of SHCN for children living in the United States is high. The trend has continued to increase over the past half century (Halfon, Houtrow, Larson, & Newacheck, 2012). A recent estimate of prevalence was that nearly 20% of children between the ages of 0 to 17 years are estimated to be living with identified SHCN (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2012), which represents approximately 14.6 million children (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2012).

Children with SHCN or DD identify with diverse cultural and personal identities. Research suggests that prevalence can vary according to child and parent characteristics, including sex, age, race/ethnicity, household structure, and insurance coverage status. In one study, male children between the ages of 0 to 17 years, school-aged children, children of ethnic minority backgrounds, and children living in single-parent households were more likely to have SHCN (Van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). In addition to gender and school age, researchers have documented a higher prevalence of SHCN for European-American children and children with insurance coverage (Newacheck & Kim, 2005).

Developmental disabilities. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 presented the following definition of DD:

> "a severe, chronic disability of an individual 5 years of age or older that: 1) Is attributable to a mental or physical impairment or combination of mental and physical impairments; 2) Is manifested before the individual attains age 22; 3) Is likely to continue indefinitely; 4) Results in substantial functional limitations in three or more of the following areas of major life activity: (i) Self-care, (ii) Receptive and expressive language, (iii) Learning, (iv) Mobility, (v) Self-direction, (vi) Capacity for independent living; and (vii) Economic self-sufficiency; 5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental

delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."

(Administration on Developmental Disabilities, 2000).

Similar to children with SHCN, the above definition of DD addresses the possible range of impairments and limitations, occurrence within a specific developmental period, potential impact on daily functioning, likelihood of higher need for services and supports, and potential chronicity across the lifespan (Centers for Disease Control and Prevention, 2011). As with children who has SHCN, children with DD can experience functional limitations that impact their development across one or more areas: physical, learning, language, or behavior (Centers for Disease Control and Prevention, 2011).

Developmental disabilities can include (but are not limited to) the following conditions: Attention-deficit/hyperactivity Disorder (ADHD); Autism Spectrum Disorder; Cerebral Palsy, Fetal Alcohol Spectrum Disorders; Fragile X Syndrome; hearing loss; Intellectual Disability; Kernicterus; speech and language disorders, including stuttering; learning disorders; Muscular Dystrophy; seizures; Tourette Syndrome; and vision impairment (Boyle et al., 2011; Centers for Disease Control and Prevention, 2011).

The estimated prevalence of DD in the United States is approximately 16% of children living in the United States, with about 1 in 6 children having one or more developmental disabilities and other developmental delays (Boyle et al., 2011). Similar to SHCN, there has been an upward trend in the estimated prevalence of DD. According to the 1994-1995 National Health Interview Survey, developmental, emotional, and behavioral conditions surpassed physical conditions that result in activity limitations for

children (Ward, Ridolfo, Creamer, & Gray, 2015). In the same survey, the most prevalent chronic conditions affecting activity limitations for children under 18 years of age were: 1) speech problems; 2) learning disabilities; 3) Attention-Deficit Hyperactivity Disorder (ADHD); 4) other mental, emotional, or behavioral problems; and 5) other developmental problems. The most prevalent physical condition was asthma/breathing, which was less prevalent than the fifth most common condition category of "other developmental problems".

Per the presented definitions, both SCHN and DD reflect developmental vulnerability for a significant part of a child's development, with the potential to pose chronic issues over the course of their lives (McManus, Carle, & Rapport, 2014). In the existing research, these two categories of child health (SHCN) and disability (DD) have been conceptualized as potentially overlapping or comorbid (rather than mutually exclusive) categories (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2012). The NS-CSHCN 2009/10 results revealed that approximately 30% of children with SHCN or DD experience comorbid health conditions, and approximately 1 in 3 children with SHCN or DD experience other behavioral, emotional, or developmental health problems in addition to their health conditions. For the purposes of this study, DD were conceptualized as a sub-category or sub-set within the larger category of SHCN (Center for Disease Control and Prevention- CDC, 2011).

Patient- and family-centered care. According to the Maternal and Child Health Bureau (MCHB), the six core outcomes for serving children with SHCN or DD and their families are the following:

> "(1) All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home; (2) all families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need; (3) all children will be screened early and continuously for special health care needs; (4) services for children with special health care needs and their families will be organized in ways that families can easily access them; (5) families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services that they receive; (6) all youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence". (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2015)

These six outcomes highlight the multifaceted experiences of caregivers in these families across various levels of their social ecologies. The MCHB recommendations also highlight the possible roles, demands, and challenges faced by the caregivers of children with SHCN or DD and their families (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2015). In a recent policy statement addressing patient-centered (in this case, the child with SHCN or DD) and Family-Centered Care and the Pediatrician's Role (2012), the American Academy of Pediatrics (AAP) proposed that "patient- and family-centered care is based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives and information are important in clinical decision-making" (p. 395). The practice of patient- and family-centered care has positive

impacts on health and well-being, including improving the experience of patient and family care; improving and promoting health; and reducing the cost of care (Berwick, Nolan, & Whittington, 2008). In addition, the patient- and family-centered care approach assumes a strengths-based approach, increases families' satisfaction, and facilitates efficient and effective access to health care resources (American Academy of Pediatrics, 2012, p. 395). In the next section, the concepts of stress and coping as they relate to caregiving for children with SHCN or DD will be further explored.

A Theoretical Framework for Examining Caregiver Stress and Family Support

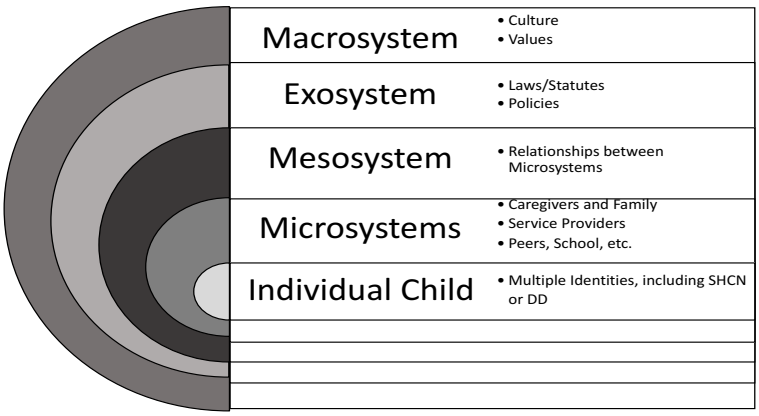
The overarching study aims were to examine the experiences of pediatric parenting stress and family support for a study sample of caregivers of children with SHCN or DD. The exploration of these caregiving experiences was informed theoretically by examining caregiver reports of pediatric parenting stress across levels of the ecology, aspects of caregivers and families' support from a theoretical model informed by ecological, transactional, family systems, biopsychosocial, and developmental perspectives. The following sections detail the three models that formed the foundation of the study's theoretical framework.

The ecological context of caregiving for children with SHCN or DD. The ecological model (Bronfenbrenner, 1979) is considered to a metatheory for human development and provides a framework with which to examine the contextual factors that impact children's and their caregiver's health and well-being outcomes, including risk and protective factors (see Figure 1). Such a contextual examination is critical to a developmental perspective, premised upon an identification of key relationships and targets for prevention and intervention within service provision to families of children

with SHCN or DD. Dunst, Trivette, & Deal (1994) adapted the ecological model for the theoretical foundation for the Family Support Scale (FSS), which is one of the three measures used in this study.

Figure 1

The Ecological Model (Bronfenbrenner, 1979)



Factors that could affect negative well-being and health outcomes for the caregivers of children with SHCN or DD and their families will be addressed for each of the five ecological levels: microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1979). At the microsystemic level, a number of factors have been identified that could affect negative well-being and health outcomes for the caregivers of children with SHCN or DD and their families, including (but not limited to): the relationships with their children with SHCN or DD and other family members, e.g., spouses, other children, extended family members; higher levels of depression and

anxiety for the caregivers; increased risk for burnout and caregiver burden, in particular among primary caregivers and caregivers from ethnic minorities (Raina et al., 2004); increased likelihood of have other children- the siblings of children with SHCN or DD- higher levels of depression and anxiety than their peers (Seltzer et al., 2004) as well as can exhibit more psychological and behavioral issues over time (Fisman, Wolf, Ellison, & Freeman, 2003; Stoneman & Gavidia-Payne, 2006), which can result in additional roles, demands, and challenges for their caregivers. In a study examining siblings of children with cancer, siblings were found to have higher levels of posttraumatic stress symptoms as compared with their peers who did not have siblings with SHCN (Alderfer, Labay, & Kazak, 2003).

At the mesosystemic level, factors that can increase caregivers' and their families' negative health and well-being outcomes include (but are not limited to): more complex family-school interactions, e.g., an increased need for school support such as special education services and caregiver expertise in child care. For example, children with SHCN or DD are at a higher risk for school failure or educational difficulty; more complex family-medical system interactions, e.g., more communications among families and service providers, frequent need for self-advocacy by the caregivers to address the unmet medical needs of the children in their care (Wang, Mannan, Poston, Turnbull, & Summers, 2004; Wiltshire, Cronin, Sarto, & Brown, 2006). As an outcome of the above mesosystemic risks, children with SHCN or DD have been found to have significantly more sick days and school absences when compared with their peers who do not have SHCN or DD (Newacheck et al., 1998); more difficult family-work interactions, e.g., higher levels of underemployment or unemployment for primary caregivers (Looman,

O'Conner-Von, Ferski, & Hildenbrand, 2009); more challenging family-community interactions, e.g., the location of residence (rural versus urban communities), the size, strength, and helpfulness of support networks, and the ease or, conversely, difficulty of access to necessary support services (Easters Seals & National Alliance in Caregiving, 2007).

At the exosystemic level, several factors were found to increase the risk faced by caregivers and the family systems for negative well-being and health outcomes including: poverty/low-income family status and limited health literacy. Poverty, as an indicator of socioeconomic risk, is often correlated with child disability (Fujijura & Yamaki, 2000; Parish, Magaña, & Cassiman, 2008; Wood, 2003). Families with children with SHCN and DD are more likely to experience poverty (Park, Turnbull, & Turnbull, 2000). Research findings have identified a higher prevalence of SHCN among children living in rural regions (DeVoe, Tillotson, & Wallace, 2009), which are associated with higher levels of poverty and more restricted access to services when compared to urban regions (Easters Seals & National Alliance in Caregiving, 2007). For example, in the state of Oregon, families living in rural geographic regions have less access to health care services (DeVoe et al., 2009; Farmer, Marien, Clark, Sherman, & Selva, 2005; Marcin et al., 2004; Skinner & Slifkin, 2007). Low caregiver health literacy (Chew, Bradley, & Boyko, 2004; DeWalt & Hink, 2009; Sanders, Thompson, & Wilkinson, 2007) has also been linked to poor health outcomes for children and their families due to limited access to educational resources (Healthy People 2020).

At the macrosystemic level, numerous factors increase caregivers' and family systems' risks for negative well-being and health outcomes including a lack of access to

high quality care or services or lack of access to a comprehensive medical home (Turchi, Gatto, & Antonelli, 2007; U.S. Department of Health and Human Services, Health Resources and Services Administration, 2015); financial burden; and the "invisibility" of informal caregiving (Bruhn & Rebach, 2014). Limited or insufficient insurance coverage is another key risk factor for poor health outcomes. In the NS-CSHCN 2009/10, although the majority of children had health insurance coverage, more than 1/3 reported unmet health care needs (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2012). Disparities also exist between families with private versus public insurance coverage (Chen & Newacheck, 2006; Oswald, Bodurtha, Willis, & Moore, 2007).

At the chronosystemic level, the establishment of additional, intensive support services necessary during childhood or adolescence can continue into adulthood. In the most recent NS-CSHCN 2009/10 data, only 40% of children with SHCN had made successful transitions into adult heath care and other settings (Lotstein, McPherson, Strickland, & Newacheck, 2005).

In sum, several ecological factors, and the interaction among those factors, impact caregiver health and well-being at the individual- as well as family-level. The ecological framework for examining development, more specifically, the interactions between caregivers and their children with SHCN or DD, highlights the dynamic, bidirectional person-environment interactions that inform the caregiving relationship (Bronfenbrenner, 1979). This framework can also be examined to better understand the factors that affect families' adaptation and adjustment, such as their ability to cope with stress, given the risk and protective factors that exist within their ecologies (Bronfenbrenner, 1979).

The transactional model of stress and coping. The Transactional Model of Stress and Coping (TMSC) model forms the theoretical and clinical foundation for the Pediatric Inventory for Parents (PIP- Streisand et al., 2001). Caregivers in the families of children with SHCN or DD must first assess a situation as stressful or a threat to well-being (*primary appraisal*) prior to determining if they have the necessary resources to address the stressor (*secondary appraisal*) (Patterson, 1988). The associated processes of cognitive appraisal and coping can determine how families negotiate potentially stressful person-environment interactions (Lazarus & Folkman, 1984, 1987). Person factors, (e.g., beliefs, commitments) and situational or environmental factors (e.g., predictability, uncertainty, life cycle) can affect the cognitive appraisal process. For example, a child's chronic health condition, illness, or developmental disability could potentially present a stressor for their family system, requiring adjustment and adaptation to support family functioning (Rolland & Walsh, 2006). Coping in the context of caring for children with SHCN or DD can include (but is not limited to) seeking, accessing, and receiving high-quality health or other health related services necessary to meet their children's health and other related needs (Rolland & Walsh, 2006).

The TMSC model highlights the importance of cognitive appraisal and coping in the experience of stress. Empirical evidence for the transactional model provides support for viewing cognitive appraisals and coping as key factors in the adaptation and adjustment to stress (Lazarus & Folkman, 1984, 1987). Cognitive appraisal consists of two stages: primary appraisal and secondary appraisal (Lazarus and Folkman, 1984, 1987). Primary appraisal and secondary appraisal exert mutual influence upon one another and do not have a set temporal order (Lazarus & Folkman, 1984, 1987). The

concepts of stress, coping, and social support will each be discussed in turn as they relate to the TMSC.

Stress. Stress is one of two key components in the Transactional Model of Stress and Coping. Scholars have proposed that the stress associated with being a caregiver of a child with a chronic health condition or illness can differ significantly from the stress of being a caregiver of a child who does not have SHCN or DD (Streisand et al., 2001). As such, theorists have proposed that the use of a general parenting stress measure, such as the Parenting Stress Index (Abidin & Abidin, 1990), to assess parenting stress related to caring for a child with a chronic health condition or illness will not adequately capture the full breadth of parents' or families' experiences (Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, 2011; Smith, Oliver, & Innocenti, 2004; Streisand et al., 2001). For example, caregivers of children with SHCN or DD can face "critical illness events", such as managing medical regimens, interactions with the medical system, condition or illness specific factors (Streisand et al., 2001- p. 156). As previously addressed, the concept of pediatric parenting stress (PPS) is defined as "the stress of caring for a child with an illness" (Streisand et al., 2001- p. 156) and spans four life domains: 1) communication, 2) medical care, 3) emotional distress/functioning, and 4) role function. An additional dimension of PPS is the perceived frequency and the perceived difficulty of the four domains of stress.

Empirical evidence shows that PPS is associated with numerous negative outcomes for the health and well-being of caregivers, their children with SHCN or DD, and their family systems. At the child-level, PPS is associated with child externalizing problems or other problematic behavior (Hilliard et al., 2011; Mitchell et al., 2009), child

internalizing or affective problems (Lewin et al., 2005), or both (Ohleyer et al., 2007; Preston et al., 2005). At the caregiver level, PPS is associated with lower parental quality of life (Monaghan, Hilliard, Cogen, & Streisand, 2009; Monaghan, Hilliard, Cogen, & Streisand, 2011), higher levels of parental depressive symptomatology (Patton, Dolan, Smith, Thomas, & Powers, 2011; Streisand et al., 2008), higher levels of parental anxiety symptomatology (Streisand et al., 2001; Streisand et al., 2008; Vrijmoet-Wiersma, Egeler, Koopman, Bresters, Norberg, & Grootenhuis, 2010), both depressive and anxiety symptomatology (Cohen, Vowles, & Eccleston, 2010; Monaghan et al., 2012; Streisand et al., 2008), lower psychological functioning (Hansen, Weissbrod, Schwartz, & Taylor, 2012), and lower parental self-efficacy (Streisand et al., 2005). At the family level, PPS is associated with lower family functioning (Streisand et al., 2003), higher family burden (Muller-Godeffroy, Treichel, & Wagner, 2009), and general stress (Vrijmoet-Wiersma, Ottenkamp, van Roozendaal, Grootenhuis, & Koopman, 2009), amongst other outcomes. Further exploration of risk factors and outcomes associated with the four domains of pediatric parenting stress (emotional distress/functioning, communication, medical care, and role function) will now be presented.

Pediatric parenting stress- emotional distress/functioning. The results of previous studies to-date suggest that caregivers, including parents, of children with SHCN or DD report higher levels of parenting stress. It has been proposed that the elevated level of stress is due to the unique parenting stressors and demands related to childhood illness and disability (Murphy, Christian, Caplin, & Young, 2007). This specific type of parenting stress is associated with long-term impacts on parental well-being across the life course, including higher rates of alcohol and substance use, lower

employment rates, higher rates of depression, lower levels of social participation, physical symptoms, and depression (Seltzer et al., 2009). In a 10-year longitudinal study of parents of children with SHCN, study findings revealed negative effects upon mental health in terms of higher levels of depression symptoms as well as lower levels of engagement in activities of daily living (ADL) as compared to caregivers of children who did not have SHCN (Smith & Grzywacz, 2014). These effects were longitudinal in nature, with parents of children with SHCN demonstrating increases in depression and decreases in ADL engagement over time (Smith & Grzywacz, 2014) as compared to parents of children who did not have SHCN or DD.

Both physical and mental health are inextricably related to overall well-being. In a study examining the health of caregivers to children with SHCN or DD, parents reported lower health across the areas of physical, emotional, and functional health (Murphy et al., 2007). Rates of depression have been found to be higher in parents of children with SHCN and children with DD than parent of healthy children. In a meta-analysis study of mothers with and without children with DD, mothers of children with DD were found to experience significantly higher levels of depression when compared with mothers of children without DD (Singer, 2006). Differences in depression have also been found to vary between parents of children with SHCN and children with DD with different conditions and disabilities. For example, parents of children with autism have reported higher levels of depression when compared to parents of children with other DD (Weitlauf, Vehorn, Taylor, & Warren, 2014). In a study examining parental anxiety and depression for parents of children who were newly diagnosed with Type 1 Diabetes, parents' depression and anxiety scores were positively correlated with higher PPS for

both frequency and difficulty (Streisand et al., 2008).

Research findings also suggest that different conditions are associated with differing levels of parental stress (Gupta, 2007). In a comparison study, parents of children with ADHD and developmental disorders reported higher levels of stress when compared with parents of children with HIV and asthmas as well as healthy children in the control group (Gupta, 2007). In addition to parental or caregiver risk factors and outcomes, key psychosocial risk factors exist for children with SHCN or children with DD and their siblings. Children with SHCN and children with DD are at higher risk for emotional dysfunction and mental health concerns (Inkelas, Raghavan, Larson, Kuo, & Ortega, 2007). For example, children with chronic health conditions have been found to experience higher levels of depression and anxiety than their healthy peers (Bennett, 1994). In one study, children's significant mental health needs were linked to their experiences of adjustment and limitations related to SHCN or DD (Inkelas et al., 2007). In another study examining the national data set of the 1994/1995 National Health Survey Interviews- Disability Supplement, there were several significant, positive correlations between children having DD and psychosocial maladjustment: children's functional impairments in the areas of communication or learning, poor maternal health and mental health, family burden, and poverty (Witt, Kasper, & Riley, 2003). Another possible psychosocial risk is the increased risk of being bullied for children with SHCN (Twyman et al., 2010; Twyman, Saylor, Taylor, & Comeaux, 2010; Van Cleave & Davis, 2006). Being a victim of bullying has been linked with more loneliness, greater school avoidance, more suicidal ideation, and less self-esteem depression, anxiety, insecure, and additional physical health problems (possibly related to the psychosocial stress associated

with bullying) (Hawker & Boulton, 2000; Kochenderfer & Ladd, 1996; Craig, 1998; Rigby & Slee, 1993; Olweus, 1993; Swearer, Song, Cary, Eagle, & Mickelson, 2001). The range of outcomes and impact associated with being a victim of bullying persists over time. For example, Olweus (1993) conducted a longitudinal study, in which findings were that victims of bullying in their youth reported more depression symptoms and lower self-esteem than their peers at age 23.

The existing research addressing the range of experiences related to the well-being and functioning for the siblings of children with SHCN and DD is mixed. Several studies examining the experiences of siblings of children with SHCN have identified elevated levels of depression and anxiety (Seltzer et al., 2004). These effects on siblings have also been found to persist over time/across the lifespan (Stoneman & Gavidia-Payne, 2006). In one study, the siblings of a child with autism were found to be more risk for negative psychological and behavioral outcomes than children whose siblings either had no disability or DD other than autism (Fisman et al., 2003). Siblings of children with SHCN and children with DD often find themselves in the role across the lifespan, beginning early on in childhood and continuing through adulthood (Seltzer et al., 2005). An additional stressor can stem from the demands placed upon the entire family system to meet the needs of the children with SHCN and children with DD, which require resources that are often limited in nature, such as caregiver time. The high heritability of certain health conditions, such as autism (Hallmayer et al., 2011) and attention problems (Rietveld Hudziak, Bartels, Beijsterveldt, & Boomsma, 2004) and their combined heritability (Rommelse, Franke, Geurts, Hartman, & Buitelaar, 2010) contributes to the possibility of multiple children in one family with SHCN and DD. In a

study examining the experiences of such families, mothers of one child with a diagnosis on the autism spectrum disorder (ASD) and another child with a different DD reported higher levels of depression and anxiety when compared with mothers who only had one child with ASD. Furthermore, the mothers of multiple children with DD also reported that their families were less adaptive and cohesive family than those of the comparison sample (Orsmond, Lin, & Seltzer, 2007). In sum, the emotional functioning of children and families can be shaped significantly by the presence of SHCN or DD.

Pediatric parenting stress- communication. The complex, interpersonal nature involved in caring for children with SHCN and children with DD, such as seeking social support and interacting with health care providers, necessitates effective communication skills.

A key interpersonal stressor is the increased level of conflict for spouses who are parents of children with SHCN and children with DD (Berge, Patterson, & Rueter, 2006; Patterson, 2002; Risdal & Singer, 2004; Quittner et al., 1998; Stoneman & Gavidia-Payne, 2006). Given the protective role that social support can play, this possible barrier to family functioning and well-being can be critical for identification of at-risk family systems and for intervention (Kersh et al., 2006). In a study examining the effects of paternal involvement in the care of children with Type 1 diabetes, fathers endorsed higher levels of PPS and anxiety with higher levels of involvement; however, mothers' ratings of marital satisfaction and depression were inversely related to fathers' involvement (e.g., Hansen et al., 2012).

Another key interpersonal factor is parenting style, which can shape the communication between different family members, especially in parent-child

interactions. An authoritative parenting style is considered preferable to authoritarian or permissive parenting (Baumrind, 1971). For example, parents of children with congenital heart conditions have been found to have a higher endorsement of permissive parenting (Brosig et al., 2007; Uzark & Jones, 2003). In a study of parents of adolescents with Type 1 diabetes, parents who endorsed having an authoritative parenting style endorsed lower levels of PPS (Monaghan et al., 2011).

Researchers have found positive outcomes for children with SHCN whose parents engage in advocacy on their behalf across systems and contexts, e.g., within the school context (Hess et al., 2006) and home-school interactions contexts (Berger et al., 2004; Trainor, 2010). Parents of children with SHCN and children with DD have reported a higher level of need for advocacy efforts across contexts (e.g., Patterson, 2002). In qualitative study of parent advocates, Wang et al. (2004) proposed that advocacy can be experienced as an obligatory role in which parents of children with SHCN must engage to access the services received by their families.

Pediatric parenting stress- medical care. Caregivers of children with SHCN must seek out a broader array of services for their children, more frequently, and for longer periods of their children's development than parents who do not have children with SHCN (Children and Adolescent Health Measurement Initiative, 2012; Hagan et al., 2008; Newacheck et al., 2004). Associated with this elevated services need is the required expenditure of resources, including time and money, by the families of children with SHCN or DD. Given their high level of health care and other related service needs, the families of children with SHCN or DD tend to spend more money than families of children who do not have SHCN or DD on health care needs.

The access to and use of resources has been found to improve health outcomes (Andersen, 1968, 1995; Andersen & Aday, 1978; Szilagyi, 2012). Such examples of access of resources include gathering information and building knowledge about health conditions. Gathering information has been linked with self-care as a positive outcome (Brashers et al., 1999; Brashers et al., 2002). Seeking to build knowledge about health conditions has also been associated with positive outcomes, such as increased collaboration between patients and providers (Brashers et al., 1999). Importantly, high levels of family stress have been linked with lower access and use of health care services, (Fairbrother, Kenney, Hanson, & Dubay, 2005; Farmer et al., 2005), which in turn predicts more negative individual and family well-being outcomes over time. In national survey data, children's behavioral, emotional, and developmental health problems can negatively affect families' experiences of accessing services and resources in their communities (NS-CSHCN 2011/12). This common barrier of resource access is particularly important and concerning for these families in light of children with SHCN who often require additional health, education, and social services, and, if so, for longer periods of time (Newacheck et al., 2004; Boyle et al., 2011) as compared with children who do not have SHCN or DD.

Children with SHCN and children with DD often experience increased, persistent needs for services over their lifespan. In light of the focus on transition from childhood to adulthood for individuals with SHCN, this study's findings highlight the importance and relevance of SHCN-related services over the course of the lifespan development (American Academy of Pediatrics, 2002; Lotstein et al., 2005; Reiss et al., 2005). Per the aforementioned MCHB core outcomes, the transition from adolescence to adulthood is an

important process that can often be an incredibly stressful process for families of children with SHCN and children with DD.

Pediatric parenting stress- role function. As previously addressed, the American Psychological Association (APA) proposed that caregiver problems can span mental health, physical health, functional impairment, secondary strains, care decisions, resources and eligibility for services, family challenges, and advocacy for care (APA, 2010). The combined weight of managing and addressing these problems can result in caregiver burden (Chou, 2000). Additionally, the strain or burden of assuming multiple roles, such that of a parent, a teacher, an advocate, and a caregiver who has expertise in the child's condition (Brehaut et al., 20004; Raina et al., 2004), can also contribute to caregiver well-being and functioning.

Financial stress is a common experience for families of children with SHCN and children with DD (Kuhlthau, Hill, Yucel, & Perrin, 2005). Due to their high health care needs, the families of children with SHCN tend to spend more financial resources than other families upon health care needs. One study estimated that, while children with one or more chronic health conditions account for only about 10% of the population in the United States, they account for approximately 40% to 50% of the health care expenditures for children (Neff & Anderson, 1995). Families of children with SHCN and children with DD will likely make larger expenditures for health care and child care than families of healthy children (Parish et al., 2004; Szilagyi, 2012). In national survey data, nearly 1 in 5 children with SHCN have conditions that cause financial stress to their families (NSCHSN 11/12). In a study with the caregivers of preschool and adolescent youth with sickle cell disease found that families with lower household incomes reported

higher levels of PPS (Barakat et al., 2007).

In light of the financial costs associated with employment and health insurance are particularly important for this population. With regard to work roles, families of children with SHCN and children with DD often experience underemployment. For example, in national survey data, a quarter of families reported reduced or stopping employment to care for their children with SHCN (NSCHSN 11/12). The parents of children with SHCN and children with DD have been found to often experience work family conflicts (e.g., Chung et al., 2007), such as the need for family medical leave. These work-related challenges tend to persist over time. In a longitudinal study, mothers of children with SHCN were found to have lower rates of employment (Parish et al., 2004).

Another key important factor in differing access to as well as of resources, in particular health care services, is health insurance coverage (Chwalisz & Obasi, 2008) as a proxy for SES. According the U.S. Census Bureau's 2012 report, over 35 million families in the U.S. were uninsured, representing over 6 million children under the age of 18 years (of whom nearly 2 million were under the age of 6). According to the most recent Census, children's access to health insurance varied according to the following cultural and personal identities: age, socioeconomic status (poverty level), race, and national origin (U.S. Census, 2012). In a study examining the relationship between health insurance and unmet needs, uninsured children with SHCN reported more unmet needs than their insured counterparts (Newacheck et al., 2000). Furthermore, families with private insurance have reported a larger financial burden as compared with those with public health insurance (NS-CSHCN 11/12). Financial burden for families of

children with SHCN and children with DD has also been found to vary by geographic location. In a study examining the out-of-pocket expenditures for families, differences were found based upon the state of residence (e.g., Shattuck et al., 2008).

For children with SHCN or DD, the important life role as a student can often be negatively impacted. Missing school days due to illness, attending doctors' appointments, and other aspects of their daily lives, can significantly affect children's academic performance and progress. In a study detailing the epidemiological profile of children with SHCN, they were found to have significantly more (nearly triple) the number of sick days and school absences when compared with healthy children (e.g., Newacheck et al., 1998).

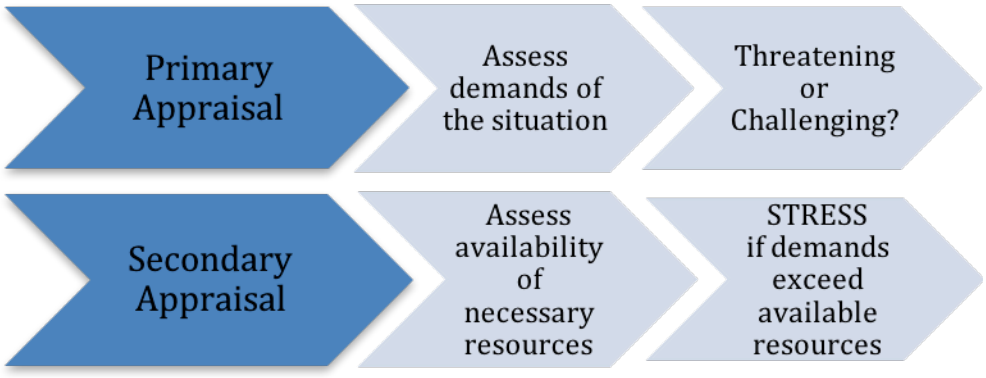
Coping. Coping is the second key component of the Transactional Model of Stress and Coping. Coping has been defined as the "constantly changing cognitive and behavioral efforts to manage external and/or internal demands are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). As such, coping is considered to be a dynamic, rather than a static, process (Lazarus & Folkman, 1984, 1987). Furthermore, coping is considered to be a state characteristic (a strategy that changes across different situations) rather than a trait characteristic. Coping can entail different strategic approaches to meeting the demands of a particular situation; problem-focused coping and emotion-focused coping. Problem-focused coping is, typically, an action to directly address an identified problem within the person-environment relationship, such as gathering more knowledge and skills. Emotion-focused coping is used to address the emotional distress that results from the situation (Lazarus & Folkman, 1987). According to the stress-support matching hypothesis

(Cohen & McKay, 1984; Cutrona & Russell, 1990), coping is maximized when the specific type of social support that is received matches the demands of the situation and the needs of the individual.

Effective coping strategies are considered to be a key buffer for stress management (Chwalisz & Obasi, 2008). In a study examining the coping strategies for parents of children with SHCN or DD, an inverse relationship was found between coping skills and levels of depression, with greater coping skills related to lower levels of depressive symptomatology (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010). Parental levels of social participation can be understood as a coping strategy as well as a determinant of quality of life (QOL). In a study examining family quality of life (FQOL) for families of children with Down's Syndrome, children with autism, and children with no DD, caregivers reported lower levels of FQOL when their child had either of the identified DD as compared to caregivers of children without DD (Brown, MacAdam–Crisp, Wang, & Iarocci, 2006) in all of the following domains: health, financial well-being, family relationships, support from other people, spiritual and cultural beliefs, careers and preparing for careers; leisure and enjoyment of life; and community and civic involvement. Notably, the only domain in which the families of children with DD reported higher satisfaction than families of children without DD was for the support from disability services (Brown et al., 2006).

Figure 2

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)



Social support. Social support has been defined as "the emotional, psychological, affirmative, information, instrumental, or material aid and assistance provided by personal social network members that influence the behavior of the recipient of help or advice in a positive manner" (Dunst, Trivette, & Jodry, 1997, p. 501). Vaux (1988) proposed that social support is a complex, ongoing, transactional process between individuals and their social networks that is anchored in a socioecological context.

In the existing social support research, the two main conceptualizations of the social support-health relationship are the buffering hypothesis and the direct (or main) effects hypothesis (Taylor, 2011). The distinction between the two hypotheses is the role of timing for the social support in determining its perceived benefit by the intended recipient of the support. The direct or main effects hypothesis proposes that social support is always beneficial (regardless of timing). The buffering hypothesis conceptualizes social support as being particularly beneficial to an individual's health and well-being in the face of stress (Cohen & McKay, 1984). As previously addressed, social support can be conceptualized as a form of coping via the stress-buffering hypothesis (Thoits, 1986).

Social support can comprise objective and subjective aspects. Objective social support addresses the availability or lack of availability for the particular resources. Subjective social support addresses whether an individual is satisfied with the support received and experiences it to be helpful (Crnic and Stormshak, 1997; Uchino, 2009). There exist different types of social support, which are the following: instrumental, emotional, informational, and appraisal.

Relationships between social support and various aspects of the caregiver, child, or family adjustment and adaptation have been examined (Dunst et al., 1997). For example, in study of parents with children with SHCN, parents reported that they derived benefit from participation in group social support services, such as expanded support networks, increased insight about their caregiving experiences, and improved relationships with their children with SHCN (Baum, 2004). In a study of experiences of pediatric parenting stress, parents of young children with Type 1 Diabetes reported lower levels of stress and higher level of knowledge after participating in a telephonic intervention program (Monaghan et al., 2011). In Dunst et al.'s (1997) study, social support was associated with well-being at the individual as well as family levels (Dunst et al., 1997). In another FSS study, mothers and fathers of school-aged children with disabilities benefit from different types of support: specialized support services for fathers and respite support services for mothers (Keller & Honig, 2004). For a study with adolescents with severe intellectual disabilities and their parents, informal sources of support (e.g., kinship, spouse) and not professional sources of support were positively associated with parental well-being (White & Hastings, 2004). Further examination of social support as a key coping mechanism for functioning of caregivers of children of

SHCN or DD holds promise as an intervention to support caregiver- as well as family-level functioning (in terms of coping with stress). Therefore, children with SHCN or DD as well as their caregivers and families warrant clinical and research attention to better understand and meet their needs.

A biopsychosocial, developmental framework for chronic illness and disability. The Family Systems Illness (FSI) model is a complementary theoretical foundation of this study. In his Family Systems Illness model, Rolland (1984, 1987, 1994, 2006) augments Engel's (1977, 1980, 1997) biopsychosocial model to develop a psychosocial, systemic, and developmental approach to working with children with health conditions and their families. The FSI model offers a systemic, ecological, and developmental framework through which to explore and seek to understand the experiences of children with SHCN or DD and their families. Rolland used the biopsychosocial model as a philosophy and guide for systems-oriented work with children and their families (Borrell-Carrió, Suchman, & Epstein, 2004). The FSI model is, therefore, a psychosocial model that can inform various aspects of work with families, including psychoeducation, assessment, and intervention (Rolland, 2006). There are four key assertions of the FSI model. First, the FSI model illustrates how the family's experience of child illness unfolds psychosocially, with a tripartite model of illness shaped by time phases, illness types, and factors in family functioning. Different systems, including the child, the child's illness, the family, and the health care providers, interface to inform the context for the child's and family's experiences. Second, the FSI model uses a developmental approach to understand the development of the illness (or health condition), the individual child, and the child's family (Rolland, 1994). Third, the

FSI model presents four characteristics of illness that are critical to consider when attempting to understand and assist children living with SHCN or DD and their families: time phase (crisis, chronic, or terminal), onset (acute/gradual), course (progressive, constant, relapsing), prognosis (fatal or shortened life span/non-fatal), and incapacitation (yes/no). Fourth, illnesses follow a timeline that impact child and family development and functioning: crisis (consisting of pre-diagnosis with symptoms, diagnosis, and initial adjustment period), chronic ("long haul"), and terminal (pre-terminal, death, and mourning or resolution of loss) (Rolland, 2006).

Summary. In sum, the ecological, transactional, and family systems illness theoretical framework support the examination and assessment of the following: self-reported levels of stress (in terms of frequency and difficulty of events) associated with caregiving across the domains of communication, medical care, emotional distress/functioning, and role function; perceived objective social support (access to informal and formal sources of support) as well as perceived subjective social support (helpfulness of such sources of support). When taken together, this information about stress and coping (more specifically, social support) offers the possibility of tailoring interventions to support and optimize the coping, resilience, functioning, and adaptation of caregivers and their families, including their children with SHCN or DD.

Study Purpose

The purpose of the current study was to use a quantitative descriptive research design, with data collected at one time point, to examine the experiences of pediatric parenting stress and family support for a sample of caregivers of children with SHCN or DD. Study objectives were to: (a) examine the psychometric properties of the Pediatric

Inventory for Parents (PIP) and Family Support Scale (FSS) measures with caregivers of children with SHCN or DD; (b) explore the experiences of pediatric parenting stress (PPS) and family support for caregivers in this study sample as well as compare the levels of stress and support for caregiver study participants to previously published rates/data recorded for other caregiver participant samples; (c) examine how levels of pediatric parenting support and family support vary by child, caregiver and family correlates; and (d) to examine the relationship between pediatric parenting stress and family support for this study sample.

Contributions of the Study. Few scholars have examined the relationship between pediatric parenting stress and social support for the caregivers of children with SHCN or DD. This dissertation was designed to contribute to the literature by serving as the first study, to my knowledge, to use the PIP and FSS measures in combination to assess caregiver stress (pediatric parenting stress) and support (family support). The purpose of using both measures was to examine the relationship between stress and support for this caregiver population. Furthermore, caregiver stress was examined for a sample comprising caregivers of children with SHCN, DD, or comorbid SHCN and DD. In addition, few studies have assumed a multi-site approach to data collection. It was hoped that study findings would provide new knowledge about the types of stress and supports that caregivers of children with SHCN or DD experience, and ultimately, illuminate avenues that may be targeted to increase the health-related and other resources that these families can access across contexts of care.

Study Aims and Hypotheses. The study aims and hypotheses will be discussed in the following section.

Study Aim 1: To determine the psychometric properties of the Pediatric Inventory for Parents (PIP) and Family Support Scale (FSS) measures for caregivers of children with SHCN or DD.

Hypotheses: For the PIP, it was hypothesized that the authors' original (Streisand et al., 2001) four-factor structure of the PIP would be the best psychometric fit for this sample. For the FSS, it was hypothesized that the authors' (Dunst et al., 1997) original five-factor structure of the FSS would be the best psychometric fit for this sample.

Study Aim 2: To Describe the Experiences of Pediatric Parenting Support (PPS) and Family support (SS) for Caregivers of Children with SHCN or DD.

Hypotheses: It was hypothesized that the Pediatric Inventory for Parents (PIP) scores for caregivers of children with SHCN and DD would be comparable to what has been documented empirically with other samples of caregivers of children with chronic health conditions (more specifically, cancer, inflammatory bowel disease, Type 1 diabetes, obesity, sickle cell anemia, and bladder exstrophy). It was also hypothesized that participants would report higher levels of family support, in particular formal social support (e.g., professional agencies), given that this sample was connected to health support services (an eligibility requirement for participation in the study).

Study Aim 3: To Determine Relationships between Key Child, Caregiver, and Family Factors and Pediatric Parenting Stress (PPS) and Social Support (SS) Experiences.

Hypotheses: Extant empirical research shows that caregivers from more marginalized or underserved backgrounds are at risk of experiencing higher levels of PPS. Thus, it was hypothesized that single caregivers, younger caregivers, caregivers with young children, caregivers (and children) who hold ethnic/racial minority identities, and caregivers from low-income families would report higher levels of PPS. Additionally, it was hypothesized that single caregivers and caregivers from low-income families would

report lower levels of family support.

Study Aim 4: To Determine the Nature of the Relationship between Pediatric Parenting Stress (PPS) and Family support (SS) for Caregivers of Children with SHCN or DD.

Hypothesis: Per the Transactional Model of Stress and Coping, it was hypothesized that caregivers who perceived higher levels of family support would report lower levels of pediatric parenting stress.

CHAPTER III

METHODS

Participants

Participants were 167 caregivers of children who have special health care needs (SHCN) or developmental disabilities (DD). Participant inclusion criteria included any adult caregiver (including biological, adoptive, and foster parents or legal guardians) (1) who had legal custody of the child between the ages of 0 to 21 years; (2) was able to read and write in the English language; (3) whose child had SHCN or DD; and (4) whose child/family was receiving services at the Oregon Health and Science University's Child Development and Rehabilitation Center (CDRC); the University of Oregon's HEDCO Clinic; Early Childhood CARES (EC CARES); and The Arc of Lane County. Study participation was limited to only one caregiver per family (as noted in the study flyers and the informed consent form).

Procedures

Data collection sites. Data were collected from children and families receiving services at four sites: (1) the Oregon Health & Science University (OHSU) Child Development and Rehabilitation Center (CDRC) clinic located in the Clinical Services building on the UO campus at 901 East 18th Avenue in Eugene, Oregon. The CDRC provides comprehensive, interdisciplinary clinical (assessment and treatment services) to children presenting with a wide range of developmental disabilities and other special health care needs; (2) UO College of Education HEDCO Clinic located in the HEDCO Clinic building on the UO campus at 1655 Alder Street #170, Eugene, Oregon. The HEDCO Clinic is a multidisciplinary training clinic for the UO College of Education.

The range of services provided include couple and family therapy; speech, language, and hearing therapy; and reading and math support services; (3) The Arc of Lane County located at 4181 E Street, Springfield, Oregon. The Arc provides services to support individuals with individual and developmental disabilities as well as their families; and, (4) EC CARES at 299 E 18th Ave, Eugene, Oregon. EC CARES provides early intervention and early special education services to children and families.

Participant recruitment. Participants were informed about study participation via informational study flyers. Flyers were shared with participants using different distribution methods. At the CDRC, study posters and postcards were posted in the waiting area and treatment rooms of the CDRC. At the HEDCO Clinic, study recruitment posters and postcards were posted in the main waiting area. At the Arc of Lane Country, a link to the study recruitment poster was available to view in the monthly newsletter sent via email to families. Research team members also attended agency events, including a family support group and carnival event, to connect with families in-person. At EC CARES, a link to the study recruitment poster was available to view in the monthly newsletter sent via email to families. Participants had the following options: to click directly on the study image to be directed to the poster, which had active links to the online survey or to the pdf version of the packet; to download a copy of the survey packet and submit it to the research team via mail; or to request a survey packet by mail.

Data collection. Data collection procedures varied across the four sites. Permission letters for data collection were received from the director or manager at each of the four data collection sites (see Appendix A).

For CDRC participants, study packets were placed in document holders in the

waiting area and the big gymnasium in the CDRC. Caregivers who were interested in participating were able to pick up a study packet from one of the document holders. Enclosed in each packet (hard copy and electronic versions) for every site were the following documents: an informed consent form that included contact information for the research team (see Appendix C); a cover sheet that outlined instructions for completion of the study questionnaires (see Appendix D); and the three research questionnaires (demographic and medical information questionnaire, Pediatric Inventory for Parents questionnaire, and Family Support Scale questionnaire). Participants provided their consent either by returning the completed study packet to the research team or by completing the electronic version of the study packet via Qualtrics survey software. A $10 electronic gift card (for Amazon or Target) was provided to participants upon completion of the study measures. Participants were encouraged to keep a copy of the informed consent form for their records and for future reference. Participants provided active consent by completing and submitting their study packets to the front desk staff. For participants who required additional time to complete their study questionnaires, they were advised to take a pre-stamped, pre-addressed envelope (with the CDRC's address and sent to the attention of the support staff supervisor) from one of the study baskets. Each pre-addressed envelope had a number noted on the outside. After completing and returning the packet by mail, participants contacted the support staff supervisor directly (at the number and email noted in the informed consent form as well as on the notecard inside the envelope) with their envelope number. Upon receiving the participant's completed survey packet, the supervisor placed a gift card with the participant's envelope for pick-up at the CDRC front desk and submitted the sealed envelope into the locked

box for the research team. Of 49 pencil-and-paper survey packets that were distributed in the CDRC clinic, 35 completed packets were submitted, and 14 packets were taken but not returned.

For HEDCO Clinic participants, study packets were made available in the waiting room area. Please see the "CDRC" section for information about the study packets and submission upon completion. Of five packets that were taken by participants, all five were completed and returned.

For The Arc of Lane County participants, caregivers who received the monthly newsletter were invited to participate in the study by completing an electronic version of the survey or requesting a hard copy of the survey packet. Of 74 online surveys, 73 were submitted and 1 was empty. Of the 15 pencil-and-paper survey packets, all were completed and returned.

For EC CARES participants, caregivers who received the monthly newsletter were invited to participate in the study by completing an electronic version of the survey or requesting a hard copy of the survey packet. Of 58 online surveys that were submitted, 16 were empty.

The project manager and I collected all of the data (in the form of completed study packets) from the CDRC and HEDCO clinic on a regular basis. Completed questionnaires were stored in a locked filing cabinet in Dr. Krista Chronister's office, located in 130 HEDCO College of Education. Research team members were the only people who had access to the data. Data entered into SPSS were stored in computer files that were located on password protected computers that belonged to me and team

members. Data collected from electronically-completed surveys were made available to me and the project manager through Qualtrics survey software.

Study Measures

All of the measures described in this section were a part of all hard copy survey packets as well as the electronic surveys.

Demographic and Medical Information. I consulted Krista Chronister (co-investigator) and Debra Eisert (service provider at one of the data collection sites), to create an original demographic and medical information form for use in the current study. The form comprises sixteen questions that address various aspects of caregivers' demographic information (e.g., age, race, educational attainment), child's demographic and medical information (e.g., diagnoses, support services received), and household information (e.g., insurance coverage, household structure).

Pediatric Parenting Stress. The Pediatric Inventory for Parenting (PIP; Streisand et al., 2001) was used to measure pediatric parenting stress. The PIP consists of a list of events that can be stressful for parents of children who have or have had chronic health conditions. The PIP is a 42-item measure comprising four stress domains (Communication, Emotional functioning, Medical Care, and Emotional function) that reflect two dimensions: frequency of occurrence (PIP-F; over the past 7 days) and degree of difficulty/stress (PIP-D; in general). For each frequency item, participants provided a response on a 5-point Likert scale 1 (never) to 5 (very often) and for each difficulty/stress item from 1 (not at all) to 5 (extremely). The PIP-F domain reflected the most common events and the PIP-D domain reflects the most stressful events. Higher scores on the frequency dimension indicate higher frequency for the subscale and higher scores on the

degree of difficulty/stress dimension indicate higher difficulty for the subscale. The present study scores across the four domains and scales were converted into a mean score. Sample items for the *Communication domain* are: "speaking with the doctor" and "feeling confused about medication information". Sample items for the *Emotional functioning* domain are: "waiting for my child's test results" and "worrying about the long-term impact of the illness". Sample items for the *Medical Care domain* are: "bring my child to the clinic" and "making decisions about medical care or medicines". Sample items for the *Role Function domain* are: "being unable to go to work/job" and "noticing a change in my relationship with my partner." Internal consistency reliability for the PIP was calculated with a sample of 160 mothers and 21 fathers of children with cancer (Cronbach α range was .80 to .96). The Cronbach alphas for the current study sample ranged from .73 to .96.

With the lead author's permission, I revised the original question stem to read, "Below is a list of difficult events which caregivers of children who have (or have had) special health care needs or developmental disabilities sometimes face." For the online survey packet, I converted the PIP measure from a paper-and-pencil format into an electronic survey format using the Qualtrics survey software program.

Family Support Scale. The Family Support Scale (FSS; Dunst et al., 1984) was used to measure the availability and perceived helpfulness of social support for families. The FSS consists of a list of 19 possible sources of informal and formal support. The final two items on the FSS are respondent-initiated items, which allows respondents to provide information about any additional sources of support that are not captured by the measure. Samples items addressing *informal support* include spouse or partner, other

children, friends, or neighborhoods. Sample items addressing *formal support* include professional helpers and professional agencies. For each item, respondents are asked to rate the perceived level of helpfulness on a 5-point Likert scale ranging from 1 (not at all helpful) to 6 (extremely helpful) with a NA (not available) option. Higher subscale and total scores indicate higher levels of social support that is perceived to be available and helpful. With a sample of 174 mothers and 50 fathers of children with DD or at risk for developmental conditions, internal consistency reliability was calculated as $\alpha = .79$. The Cronbach alphas for the present study sample ranged from .50 to .82.

With the lead author's permission, I revised the original question stem to read, "How *helpful* has each of the following been to you in terms of raising your child(ren) with special health care needs or developmental disabilities"? For the online survey packet, I converted the FSS measure from a pencil-and-paper survey format into an electronic format using the Qualtrics survey software program.

The University of Oregon Institutional Review Board determined that the present study was of "minimal risk" level and, thus, determined to be exempt (see Appendix E). Quantitative descriptive analyses (including survey, data reduction, and correlational method) were used to address the study aims. Results from these analyses are detailed in the next chapter.

CHAPTER IV

RESULTS

The results from all preliminary and main study analyses are presented in this chapter.

Power Analyses

A power analysis was conducted using the G*Power 3.1 program (Faul, Erdfelder, Lang, & Buchner, 2007). It was determined that the minimum sample size was 128 participants (to achieve an effect size of 0.3 with a statistical significance of 0.05).

Data Screening and Data Management

A total of 187 participants returned study surveys, of which a total of 138 surveys had complete data and 49 survey packets (of which 16 were empty) had varying levels of missing data. The data for 167 participants were included in the initial and main study analyses.

I consulted the lead authors of the PIP and FSS measures to confirm their guidelines for addressing any missing data. All missing item-level responses on the PIP-Difficulty subscale were entered as a "1" (to reflect "not at all" with regard to difficulty) if the corresponding PIP-Frequency item had been reported by the participant as a "1" (to reflect "never" with regard to frequency); that is, an item-level response for PIP-D of "1" was imputed because an event could not be experienced as difficult if it did not occur at all. All of the missing item-level responses on the FSS measure were imputed as a "1" (to reflect "not at all helpful"); that is, if a participant had not endorsed the helpfulness of a particular source of support, then the source was inferred as being "not at all helpful".

Upon completion of the recommended data imputation methods, between 95% to 100% of study participants had complete data on each of the study variables. IBM SPSS Statistics Standard Grad Pack 24 for Mac (IBM SPSS, 2017) was used to perform Little's test (Little, 1998). The result of Little's test was not statistically significant, $\chi^2(3530) = 3518.56$, $p > .05$ (Little, 1998); therefore, I inferred that all of the missing data (following the data imputation) were Missing Completely At Random (MCAR). I selected listwise deletion as the technique for handling all of the remaining missing data (Schaefer & Graham, 2002).

Preliminary Study Analyses

Preliminary data analyses were conducted using IBM SPSS Statistics Standard Grad Pack 24 for Mac (IBM SPSS, 2017). Data were screened for outliers, skewness, and kurtosis, to test statistical assumptions. The limits for skew and kurtosis limits were set between - 2.0 to +2.0, and any scores outside of the range of possible domain, subscale, or total scores on the PIP and FSS measures were considered outliers (Field, 2013). Skewness of PIP scores ranged between -.48 to .02 (indicating a slightly positive skew) and between -.19 to .32 for FSS scores (indicating a slightly negative skew). Kurtosis of PIP scores were between -1.18 to -.22 and between -.80 to -.13 for FSS scores (indicating a flatter distribution). There were no significant outliers for either the PIP or FSS measure. These preliminary analyses results suggest that participants' data were relatively normally distributed and that statistical assumptions were met for the main study analyses (Schumacker & Lomax, 2004). Descriptive statistics for the PIP and FSS overall scales and subscales are presented in Table 1.

Table 1

Descriptive Statistics for the PIP and FSS Overall Scales and Subscales

	Min, Max	*M* (SD)	Skewness (SE)	Kurtosis (SE)	Score Range
PIP-Frequency					
Communication	1.00, 4.00	2.68 (.68)	-.48 (.19)	-.67(.37)	1-5
Medical Care	1.00, 4.75	2.79 (.87)	-.13 (.19)	-1.11 (.37)	1-5
Emotional Distress	1.29, 4.60	3.01 (.73)	-.40 (.19)	-.72 (.37)	1-5
Role Function	1.00, 4.50	2.76 (.66)	-.23 (.19)	-.22 (.37)	1-5
Overall Frequency	1.11, 4.21	2.84 (.65)	-.42 (.19)	-.58 (.37)	1-5
PIP-Difficulty					
Communication	1.00, 4.11	2.62 (.80)	-.17 (.19)	-.89 (.37)	1-5
Medical Care	1.00, 4.75	2.66 (.99)	.02 (.19)	-1.18 (.37)	1-5
Emotional Distress	1.00, 4.73	3.12 (.91)	-.33 (.19)	-.66 (.37)	1-5
Role Function	1.00, 4.80	2.76 (.82)	.01 (.19)	-.54 (.37)	1-5
Overall Difficulty	1.00, 4.31	2.84 (.80)	-.25(.19)	-.67 (.37)	1-5
FSS					
Kinship	0, 10.00	4.36 (2.47)	.05 (.19)	-.46 (.37)	0-10
Spouse/Partner Support	0, 15.00	6.80 (3.43)	-.19 (.19)	-.50 (.37)	0-15
Informal Support	0, 23.00	9.63 (4.69)	.28 (.19)	-.13 (.37)	0-30
Programs/organizations	0, 17.00	6.28 (4.20)	.32 (.19)	-.69 (.37)	0-20
Professional Services	2, 20.00	10.89 (4.35)	0 (.19)	-.80 (.37)	0-20
Overall Support	10, 79.00	37.96 (13.51)	.12 (.19)	-.51 (.37)	0-95

Note. PIP = Pediatric Inventory for Parents; FSS = Family Support Scale; SD = standard deviation.

Descriptive Statistics. A summary of key child, caregiver, and family characteristics for current study participants are presented in Table 2.

Table 2

Summary of Child, Caregiver, and Family Characteristics

	n
Child characteristics	
Age (*M* [SD])	9.27 [4.88]
Female	49 (30%)
Ethnic Minority	51 (31%)
Number of Diagnoses	-
Unknown	39 (23%)
One	26 (16%)
Two or more	107 (61%)
Caregiver characteristics	
Age (*M* [SD])	39.98 [8.17]
Female	125 (75%)
Ethnic Minority	30 (28%)
Education	-
High school or less	17 (10%)
Some college/AA/AS	77 (46%)
BA/BS	49 (29%)
Advanced/graduate degree	24 (15%)
Family characteristics	-
Insurance	
Medicaid	63 (38%)
Private	85 (52%)
Other	21 (10%)
Household Structure	
Single-caregiver	11 (14%)
Two-caregiver	121 (74%)
Other	20 (12%)
Biological Parent of Child	141 (84%)

Table 2 continued

Summary of child, caregiver, and family characteristics

	n (%)
Support services received by child	
Multiple services	148 (88.6%)
One service	12 (0.07%)
None reported	7 (0.04%)
Most prevalent support services received by child	
In-school services	101 (61%)
Primary care services	94 (56%)
Speech/language therapy	83 (50%)
Occupational therapy services	80 (48%)
DDS/ SSI	64 (38%)
Physical therapy services	56 (34%)
Mental health services	47 (28%)
Social skills training	36 (22%)
Educational services in community	29 (17%)
Organizational skills training	3 (2%)
Most prevalent child diagnoses	
Multiple Diagnoses	136 (81%)
Attachment disorder	36 (22%)
Sensory issues	34 (20%)
Developmental delays	33 (19%)
ADD/ADHD	31 (18%)
Deformities	29 (17%)
Anxiety	28 (16%)
Autism Spectrum Disorder	24 (14%)
Learning disorder	23 (13%)
Intellectual disability	21 (12%)
Speech/communication problems	19 (11%)

Note. DDS/SSI= Developmental Disabilities Services/ Supplemental Security Income; ADD/ADHD= Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder.

Table 3

Summary of Child and Caregiver Characteristics: Race

	n (%)
Child characteristics	
African-American or Black	5 (3%)
American Indian or Alaska Native	4 (2.4%)
Asian	6 (3.6%)
Caucasian or White	115 (68.9%)
Hispanic, Latino, or Spanish Origin	8 (4.8%)
Two or more races	28 (16.8%)
Missing	1 (99.4%)
Total	167 (100%)
Caregiver characteristics	
African-American or Black	2 (1.2%)
American Indian or Alaska Native	3 (1.8%)
Asian	4 (2.4%)
Caucasian or White	135 (80.8%)
Hispanic, Latino, or Spanish Origin	8 (4.8%)
Two or more races	13 (7.8%)
Missing	2 (1.2%)
Total	167 (100%)

In sum, the present study sample comprised primarily European-American biological mothers who were well-educated, had private or other health insurance, were in partnered relationships (the majority were in a relationship with the biological father of their child), and in middle adulthood.

Main Study Analyses

Main study analyses are discussed for each of the study aims.

Study Aim 1: To determine the psychometric properties of the Pediatric Inventory for Parents (PIP) and Family Support Scale (FSS) measures for caregivers of children with SHCN or DD

The first study aim was to examine the psychometric properties (more specifically, internal consistency, reliability, and factor structure) of the Pediatric Inventory for Parents (PIP) and Family support (FSS) measures for the current study sample.

Internal consistency reliability. To determine the internal consistency reliability for the PIP and FSS measures, Cronbach's alphas (α) and Pearson product-moment correlation coefficients (r) were calculated. Given the two scales of the PIP measure, Cronbach alphas were calculated separately for PIP-Frequency (PIP-F) and PIP-Difficulty (PIP-D) (Cronbach, 1951). The four PIP domains (Communication, Medical Care, Emotional Functioning/ Distress, and Role Function) were determined to have acceptable reliabilities, all with Cronbach's alphas above .70. The four PIP domains were strongly, positively, and significantly correlated with each another (rs ranged from .59 to .81, $p < .05$ for PIP-Frequency, and rs ranged from .67 to .82 for PIP-Difficulty, $p < .05$) as well as with the overall PIP scale scores (rs ranged from .83 to .94, $p < .05$ for PIP-Frequency, and rs ranged from .88 to .95 for PIP-Difficulty, $p < .05$). Correlations were in the expected direction, with increases in the all of domains of stress (Communication, Medical Care, Emotional Distress/Functioning, Role Function) correlating directly with increases in the overall frequency and difficulty of stress. Internal consistency reliability findings for the PIP measure are shown in Tables 4 and 5. For the FSS measure, the Kinship, Spouse/Partner, Informal Support, and Professional Services subscales had low reliabilities with αs ranging between .59 to .65, all of which were below the acceptable threshold of .70 (Nunnally & Bernstein, 1994). The relatively small number of items for these four FSS subscales (2 items, 4 items, 4 items, and 5 items respectively) could have affected their estimated alphas (Nunnally & Bernstein, 1994).

All five FSS subscales (Kinship, Spouse/Partner, Informal Support, Programs/ Organizations, and Professional Services) were positively and significantly correlated with one another (*r*s ranged from .19 to .61, $p < .05$) as well as with the total scale score (*r*s ranged from .50 to .79, *p*s < .05). The correlation coefficients indicated modest to strong relationships between the FSS subscale and total scale scores and in the expected directions; increases in the helpfulness and availability of the five types of support were directly associated with increases in overall support levels.

Table 4

Internal consistency for the PIP and FSS measures

	α
PIP-Frequency	
Communication	.78
Medical Care	.86
Emotional Distress	.88
Role Function	.73
Overall Frequency	.94
PIP-Difficulty	
Communication	.80
Medical Care	.89
Emotional Distress	.91
Role Function	.80
Overall Difficulty	.96
FSS	
Kinship	.50
Spouse/Partner Support	.65
Informal Support	.59
Program/Organizations	.71
Professional Services	.59
Overall Support	.82

Note. PIP = Pediatric Inventory for Parents; FSS = Family Support Scale.

Table 5

Correlations for the PIP and FSS Measures

PIP-Frequency	Overall	Communication	Medical Care	Emotional Distress	Role Function
Communication	.91*	1			
Medical Care	.83*	.73*	1		
Emotional Distress	.94*	.81*	.68*	1	
Role Function	.86*	.72*	.59*	.76*	1
PIP-Difficulty	**Overall**	**Communication**	**Medical Care**	**Emotional Distress**	**Role Function**
Communication	.92*	1			
Medical Care	.88*	.79*	1		
Emotional Distress	.95*	.82*	.76*	1	
Role Function	.88*	.75*	.67*	.77*	1
FSS	**Overall**	**Kinship**	**Spouse/Partner**	**Programs/ Organizations**	**Professional Services**
Kinship	.50*	1			
Spouse/Partner	.60*	.32*	1		
Informal Support	.79*	.27*	.40*	1	
Programs/Organizations	.79*	.23*	.26*	.51*	1
Professional Services	.74*	.21*	.19*	.41*	.61*

Note. PIP = Pediatric Inventory for Parents (Streisand et al., 2001); FSS = Family Support Scale (Dunst et al., 1994).
*$p < .05$

Factor analyses for the PIP measure. A confirmatory factor analysis (CFA) using MPlus Version 7.4 (Muthén & Muthén, 1998-2015) was conducted to examine the goodness-of-fit of the four-factor PIP model (as proposed in the original PIP study by Streisand et al., 2001) and comparative one-factor PIP model (as proposed by Vrijmoet-Wiersma et al., 2010). Goodness-of-fit was determined using a model test statistic and three approximate fit indices: Chi-square Goodness-of-fit Test (Pearson, 1900); Tucker-Lewis Fit Index (TFI; Tucker-Lewis, 1973); Bentler Comparative Fit Index (CFI; Bentler, 1990); and, Steiger-Lind Root Mean Square Error of Approximation (RMSEA; Steiger, 1990). The items on both of the PIP scales (Frequency and Difficulty) were examined separately.

CFA results are summarized in Table 7. The four-factor model for the PIP-Frequency items did not converge initially; however, it was determined that the non-convergence was caused by one item, Event 2 (Arguing with family member(s)) in the Communication domain. This specific event was found to be uncorrelated with the other eight items in the domain, except for Event 27 (Feeling misunderstood by family/friends as to the severity of my child's illness; $r = .17$, $p < .05$). After eliminating the Event 2 item, the model converged but did not fit the PIP-Frequency data well, $\chi^2(773) = 1902.84$, CFI = .68, TLI = .66, RMSEA = .09. The four-factor model did not fit the PIP-Difficulty data well, χ^2 (813, N = 167) = 2063.97, CFI = .69, TLI = .67, RMSEA = .10. Similar to the four-factor model, the comparative one-factor model did not fit the data well for either the PIP-Frequency items, $\chi^2(819) = 2112.63$, CFI = .64, TLI = .62, RMSEA = .10, or the PIP-Difficulty items, $\chi^2(819) = 2179.51$, CFI = .66, TLI = .64, RMSEA = .10. In sum, CFA results for the PIP subscales indicated a poor fit of current

study data, failing to confirm the previously proposed four- and one-factor PIP models (see Table 6).

Table 6

Goodness-of-fit Indexes for PIP Four-factor and One-factor models

Models	χ^2	df	CFI	TLI	RMSEA [95% CI]
Frequency					
Four-factor model	1902.84	773	.68	.66	.09
One-factor model	2179.51	819	.66	.64	.10
Difficulty					
Four-factor model	2063.97	813	.69	.67	.10
One-factor model	2112.63	819	.62	.62	.10

Note. χ^2 = Chi Square Goodness-of-Fit Test; df = degrees of freedom; CFI = Comparative Fit Index; TLI = Tucker-Lewis Index; RMSEA = Root mean square error of approximation.

Given the CFA results, an exploratory factor analysis (EFA) was conducted with oblique rotation (direct oblimin). Similar to the CFA, the PIP-Frequency items and PIP-Difficulty items were examined separately. To determine the initial plausibility of the structure for the PIP-Frequency items, an analysis was completed by evaluating the variance accounted for by the solution, the variance accounted for by each individual factor, factors with eigenvalues greater than 1 (Kaiser, 1960), and the interpretability of the factors. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy verified the sampling adequacy for the analysis, KMO = .893. Using principal axis factoring (PAF) as an extraction method, nine factors had eigenvalues greater than 1 and, together, accounted for 61.7% of the variance. Only two factors explained at least 5% of the variance in the items and accounted for a combined 39.42% of the variance (accounting for 31.23% and 8.18% of the variance respectively). When examining factor loadings

from the pattern matrix, the findings did not yield interpretable factors, and one of the PIP-Frequency items cross-loaded (see Table 7).

Table 7

Factor Loadings for Exploratory Factor Analysis with Oblique Rotation of PIP-Frequency Items

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	Factor 9
Event 1: Difficulty Sleeping	-.24	.07	**-.41**	.12	.03	.28	-.16	-.03	.13
Event 2: Arguing	.08	.12	.09	**.55**	-.03	.01	-.14	.05	.11
Event 3: Bringing my child to the clinic	.19	.08	-.10	-.03	.09	**.41**	-.18	.04	.16
Event 4: Learning upsetting news	.11	.25	-.25	.16	-.14	.38	.04	.26	-.12
Event 5: Being unable to go to work	.02	.22	-.07	.09	-.17	.38	-.05	.24	0
Event 6: Seeing mood change	-.02	-.05	-.01	.12	-.04	.04	**-.77**	-.09	.01
Event 7: Speaking with doctor	.12	-.01	0	-.12	.13	**.67**	-.17	-.08	.11
Event 8: Watching/eating	.17	-.02	-.29	-.03	.32	.22	-.12	.04	.03
Event 9: Waiting for test results	**.42**	.06	-.03	-.21	.05	**.47**	.11	0	.13
Event 10: Having money	.01	**.55**	.03	.19	.15	.16	.03	-.07	.01
Event 11: Trying not to think/difficulties	-.04	**.60**	-.11	.14	.03	-.05	-.10	.01	-.01
Event 12: Feeling confused	**.74**	.11	.07	.09	.05	0	-.04	-.01	.02
Event 13: Being with my child	.14	-.07	.06	-.09	.03	**.58**	-.14	.21	.03
Event 14: Knowing/hurting	.37	.08	.02	-.38	-.04	.14	-.19	0	.07
Event 15: Trying to attend/other	-.12	.28	.38	-.04	.25	.04	-.27	.25	-.01
Event 16: Seeing child sad	.23	.19	-.18	-.13	-.11	-.01	**-.57**	.11	-.12
Event 17: Talking with the nurse	.22	-.05	-.15	-.17	.13	**.51**	-.11	.09	.02
Event 18: Making decisions	.30	.12	.02	-.21	.07	.25	-.32	.14	-.03
Event 19: Thinking about/isolated	.22	**.64**	.08	-.13	-.13	-.01	-.09	.06	.06
Event 20: Being far away from family	-.02	-.04	.04	.03	.02	.06	.06	**.75**	-.03
Event 21: Feeling numb inside	.23	-.03	-.27	.10	-.09	-.13	-.15	**.41**	.14
Event 22: Disagreeing	**.56**	-.02	-.11	.06	-.03	.11	-.04	.11	.01
Event 23: Helping/Hygiene needs	.05	.01	.01	-.02	**.65**	.02	.08	.01	-.09
Event 24: Working about/impact	.07	**.53**	-.02	-.21	.01	-.01	.03	.06	.37
Event 25: Having little time	-.05	.32	.06	0	.31	-.25	-.11	.02	.24
Event 26: Feeling helpless	0	.36	-.03	-.03	-.16	-.02	-.03	.31	.33

Table 7 continued

Factor Loadings for Exploratory Factor Analysis with Oblique Rotation of PIP-Frequency Items

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	Factor 9
Event 27: Feeling misunderstood	.06	.23	-.01	.12	-.16	0	-.11	-.11	**.55**
Event 28: Handling changes	.39	-.12	-.21	-.10	.11	.22	-.09	.04	.22
Event 29: Feeling uncertain	.08	**.46**	-.38	-.11	-.13	-.12	-.04	.11	.18
Event 30: Being in the hospital	.25	-.29	**-.51**	-.07	.11	.07	-.16	.14	.12
Event 31: Thinking about/other ill	0	-.01	-.28	-.37	-.10	-.02	-.17	.06	.34
Event 32: Speaking with child	.13	-.11	.01	-.15	-.29	.17	-.10	.15	.34
Event 33: Helping/procedures	.06	-.28	-.07	-.17	.32	.34	-.28	.06	.17
Event 34: Having my heart beat fast	.05	.11	**-.75**	-.10	-.03	-.06	-.13	.06	-.02
Event 35: Feeling uncertain	.22	-.08	-.14	.39	-.14	-.20	-.12	.24	.06
Event 36: Feeling scared	.10	.04	**-.42**	-.22	.07	.20	.09	.20	.29
Event 37: Speaking with family	.18	-.03	-.11	.06	.03	.26	.09	-.07	**.65**
Event 38: Watching/procedures	.15	-.02	-.11	-.23	.06	**.51**	-.05	.08	.18
Event 39: Missing important events	.12	-.03	-.13	.02	.22	-.03	-.03	.36	.36
Event 40: Worrying	-.07	.05	0	.01	0	-.07	-.10	.20	**.54**
Event 41: Noticing a change	.19	.05	-.12	.15	.16	-.28	-.19	.25	.20
Event 42: Spending a great deal of time	**.43**	-.09	-.30	.04	.12	.06	-.06	.18	.12
Eigenvalues	13.58	3.94	2.29	1.71	1.59	1.36	1.18	1.09	1.03
Percentage of variance (%)	32.34	9.41	5.46	4.07	3.79	3.25	2.81	2.60	2.45

Note. Factor loadings > .40 are in boldface.

Similar to the PIP-Frequency items, an analysis was completed to determine the initial plausibility of the structure for the PIP-Difficulty items. The analysis comprised evaluating the variance accounted for by the solution, the variance accounted for by each individual factor, factors with eigenvalues greater than 1 (Kaiser, 1960), and the interpretability of the factors.

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy verified the sampling adequacy for the analysis, KMO = .907. Using principal axis factoring (PAF) as an extraction method, eight factors had eigenvalues great than 1. Two of the eight factors explained a total of 43.30% of the variance in the items (accounting for 35.56% and 7.74% of the variance, respectively). When examining factor loadings from the pattern matrix, the findings did not yield interpretable factors, and one of the PIP-Difficulty items cross-loaded (see Table 8).

Table 8

Factor Loadings for Exploratory Factor Analysis with Oblique Rotation of PIP-Difficulty Items

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
Event 1: Difficulty Sleeping	.04	.06	-.17	-.07	**-.61**	.13	.11	.15
Event 2: Arguing	.05	.20	-.01	-.12	-.16	0	.09	**.65**
Event 3: Bringing my child to the clinic	**.70**	.05	.13	-.07	-.03	.06	.06	0
Event 4: Learning upsetting news	.10	**.70**	-.01	.04	-.17	-.01	.03	.12
Event 5: Being unable to go to work	-.09	**.44**	-.09	-.22	-.20	.23	.05	-.14
Event 6: Seeing mood change	.13	.02	-.32	-.30	-.17	.12	-.01	.01
Event 7: Speaking with doctor	**.83**	-.03	-.11	.03	-.07	-.04	-.09	0
Event 8: Watching/eating	**.42**	.08	-.08	-.07	-.26	.17	.02	.02
Event 9: Waiting for test results	**.44**	.13	-.07	-.10	-.03	.08	-.06	-.39
Event 10: Having money	.01	**.66**	.05	-.06	.05	-.09	-.01	.11
Event 11: Trying not to think/difficulties	.11	**.61**	-.18	-.10	.21	-.18	.01	.04
Event 12: Feeling confused	**.56**	.18	-.03	-.08	.11	-.16	.09	-.02
Event 13: Being with my child	**.63**	.05	-.11	-.11	.01	.10	-.10	-.04
Event 14: Knowing/hurting	.24	.06	.19	-.26	-.10	-.09	.18	**-.41**
Event 15: Trying to attend/other	-.04	**.45**	.05	-.18	.39	.31	.14	.14
Event 16: Seeing child sad	.11	.14	-.04	-.35	-.09	-.04	.30	-.27
Event 17: Talking with the nurse	**.74**	-.05	-.08	.19	-.03	.05	.11	-.07
Event 18: Making decisions	.38	.11	.20	-.23	.01	.24	.11	-.04
Event 19: Thinking about/isolated	-.03	.24	.09	**-.61**	-.12	.06	.03	-.17
Event 20: Being far away from family	0	.35	-.15	.20	-.16	.13	.27	-.01
Event 21: Feeling numb inside	.06	.05	**-.55**	-.26	-.16	-.06	.11	-.07
Event 22: Disagreeing	.28	.36	-.15	-.02	0	.24	-.11	-.14
Event 23: Helping/Hygiene needs	.36	-.09	-.06	-.07	.04	.30	.14	.16
Event 24: Working about/impact	.03	.10	-.04	**-.74**	-.03	-.01	.02	-.03
Event 25: Having little time	.05	-.14	-.06	**-.62**	.23	.18	.13	.13
Event 26: Feeling helpless	.01	.05	-.21	**-.66**	-.05	-.02	.07	0
Event 27: Feeling misunderstood	.21	-.06	-.11	-.28	-.04	-.15	**.46**	.07

Table 8 continued

Factor Loadings for Exploratory Factor Analysis with Oblique Rotation of PIP-Difficulty Items

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
Event 28: Handling changes	.25	-.11	-.19	-.26	-.10	**.43**	-.04	-.19
Event 29: Feeling uncertain	.10	-.02	-.28	**-.49**	-.20	-.19	.12	.06
Event 30: Being in the hospital	.21	-.17	**-.41**	.06	-.09	**.50**	-.03	-.14
Event 31: Thinking about/other ill	.14	-.08	-.10	-.14	-.26	.10	.21	-.39
Event 32: Speaking with child	.04	-.11	-.24	-.12	-.17	.10	.18	-.29
Event 33: Helping/procedures	.38	-.25	-.08	0	-.13	**.42**	.13	-.13
Event 34: Having my heart beat fast	.02	.10	**-.55**	-.07	-.15	.02	.14	-.22
Event 35: Feeling uncertain	.03	.09	**-.62**	-.05	.04	.04	.12	.13
Event 36: Feeling scared	.19	-.06	-.06	-.21	-.25	.23	.14	-.24
Event 37: Speaking with family	.28	-.14	-.05	-.10	-.05	.03	**.51**	-.07
Event 38: Watching/procedures	**.44**	-.05	.02	-.10	-.10	.14	.21	-.18
Event 39: Missing important events	.06	.22	.04	-.13	-.07	.28	**.43**	.06
Event 40: Worrying	-.05	.04	0	-.10	-.17	-.05	**.72**	-.01
Event 41: Noticing a change	-.04	.04	-.27	.03	.28	.05	**.62**	.03
Event 42: Spending a great deal of time	.34	.04	-.19	.10	-.08	.14	.33	-.02
Eigenvalues	15.37	3.66	2.02	1.84	1.50	1.19	1.14	1.03
Percentage of variance (%)	36.51	8.72	4.81	4.38	3.57	2.82	2.72	2.45

Note. Factor loadings > .40 are in boldface.

Factor analyses for FSS measure. A confirmatory factor analysis (CFA) was conducted to examine the goodness-of-fit for the five-factor FSS model (as proposed in the original FSS study by Dunst et al., 1984) and the comparative one-factor model to the current study data. Goodness-of-fit was determined using a model test statistic and three approximate fit indexes: Chi-square Goodness-of-fit Test (Pearson, 1900); Tucker-Lewis Fit Index (TFI; Tucker-Lewis, 1973); Bentler Comparative Fit Index (CFI; Bentler, 1990); and, Steiger-Lind Root Mean Square Error of Approximation (RMSEA; Steiger, 1990). The five-factor model did not fit the data well, $\chi^2(142) = 363.95$, CFI = .75, TLI = .70, RMSEA = .10. In addition, the comparative one-factor model did not fit the data well, $\chi^2(152) = 535.80$, CFI = .56, TLI = .51, RMSEA = .12. CFA results are shown in Table 9.

Table 9

Goodness-of-fit Indexes for FSS Five-factor and One-factor models

Models	χ^2	df	CFI	TLI	RMSEA [95% CI]
Four-factor model	363.95	142	.75	.70	.10
One-factor model	535.80	152	.56	.51	.12

Note. χ^2= Model Chi Square; df= degrees of freedom; CFI= Comparative Fit Index; TLI = Tucker-Lewis Index; RMSEA=Root mean square error of approximation.

Given the CFA determination of poor fit for the five-factor FSS model, an exploratory factor analysis (EFA) was conducted with oblique rotation (direct oblimin). The Kaiser-Meyer-Olkin Measure of Sampling Adequacy verified the sampling adequacy for the analysis, KMO = .759. Using principal axis factoring (PAF) as the extraction

method, six factors had eigenvalues greater than 1 and, together, accounted for 64.89% of the variance. Three of the six factors accounted for a combined 45.40% of the variance (accounting for 25.92%, 10.92%, and 8.57% of the variance, respectively). The six factors accounted for 64.90% of the variance. When examining factor loadings from the pattern matrix, the findings did not yield interpretable factors, and two of the FSS items cross-loaded (see Table 10).

Summary. In sum, the Pediatric Inventory for Parents (PIP) and Family Support Scale (FSS) measures did not appear to be internally consistent for this study sample. The existing PIP and FSS factor structures (4-factor and 5-factor model respectively) did not fit the present study data well. In addition, the study data did not fit the previously-proposed 1-factor model for either the PIP or FSS measure.

Table 10

Factor Loadings for Exploratory Factor Analysis with Oblique Rotation of FSS Items

Source	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Source 1: Parents	.20	.02	-.02	-.13	**.48**	.03
Source 2: Spouse/partner's parents	.11	**.49**	-.14	.05	.38	.09
Source 3: Relatives/kin	-.14	-.02	.11	.14	**.70**	-.05
Source 4: Spouse/partner	.10	**.48**	-.14	.19	**.50**	.06
Source 5: Spouse/partner's relatives/kin	.12	.39	-.07	.14	-.18	**.55**
Source 6: Friends	.07	-.14	.04	**.79**	.09	-.17
Source 7: Spouse/partner's friends	-.04	.28	.13	**.66**	-.05	.19
Source 8: Older child(ren)	-.04	-.12	.07	-.07	.04	**.65**
Source 9: Neighbors	**.56**	-.06	-.09	.07	.03	.06
Source 10: Other parents	**.46**	-.30	.01	.28	-.01	-.11
Source 11: Co-workers	**.54**	.25	.13	-.02	-.11	-.06
Source 12: Parent group members	**.78**	0	.21	-.12	.06	-.07
Source 13: Social groups/clubs	**.59**	.04	.22	0	.14	.04
Source 14: Church members/minister	**.49**	.06	.01	.15	.15	.19
Source 15: Family/child's physician	.16	-.12	.28	.20	.22	.14
Source 16: Early childhood intervention program	0	**.48**	**.46**	-.06	0	-.03
Source 17: School/daycare center	.11	.10	**.52**	.08	-.03	-.07
Source 18: Professional helpers	-.03	-.06	**.71**	.02	.10	.11
Source 19: Professional agencies	.14	-.14	**.50**	.06	-.05	.05
Eigenvalues	4.92	2.08	1.63	1.35	1.25	1.11
Percentage of variance (%)	25.92	10.92	8.56	7.09	6.56	5.85

Note. Factor loadings > .40 are in boldface.

Study Aim 2: To Describe the Experiences of Pediatric Parenting Support (PPS) and Family support (SS) for Caregivers of Children with SHCN or DD

The second study aim was two-fold: 1) to determine the levels of pediatric parenting stress (PPS) and social support (SS) for study participants and 2) to compare participants' scores on the Pediatric Inventory for Parents (PIP; Streisand et al., 2001) and Family Support Scale (FSS; Dunst et al., 1984) measures to those reported in previously-published studies.

Comparison of PIP data for current and past studies. Independent samples *t*-tests were conducted to compare the current study sample's averaged mean PIP-Frequency and PIP-difficulty scores to the scores reported (in previously published studies) by caregivers of children with the following chronic conditions: cancer (Streisand et al., 2001), inflammatory bowel syndrome (Guilfoyle et al., 2012), type 1 diabetes (Streisand et al., 2005), obesity (Ohleyer et al. 2007), sickle cell disease (Logan et al., 2002), and bladder exstrophy (Mednick et al., 2009). This comparative analysis was a replication of Guilfoyle at al.'s (2012) study. Current study results show that there were statistically significant differences between study participants' pediatric parenting stress scores (as calculated by average mean PIP scale and domain scores) when compared to those for previously-studied samples of caregivers of children with five other conditions as an extension of Guilfoyle et al.'s (2012) comparative data across studies.

For overall PIP-Frequency mean scores, caregivers in the current study reported significantly higher scores overall compared to caregivers of children with cancer (M = 2.24, SD = .79), $t(291) = 7.13$, $p < .0001$, $d = .82$, inflammatory bowel disease (M = 2.01, SD = .66), $t(227) = 8.55$, $p < .0001$, $d = 1.27$, type 1 diabetes (M = 2.13, SD = .62, $t(299)$

= 9.61, $p < .0001$, $d = 1.12$, obesity ($M = 2.33$, $SD = .82$), $t(237) = 5.13$, $p < .0001$, $d = .69$, sickle cell disease ($M = 2.51$, $SD = .65$), $t(235) = 3.57$, p = .0004, d = .51, and bladder exstrophy ($M = 2.14$, $SD = .55$), $t(185) = 4.62$, $p < .0001$, $d = 1.16$. For overall PIP-Difficulty mean scores, caregivers in the current study reported significantly higher scores compared to caregivers of children with cancer ($M = 2.68$, $SD = .84$), $t(291) = 1.66$, p = .10, $d = .20$, inflammatory bowel disease ($M = 1.86$, $SD = .60$), $t(227) = 8.77$, $p < .0001$, $d = 1.39$), type 1 diabetes ($M = 1.86$, $SD = .62$, $t(299) = 11.65$, $p < .0001$, $d = 1.37$, obesity ($M = 2.19$, $SD = .81$), $t(237) = 5.74$, $p < .0001$, $d = .81$, sickle cell disease ($M = 2.17$, $SD = .79$), t(235) = 5.90, p < .0001, d = .84, and bladder exstrophy ($M = 2.10$, $SD = .69$), $t(185) = 3.96$, $p = .0001$, $d = .99$. Notably, caregivers of children with cancer (Streisand et al., 2001) reported higher mean scores on the "emotional distress" ($M = 3.23$, SD = .97) and "overall difficulty" ($M = 2.99$, SD = .93) domains than did current study participants. In addition, the difficulty of "emotional distress" and "overall difficulty" (PIP-D scores) for the current sample and a sample of caregivers of children with cancer were not statistically different. For the PIP-Frequency subscale mean scores, caregivers in the current study reported significantly higher scores overall compared to caregivers of children with cancer for communication ($M = 2.00$, $SD = .74$), $t(291) = 8.16$, $p < .0001$, $d = .95$, medical care ($M = 2.01$, $SD = .89$), $t(291) = 7.53$, p< .0001, d = .89, emotional distress ($M = 2.63$, $SD = .97$), $t(291) = 3.83$, $p = 0.0002$, $d = .44$, and role function ($M = 2.06$, $SD = .81$), $t(291) = 8.15$, $p < .0001$, $d = .95$. For the PIP-Frequency subscale mean scores, caregivers in the current study reported significantly higher scores overall compared to caregivers of children with cancer for communication ($M = 2.00$, $SD = .74$), $t(291) = 8.16$, $p < .0001$, $d = .95$, medical care ($M = 2.01$, $SD = .89$), $t(291) = 7.53$,

$p < .0001$, $d = .89$, emotional distress ($M = 2.63$, $SD = .97$), t(291) = 3.83, $p = 0.0002$, $d = .44$, and role function ($M = 2.06$, $SD = .81$), $t(291) = 8.15$, $p < .0001$, $d = .95$. For the PIP-Difficulty subscale mean scores, caregivers in the current study reported significantly higher scores overall compared to caregivers of children with cancer for communication ($M = 2.20$, $SD = .82$), $t(291) = 4.40$, $p < .0001$, d = .52), medical care ($M = 2.43$, $SD = .93$), $t(291) = 2.02$, $p = .043$, $d = .24$), and role function ($M = 2.06$, $SD = .81$), $t(291) = 8.15$, $p < .0001$, $d = .95$. There were no significant differences between the current caregiver sample and the sample of caregivers for children with cancer for the difficulty of emotional distress ($M = 3.23$, $SD = .97$, $t(291) = 1.00$, $p = .32$, $d = .15$. For the PIP-Frequency subscale mean scores, caregivers in the current study also reported significantly higher scores overall compared to caregivers of children with irritable bowel disease for communication ($M = 1.98$, $SD = .61$), $t(227) = 7.11$, $p < .0001$, $d = 1.08$), medical care ($M = 1.99$, $SD = .83$), $t(227) = 6.25$, $p < .0001$, $d = .94$), emotional distress ($M = 2.20$, $SD = .77$), t(227) = 7.35, $p < .0001$, $d = 1.08$), and role function ($M = 2.01$, $SD = .66$), $t(227) = 9.46$, $p < .0001$, $d = 1.39$). For the PIP-Difficulty subscale mean scores, caregivers in the current study also reported significantly higher scores overall compared to caregivers of children with irritable bowel disease for communication ($M = 1.59$, $SD = .52$), $t(227) = 9.42$, $p < .0001$, $d = 1.53$), medical care ($M = 1.55$, $SD = .58$), $t(227) = 8.31$, $p < .0001$, $d = 1.37$), emotional distress ($M = 2.32$, $SD = .87$), $t(227) = 5.98$, $p < .0001$, d = .90, and role function ($M = 1.73$, $SD = .60$), t(227) = 9.03, $p < .0001$, $d = 1.43$). Notably, researchers for two of these previous studies (Logan et al., 2002; Ohleyer et al., 2007) included in Guilfoyle et al.'s (2012) comparative study examined comorbidity between medical or developmental conditions and aspects of children's psychosocial

functioning, including behavioral and emotional problems such as anxiety. The comparison of PIP mean scores for the current study sample and the previous study samples is shown in Table 11.

In sum, current study results show that study participants' pediatric parenting stress scores (as calculated by average mean PIP scale and domain scores) were statistically higher overall than those for previously-studied samples of caregivers of children with five other conditions as an extension of Guilfoyle et al.'s (2012) comparative data across studies.

Table 11

Comparison of PIP Mean Scores Across Current Study Sample and Previous Study Samples

	Current Sample (N = 167) *M* (SD)	Cancer (N = 126) *M* (SD)	Inflammatory Bowel Disease (N = 62) *M* (SD)	Type 1 Diabetes (N = 134) *M* (SD)	Obesity (N = 72) *M* (SD)	Sickle Cell Disease (N = 70) *M* (SD)	Bladder Exstrophy (N = 20) *M* (SD)
PIP-Frequency							
Communication	2.68 (.68)	2.00** (.74)	1.98** (.61)				
Medical Care	2.79 (.87)	2.01** (.89)	1.99** (.83)				
Emotional Distress	3.01 (.73)	2.63** (.97)	2.20** (.77)				
Role Function	2.76 (.66)	2.06** (.81)	1.82** (.69)				
Overall Frequency	2.84 (.65)	2.24** (.79)	2.01** (.66)	2.13** (.62	2.33** (.82	2.51** (.65)	2.14** (.55)
PIP-Difficulty							
Communication	2.62 (.80)	2.20** (.82)	1.59** (.52)				
Medical Care	2.66 (.99)	2.43* (.93)	1.55** (.58)				
Emotional Distress	3.12 (.91)	3.23 (.97)	2.32** (.87)				
Role Function	2.76 (.82)	2.99* (.93)	1.73** (.60)				
Overall Difficulty	2.84 (.80)	2.68 (.84)	1.86** (.60)	1.86** (.62	2.19** (.81	2.17** (.79)	2.10** (.69)

Note. *Mean significantly differs from the current sample mean at $p < .05$.

**Mean significantly differs from the current sample mean at $p < .01$.

Comparison of FSS data for current and past studies. Current study results also show that participants' overall experiences of family support (as calculated by mean FSS total scale scores) were statistically significant from the original study FSS study (Dunst et al., 1984) sample of parents of young children with disabilities, (M = 48.42, SD = 10.73), $t(389) = 8.53$, $p < .05$, $d = .86$. Comparison scores for the current and previous study samples are shown in Table 12.

Table 12

Comparison of FSS Mean Scores Across Current and Previous Study Samples

	Current Sample (N = 167) *M* (SD)	**Young Children with Disabilities** (N = 224) *M* (SD)
FSS		
Kinship	4.36 (2.47)	
Spouse/Partner	6.80 (3.43)	
Informal Support	9.63 (4.69)	
Organizational Support	6.28 (4.20)	
Professional Support	10.89 (4.35)	
Overall Support	37.96 (13.51)	48.42* (10.73)

Note. *Mean significantly differs from the current sample mean at $p < .05$.

Study Aim 3: To Determine Relationships between Key Child, Caregiver, and Family Factors and Pediatric Parenting Stress (PPS) and Social Support (SS) Experiences

The third study aim was to determine key correlates between child, caregiver, and family factors associated with the levels of pediatric parenting stress and family support reported by the current study sample. Pearson product moment correlations, independent-samples *t*-tests (*t*-tests), and one-way analysis of variance (ANOVA) tests were conducted to examine the relationships between caregiver, child, and family factors with caregivers' scores on the Pediatric Inventory for Parents (PIP) and Family support

(FSS) measures (see Table 13 for test statistics, means, and standard deviations). For the current study sample, caregivers' experiences of pediatric parenting stress (PPS) and family support (SS) differed significantly by the sex of child and caregiver, number of child diagnoses, type of child-caregiver relationship, household structure, type of insurance coverage, caregiver education level, and survey format.

Sex differences. An independent samples *t*-test was conducted to compare male and female caregivers' experiences of pediatric parenting stress. There were significant differences between the two caregiver groups' scores on the Pediatric Inventory for Parents (PIP) measure. Male caregivers reporting significantly higher scores on all four PIP domains (Communication, Medical Care, Emotional Distress/Functioning, and Role Function) across the two PIP scales (Frequency and Difficulty) (see Table 13 for means, standard deviations, and test statistics). More specifically, male caregivers reported the following: more frequent (t [164] = 3.92, $p < .05$) and more difficult (t [164] = 3.38, $p < .05$) communication-related stressful events; more frequent (t [164] = 5.35, $p < .05$) and more difficult (t [164] = 5.00, $p < .05$) medical care-related stressful events; more frequent (t [164] =3.88, $p < .05$) and more difficult (t [164] =3.21, $p < .05$) emotional distress-related stressful events; more frequent (t [164] = 2.20, $p < .05$) and more difficult (t [164] = 2.35, $p < .05$) function-related stressful events as compared with female caregivers; and, more overall stress frequency (t [164] = 4.35, $p < .05$) and overall stress difficulty (t [164] = 3.77, $p < .05$). These study results suggest that caregiver gender differences were associated with their experiences of stress with male caregivers reporting more stress on the PIP as compared to female caregivers.

An independent samples *t*-test was conducted to compare male and female caregivers' experiences of family support. There were significant differences between the two caregiver groups' scores on the Family support (FSS) measure. Male caregivers reported significantly higher scores on four of the five FSS subscales (Spouse/Partner, Informal Support, Programs/ Organizations, and Professional Services); however, male and female caregivers' scores did not differ significantly on the Kinship subscale (see Table 13 for means, standard deviations, and test statistics). More specifically, male caregivers reported the following: more available and helpful spouse/partner support (t [164] = 5.62, $p < .05$); more available and helpful informal support (t [164] = 3.25, $p < .05$); more available and helpful support from programs/organizations; more available and helpful support from professional services (t [164] = 3.64, $p < .05$); as well as, more available and helpful overall support (t [164] = 5.08, $p < .05$). These study results suggest that caregiver gender differences were associated with aspects of caregivers' experiences of support with male caregivers reporting more support on the FSS than female caregivers. In sum, male caregivers in the current study reported more frequent and more difficult stressful events as well as more helpful and available support in general as compared with female caregivers (see Table 12).

An independent samples *t*-test was conducted to the experiences of pediatric parenting stress for caregivers of male children with caregivers of female children. There were significant differences between the two caregiver groups' scores on the Pediatric Inventory for Parents (PIP) measure. Caregivers of male children reporting significantly higher scores on the PIP-Difficulty scale for Role Function (t (163) = 2.39, $p < .05$). There were no other significant differences between caregivers of male and female

children on the remaining PIP subscales (Communication, Emotional Functioning/ Distress, Medical Care), any of the FSS subscales, or the total scale scores (*t*s [163] > 2.00, $p > .05$).

In sum, these study results show that child gender differences were associated caregivers' experience of stress with caregivers of male children reporting more difficult stressful events related to their caregiver role as compared to caregivers of female children. Child gender differences were not, however, associated with caregivers' experiences of social support in the current study.

Type of child-caregiver relationship differences. An independent samples *t*-test was conducted to the experiences of pediatric parenting stress for biological and non-biological caregivers. There were significant differences between the two caregiver groups' scores on the Pediatric Inventory for Parents (PIP) measure. Biological caregivers reported significantly higher scores for the frequency (t [165] = 2.15, $p < .05$) and difficulty of Emotional Distress relative to non-biological caregivers (t [165] = 2.13, $p < .05$). Biological caregivers also reported significantly more Spouse/Partner support relative to non-biological caregivers (t [165] = 3.26, $p < .05$). Biological and non-biological caregivers did not differ significantly on any of the remaining PIP scales or FSS subscales or total scale (*t*s [163] > 2.00, $p > .05$).

In sum, these study results suggest that the type of child-caregiver relationship was associated with caregivers' stress and social support experiences with biological caregivers reporting more frequent and difficult stressful events related to emotional distress as well as more helpful and available spouse/partner support as compared to non-biological caregivers.

Number of child diagnoses differences. A one-way ANOVA was conducted to compare pediatric parenting stress experiences between three groups of caregivers: children with unknown diagnoses, children with one diagnosis, and children with two or more diagnoses (see Table 13 for test statistics, means, and standard deviations). Caregivers of children with one diagnosis or two or more diagnoses differed significantly from caregivers of children with unknown diagnoses on pediatric parenting stress (*F*s [2, 164] ranged from 6.95 to 17.78, $p < .05$). Post-hoc comparisons using the Tukey HSD test revealed that caregivers of children with one diagnosis (*M*s ranged from 2.97 to 3.47, *SD*s ranged from .66 to .90) or with two or more diagnoses (*M*s ranged from 2.71 to 3.20, *SD*s ranged from .57 to .98) had significantly higher scores on all PIP subscales (Communication, Medical Care, Emotional Distress/Functioning, and Role Function) for both the Frequency and Difficulty scales as compared to caregivers of children with unknown diagnoses (*M*s ranged from 1.93 to 2.58, *SD*s ranged from .66 to .90). Caregivers of children with one diagnosis and caregivers of children with two or more diagnoses did not differ significantly on PIP domain or scale scores. In sum, these study results suggest that the number of child diagnoses was associated with caregivers' experiences of stress, with caregivers of children with one diagnosis and with two or more diagnoses reporting more frequent and more difficult stressful events as compared with caregivers of children with unknown diagnoses.

A one-way ANOVA was conducted to compare family support experiences between the same three groups of caregivers (see Table 13 for test statistics, means, and standard deviations). Caregivers' experiences of family support differed significantly based upon the number of child diagnoses. Caregivers of children with one diagnosis

(and caregivers of children with two or more diagnoses reported significantly higher scores for three of the FSS subscales (Spousal/Partner, Informal, and Programs/Organizations) as compared to caregivers of children with unknown diagnoses (Fs [2, 164] ranged from 4.41 to 7.15, $p < .05$). Notably, caregivers of children with one diagnosis reported significantly higher scores on the FSS measure ($M = 45.65$, $SD = 15.01$) as compared to caregivers of children with unknown diagnoses ($M = 35.08$, SD = 12.60) or children with two or more diagnoses ($M = 37.10$, $SD = 17.86$). Although the ANOVA omnibus test indicated significant differences between the three caregiver groups for their scores on the Professional Services subscale, Tukey post-hoc follow-up tests revealed no significant between-caregiver group differences (see Table 13). In other words, caregivers' experiences of Professional Services were similar across the three caregiver groups regardless of the number of child diagnoses.

Taken together, these study results suggest that the number of child diagnoses was associated with aspects of caregivers' experiences of stress and social support: caregivers of children with one diagnosis or with two or more diagnoses reported more stress overall on the PIP as well as more available and helpful support overall on the FSS measure as compared with caregivers of children with unknown diagnoses.

Household structure differences. A one-way ANOVA was conducted to compare pediatric parenting stress experiences between three types of household structures: single-caregiver, two-caregiver, and other caregiver (see Table 14 for test statistics, means, and standard deviations). Caregivers with different household structures reported significantly different experiences of pediatric parenting stress (see Table 13 for test statistics, means, and standard deviations). Caregivers in two-caregiver

households reported significantly higher scores for the overall scales of pediatric parenting stress (PIP-F F [2,162] = 4.69, $p < .05$; PIP-D F [2,162] = 3.61, $p < .05$) as well as the frequency and difficulty for Medical Care-related stress than the other two caregiver groups [PIP-F; F [2,162] = 1.74, $p < .05$) and PIP-D (F [2,162] = 5.56, $p < .05$]. Caregivers from two-caregiver households did not differ significantly from single-caregiver households on the remaining three PIP subscales (Communication, Emotional Functioning/Distress, Role Function). Although ANOVA omnibus tests indicated that there were significant differences between the three household structures on frequency scores for the Communication and Role Function subscales, Tukey post-hoc follow-up tests revealed no significant between-group differences.

In sum, study results suggest that household structure was associated with aspects of caregivers' experiences of stress, with caregivers in two-caregiver households reporting more frequent and difficult stressful events overall as well as more frequent and difficult stressful events related to medical care as compared to the single-caregiver and other household structure groups. In addition, caregivers of two-caregiver households and single-caregiver households reported similar experiences of stressful events related to communication, emotional distress/functioning, and role function.

A one-way ANOVA was conducted to compare family support experiences between the same three types of household structures (see Table 14 for test statistics, means, and SDs). Caregivers with different household structure groups had significantly different experiences of family support. Caregivers from two-caregiver households reported significantly higher scores on the Spouse/Partner subscale than did the two other groups (F [2,162] = 12.35, $p < .05$), whereas caregivers from single-caregiver households

reported significantly higher scores on the Kinship subscale relative than did the other two groups (F [2,162] = 5.55, $p < .05$). In sum, results suggest that household structure was associated with caregivers' experiences of social support, with caregivers from two-caregiver households reporting more helpful and available support from their spouses/partners and caregivers from single-caregiver households reporting more helpful and available support from their kin.

Type of insurance coverage differences. A one-way ANOVA was conducted to compare scores on the Pediatric Inventory for Parents (PIP) measure between the following three types of insurance coverage: Medicaid insurance, private insurance, and other insurance. Caregivers with different types of insurance coverage had significantly different experiences of pediatric parenting stress (see Table 14 for test statistics, means, and SDs). Caregivers of families with private insurance reported significantly more frequent and difficult Medical Care-related stress (PIP-F F [2, 163] = 6.10, $p < .05$; PIP-D F [2, 163] = 4.37, $p < .05$) as well as Emotional Distress-related stress (PIP-F F [2, 162] = 4.61, $p < .05$; PIP-D F [2, 163] = 2.67, $p < .05$) as well as more frequent overall stress as compared to caregivers of families with Medicaid (F [2, 163] = 4.00, $p < .05$). Post-hoc comparisons using the Tukey Honest Significant Difference (HSD) test (Tukey, 1949) revealed that caregivers of families with Medicaid and caregivers of children with private insurance did not differ significantly from caregivers of families with other insurance on any of the remaining PIP scales or domains. In sum, results suggest that the type of insurance coverage for families was associated with caregivers' experiences of stress, with caregivers of children with private insurance reporting more frequent and

more difficult stressful events related to both medical care and emotional distress as well as more overall frequency of stress as compared to caregivers of families with Medicaid.

A one-way ANOVA was conducted to compare scores on the Family Support Scale (FSS) measure between the same three types of insurance coverage. Caregivers with different types of insurance coverage had significantly different experiences of family support (see Table 12 for test statistics, means, and SDs). Caregivers of families with private insurance reported significantly higher scores on the Kinship (F [2, 163] = 8.38, $p < .05$) and Program/Organizations subscales (F [2, 163] = 4.34, $p < .05$) as well as overall support on the FSS (F [2, 163] = 9.63, $p < .05$) as compared to caregivers of children with Medicaid. Caregivers of families with private insurance and with other insurance also reported significantly higher scores on the Spouse/Partner subscale than caregivers of children with Medicaid (F [2, 163] = 15.27, $p < .05$). Caregivers of families with private insurance did not significantly differ from caregivers of families with other insurance on any of the FSS scales.

In sum, results suggest that the type of insurance coverage for families was associated with caregivers' experiences of social support, with caregivers of families with private or other insurance reporting more helpful and more available support than caregivers of families with Medicaid. More specifically, caregivers of families with private insurance reported more helpful and more available support from their spouses/partners, kinship, and programs/organizations as compared to caregivers of families with Medicaid. In addition, caregivers of families with other insurance reported more helpful and more available support from their spouses/partners as compared to caregivers of families with Medicaid. Notably, caregivers of families with private

insurance and of families with other insurance reported similar social support experiences.

Caregiver education level differences. A one-way ANOVA was conducted to compare scores on the Pediatric Inventory for Parents (PIP) measure between the following four levels of educational attainment: those who completed high school or less, some college or an Associate's degree (but no Bachelor's degree), a Bachelor's degree, or advanced/graduate degrees. Caregivers with different education levels had significantly different experiences of pediatric parenting stress (see Table 15 for test statistics, means, and standard deviations). Caregivers with a Bachelor's degree reported significantly higher scores on the PIP-Difficulty (PIP-D) scale for the Communication (F [3, 162] = 3.54, $p < .05$) 3.54 and Medical Care (F [3, 162] = 4.26, $p < .05$) domains than caregivers who completed some college or an Associate's degree. Caregivers with a Bachelor's degree also reported significantly higher scores on the PIP-Difficulty (PIP-D) scale for the Emotional Distress (F [3, 162] = 4.53, $p < .05$) domain and overall pediatric parenting stress (PIP-F F [3, 162] = 5.14, $p < .05$; PIP-D F [3, 162] = 4.01, $p < .05$) relative to caregivers who completed some college or an Associate's degree or caregivers who completed advanced/graduate degrees.

Post-hoc comparisons using the Tukey HSD test revealed that caregivers with a Bachelor's degree reported significantly higher scores on the PIP-Frequency (PIP-F) scale for the Communication (M = 2.92, SD = .61, p < .05), Medical Care (M = 3.18, SD = .78, p < .05), and Emotional Distress (M = 3.33, SD = .66, p < .05), subscales as well as the overall scales (M = 3.12, SD = .59, p < .05), of the PIP as compared to caregivers who completed some college or an Associate's degree. Caregivers who had completed high

school or less or those who had completed advanced/graduate degrees did not significantly differ from the other groups on any of the PIP scales or domains (PIP-Frequency and PIP-Difficulty). In sum, study results suggest caregivers' level of educational attainment was associated with aspects of their experiences of stress: caregivers with a Bachelor's degree reported more frequent and more difficult stressful events in general compared with caregivers of other educational attainment levels.

A one-way ANOVA was conducted to compare experiences of family support between the same four levels of caregiver educational attainment. Caregivers with different education levels had significantly different scores on the Family Support Scale (FSS) measure (see Table 15 for test statistics, means, and SDs). Caregivers with a Bachelor's degree reported significantly higher scores on the Spouse/Partner subscale (F [3, 162] = 11.47, $p < .05$) and total scale score (F [3, 162] = 9.33, $p < .05$) on the FSS measure than caregivers of all other education levels. They also reported significantly higher scores on the Informal Support subscale (F [3, 162] = 6.13, $p < .05$) than caregivers who completed high school or less or caregivers with advanced/graduate degrees. Finally, caregivers with a Bachelor's degree reported significantly higher scores on the Programs/Organization subscale (F [3, 162] = 9.08, $p < .05$) than caregivers who completed high school or less and caregivers who completed some college or obtained an Associate's degree. There were no significant differences in experiences of social support among any of the other caregiver education groups. In sum, these study results suggest that caregivers' level of education was associated with their experiences of social support: caregivers with a Bachelor's degree reported more support on the FSS in general when compared with other caregiver education groups.

Ethnic/racial differences. Caregivers' experiences of pediatric parenting stress and family support did not differ significantly by caregiver or child ethnic/racial diversity (*t*s (163) > 2.00, $p > .05$).

Age differences. Pearson's coefficient correlations were conducted to determine associations between caregiver age at the time of survey completion with experiences of parenting stress and family support (see Table 16). There was a significant, positive association between caregiver age and the Medical Care and Emotional Distress domains across both scales (frequency and difficulty) as well as overall PIP scale scores (*r*s ranged from .19 to .26, $p < .05$); however, caregiver age was not significantly associated with scores on either the Communication or Role Function domain. In addition, caregiver age at the time of survey completion was not significantly associated with any of the scores on the FSS subscales or total scale score. In sum, being an older caregiver was associated with higher medical care and emotional distress-related stress as well as overall stress. Caregiver age at the time of survey completion was not associated with experiences of social support.

Pearson's coefficient correlations were conducted to determine associations between child age with pediatric parenting stress and family support. Child age was significantly positively associated with higher scores on all four of the PIP domains across the two scales (frequency and difficulty) (*r*s ranging from .22 to .39, $p < .05$). Child age at the time of survey completion was also positively associated with the Spouse/Partner and Informal subscales as well as the total scale on the FSS (*r*s ranging from .21 to .26, $p < .05$); however, older child age was not significantly associated with the Kinship, Programs/Organizations, or Professional Services subscales. In sum, being a

caregiver to an older child was associated with stressors related to communication, medical care, emotional distress/functioning, and role function as well as overall stress in terms of frequency and difficulty. Being a caregiver for an older child was also associated with spouse/partner, informal support, as well as overall social support.

Daily and weekly hours of care differences. Pearson's coefficient correlations were conducted to determine associations between caregiver age with experiences of parenting stress and family support. There was a significant, negative relationship between the number of daily and weekly hours of care to their children (see Table 16). More daily hours of care were significantly, negatively, and moderately associated with all four of the subscales of the PIP (Communication, Medical Care, Emotional Distress/Functioning, and Role Function) across the two scales (Frequency and Difficulty). Daily hours of care were negatively related with Spouse/Partner support, (r = -.26, $p < .05$); however, daily hours of care were not associated with any of the remaining FSS subscales (Kinship, Informal, Programs/Organizations, Professional Services). Average weekly hours of care were not significantly associated with any of the PIP domains or overall scales. A higher number of average weekly hours of care was significantly, negatively, and modestly associated with Spousal/Partner (r = -17, $p < .05$), and Informal support on the FSS (r = -.26, $p < .05$). The average weekly hours of care were not associated with any other scales on the FSS.

In sum, being a caregiver who provided a higher number of daily hours of care was associated with increased stress (in terms of frequency and difficulty) as well as decreased spousal/partner support. Being a caregiver who provided a higher number of

weekly hours of care was associated with decreased spousal/partner as well as informal support.

Survey format differences. A one-way ANOVA was conducted to compare scores on the PIP measure between the following two survey formats: electronic versus pencil-and-paper. Caregivers who completed different survey formats differed significantly in their experiences of pediatric parenting stress (PPS). Caregivers who completed electronic surveys reported significantly higher frequency for Medical Care-related stress ($M = 2.89$, $SD = .89$) as compared to caregivers who completed paper-and-pencil surveys ($M = 2.58$, $SD = .81$), $t(165) = 2.13$, $p < .05$. Caregivers who completed electronic surveys ($M = 2.79$, $SD = 1.03$) also reported significantly higher difficulty for Medical Care-related stress as compared to caregivers who completed paper-and-pencil surveys ($M = 2.40$, $SD = .87$), $t(165) = 2.37$, $p < .05$. Caregivers who completed electronic surveys ($M = 3.23$, $SD = .96$) also reported significantly more difficult Emotional Distress-related stress as compared to caregivers who completed paper-and-pencil surveys ($M = 2.90$, $SD = .75$), $t(165) = 2.16$, $p < .05$. In sum, study results suggest that the survey format was associated with aspects of caregivers' experiences of stress, with caregivers who completed electronic surveys reporting more frequent and difficult medical care-related stressors as well as more difficult emotional distress-related stressors as compared with caregivers who completed pencil-and-paper surveys.

A one-way ANOVA was conducted to compare experiences of family support between the two survey formats: electronic and pencil-and-paper. Caregivers who completed electronic surveys ($M = 7.40$, $SD = 3.10$) reported significantly higher Spouse/Partner support as compared to caregivers who completed paper-and-pencil

surveys (M = 5.56, SD = 3.76), t (165) = 3.35, $p < .05$. Caregivers who completed electronic surveys (M = 6.75, SD = 4.23) reported significantly higher Program/Organizations support as compared to caregivers who completed paper-and-pencil surveys (M = 5.28, SD = 4.23), t (165) = 2.15, $p < .05$. In sum, study results suggest that the survey format was associated with aspects of caregivers' experiences of social support, with caregivers who completed electronic surveys reporting more available and helpful spouse/partner support as well as program/organizational support as compared with caregivers who completed pencil-and-paper surveys. Taken together, caregivers who completed electronic surveys reported more stress and more support in general as compared to caregivers who completed pencil-and-paper surveys.

Summary. Present study findings revealed statistically significant differences based upon the following caregiver, child, and family correlates: gender, age, child-caregiver relationship number of child diagnoses, household structure, insurance coverage, caregiver education level, daily and weekly hours of care, and survey format. With regard to **gender**, being a male caregiver was associated with more frequent and more difficult stressful events as well as more helpful and available support in general. Caregiving for male children was associated with more difficult stressful events related to their caregiver role as compared to caregivers of female children. With regard to **age**, being an older caregiver was associated with more stress (overall, medical, and emotional distress). Being a caregiver to an older child was associated with stressors related to more frequent and difficult stress in general. Being a caregiver for an older child was also associated with more support in general. With regard to **child-caregiver relationship**, biological caregivers reported more frequent and difficulty emotional

distress as well as more helpful and available spouse/partner support. With regard to **child diagnoses**, caregivers of children with one diagnosis or with two or more diagnoses reported more stress overall as well as more available and helpful support overall as compared with caregivers of children with unknown diagnoses. With regard to **household structure**, caregivers in two-caregiver households reporting more frequent and difficult stress in general as well as more frequent and difficult medical care related stress as compared to the single-caregiver and other household structure groups. Caregivers from two-caregiver households reporting more helpful and available support from their spouses/partners, while caregivers from single-caregiver households reporting more helpful and available support from their kin. With regard to **insurance coverage**, caregivers of families with private or other insurance reporting more helpful and available support than caregivers of families with Medicaid. With regard to **caregiver education level**, caregivers with a Bachelor's degree reported more frequent and difficult stressful events in general as well as more support in general compared with caregivers of other educational attainment levels. With regard to **daily and weekly hours of care,** being a caregiver who provided a higher number of daily hours of care was associated with more frequent and difficulty stress as well as lower levels of spousal/partner support. Being a caregiver who provided a higher number of weekly hours of care was associated with decreased spousal/partner as well as informal support. Finally, with regard to **survey format**, caregivers who completed electronic surveys reported more stress and more support in general as compared to caregivers who completed pencil-and-paper surveys

Table 13

Associations between Caregiver Sex and Number of Child Diagnoses with the PIP and FSS Measures

	Caregiver Sex			Number of child diagnoses			
	Male *M* (SD)	Female *M* (SD)	*t* (164)	Unknown *M* (SD)	One *M* (SD)	Two or More *M* (SD)	*F* (2, 164)
PIP-Frequency							
Communication	3.03 (.46)	2.57 (.70)	3.92*	2.17 (.70)[a]	2.97 (.66)[b]	2.80 (.59)[b]	17.48*
Medical Care	3.38 (.49)	2.60 (.89)	5.35*	2.26 (.82)[a]	3.11 (.81)[b]	2.79 (.87)[b]	11.02*
Emotional Distress	3.38 (.53)	2.90 (.74)	3.88*	2.58 (.72)[a]	3.30 (.75)[b]	3.10 (.66)[b]	10.78*
Role Function	2.95 (.49)	2.69 (.70)	2.20*	2.42 (.67)[a]	2.97 (.71)[b]	2.83 (.61)[b]	7.47*
Overall Frequency	3.21 (.43)	2.72 (.67)	4.35*	2.40 (.63)[a]	3.12 (.69)[b]	2.94 (.57)[b]	14.61*
PIP-Difficulty							
Communication	2.98 (.69)	2.51 (.80)	3.38*	2.11 (.74)[a]	3.03 (.73)[b]	2.71 (.75)[b]	13.87*
Medical Care	3.29 (.69)	2.46 (.99)	5.00*	1.93 (.70)[a]	3.14 (.90)[b]	2.82 (.98)[b]	17.78*
Emotional Distress	3.51 (.79)	3.00 (.92)	3.21*	2.68 (.96)[a]	3.47 (.82)[b]	3.20 (.86)[b]	7.45*
Role Function	3.02 (.77)	2.71 (.80)	2.35*	2.38 (.78)[a]	3.08 (.78)[b]	2.83 (.80)[b]	6.95*
Overall Difficulty	3.24 (.69)	2.71 (.80)	3.77*	2.34 (.72)[a]	3.22 (.76)[b]	2.93 (.76)[b]	12.68*
FSS							
Kinship	4.54 (1.57)	4.29 (2.71)	.56	4.38 (2.64)	4.15 (1.89)	4.40 (2.55)	.11
Spouse/Partner	9.22 (2.07)	6.06 (3.39)	5.62*	5.97 (3.28)[a]	8.46 (3.14)[b]	6.70 (3.44)[a]	4.41*
Informal Support	11.66 (4.37)	8.98 (4.63)	3.25*	7.92 (4.70)[a]	11.58 (4.12)[b]	9.78 (4.64)[b]	5.12*
Programs/Organizations	8.85 (4.32)	5.44 (3.83)	4.80*	5.44 (4.43)[a]	9.00 (4.11)[b]	5.90 (3.89)[a]	7.15*
Professional Services	12.44 (4.04)	10.40 (4.36)	2.64*	11.36 (4.49)	12.46 (4.01)	10.31 (4.31)	2.88*
Overall Support	46.71 (13.31)	35.18 (12.38)	5.08*	35.08 (12.60)[a]	45.65 (15.01)[b]	37.10 (17.86)[a]	5.60*

Note. Means with different superscripts significantly differed from one another. PIP = Pediatric Inventory for Parents; FSS = Family Support Scale.
*$p < .05$

Table 14

Associations between Household Structure and Insurance with the PIP and FSS Measures

	Household Structure				Insurance Coverage			
	Two-Caregiver *M* (SD)	Single-Caregiver *M* (SD)	Other *M* (SD)	F(2,162)	Medicaid *M* (SD)	Private *M* (SD)	Other *M* (SD)	F(2,163)
PIP-Frequency								
Communication	2.78 (.65)[a]	2.54 (.78)[a]	2.42 (.61)[a]	3.21*	2.57 (.67)[a]	2.80 (.67)[a]	2.67 (.66)[a]	2.08
Medical Care	2.96 (.85)[a]	2.51 (.78)[ab]	2.30 (.79)[b]	7.14*	2.53 (.78)[a]	3.00 (.88)[b]	2.95 (.78)[ab]	6.10*
Emotional Distress	3.10 (.73)[a]	2.92 (.78)[a]	2.70 (.55)[a]	2.95	2.87 (.68)[a]	3.19 (.68)[b]	2.83 (.84)[ab]	4.61*
Role Function	2.84 (.65)[a]	2.49 (.71)[a]	2.60 (.61)[a]	3.39*	2.70 (.68)[a]	2.84 (.61)[a]	2.67 (.73)[a]	1.08
Overall Frequency	2.94 (.64)[a]	2.66 (.67)[ab]	2.54 (.53)[b]	4.69*	2.70 (.61)[a]	2.99 (.62)[b]	2.78 (.66)[ab]	4.00*
PIP-Difficulty								
Communication	2.72 (.78)[a]	2.49 (.89)[a]	2.28 (.67)[a]	3.11	2.52 (.76)[a]	2.72 (.82)[a]	2.48 (.80)[a]	1.62
Medical Care	2.83 (1.00)[a]	2.35 (.80)[ab]	2.17 (.89)[b]	5.56*	2.40 (.92)[a]	2.88 (1.03)[b]	2.67 (.84)[ab]	4.37*
Emotional Distress	3.23 (.92)[a]	3.02 (.98)[a]	2.75 (.70)[a]	2.61	2.97 (.87)[a]	3.29 (.92)[a]	2.94 (.91)[a]	2.67*
Role Function	2.84 (.82)[a]	2.64 (.92)[a]	2.51 (.70)[a]	1.71	2.73 (.82)[a]	2.80 (.83)[a]	2.74 (.84)[a]	.14
Overall Difficulty	2.95 (.80)[a]	2.69 (.85)[ab]	2.48 (.65)[b]	3.61*	2.71 (.75)[a]	2.97 (.83)[a]	2.74 (.78)[a]	2.21
FSS								
Kinship	4.33 (2.35)[ab]	5.64 (2.97)[a]	3.15 (2.18)[b]	5.55*	3.41 (2.58)[a]	5.04 (2.09)[b]	4.50 (3.03)[ab]	8.38*
Spouse/Partner	7.61 (3.02)[a]	5.05 (3.98)[b]	4.50 (3.29)[b]	12.35*	5.11 (3.48)[a]	7.98 (2.98)[b]	7.63 (2.87)[b]	15.27*
Informal Support	9.86 (4.52)[a]	8.73 (4.41)[a]	10.35 (5.66)[a]	.73	8.79 (4.08)[a]	10.31 (4.37)[a]	9.94 (7.51)[a]	1.94
Programs/Organizations	6.43 (4.14)[a]	6.95 (4.26)[a]	5.10 (4.55)[a]	1.13	5.25 (3.84)[a]	7.22 (4.06)[b]	5.63 (5.55)[ab]	4.34*
Professional Services	10.97 (4.09)[a]	12.05 (5.32)[a]	10.00 (4.72)[a]	1.17	10.19 (4.58)[a]	11.59 (3.92)[a]	10.88 (5.21)[a]	1.90
Overall Support	39.20 (13.32)[a]	38.41 (13.06)[a]	33.10 (13.95)[a]	1.79	32.76 (11.69)[a]	42.13 (12.25)[b]	38.56 (19.11)[ab]	9.63*

Note. Means with different superscripts significantly differed from one another. PIP = Pediatric Inventory for Parents; FSS = Family Support Scale.

*$p < .05$

Table 15

Associations between Caregiver Education with the PIP and FSS Measures

	Caregiver Education				
	H.S. or Less *M* (SD)	Some College/ A.A./A.S. *M* (SD)	B.A./B.S. *M* (SD)	Graduate/Advanced *M* (SD)	F(3,162)
PIP-Frequency					
Communication	2.63 (.67)[ab]	2.58 (.70)[a]	2.92(.61)[b]	2.55 (.69)[ab]	3.01*
Medical Care	2.62 (.93)[ab]	2.61 (.84)[a]	3.18 (.78)[b]	2.71 (.92)[ab]	4.93*
Emotional Distress	3.16 (.56)[ab]	2.82 (.75)[a]	3.33 (.66)[b]	2.89 (.69)[ab]	5.87*
Role Function	2.80 (.58)[a]	2.66 (.72)[a]	2.96 (.58)[a]	2.63 (.61)[a]	2.45
Overall Frequency	2.86 (.56)[ab]	2.69 (.66)[a]	3.12 (.59)[b]	2.72 (.63)[ab]	5.14*
PIP-Difficulty					
Communication	2.54 (.57)[ab]	2.51 (.78)[a]	2.92 (.78)[b]	2.40 (.90)[ab]	3.54*
Medical Care	2.46(.96)[ab]	2.49 (.90)[a]	3.07 (1.00)[b]	2.52 (1.10)[ab]	4.26*
Emotional Distress	3.14 (.53)[ab]	2.94 (.85)[a]	3.50 (.93)[b]	2.93 (1.06)[a]	4.53*
Role Function	2.86 (.86)[a]	2.70 (.82)[a]	2.93 (.78)[a]	2.56 (.82)[a]	1.40
Overall Difficulty	2.81 (.60)[ab]	2.70 (.75)[a]	3.16 (.80)[b]	2.65 (.92)[a]	4.01*
FSS					
Kinship	3.47 (2.40)[a]	4.44 (2.76)[a]	4.78 (1.95)[a]	3.88 (2.40)[a]	1.55
Spouse/Partner	6.29 (2.89)[a]	6.10 (3.07)[a]	8.94 (2.94)[b]	5.04 (3.88)[a]	11.47*
Informal Support	7.18 (5.37)[a]	9.48 (5.74)[ab]	11.59 (4.04)[b]	7.83 (3.81)[a]	6.13*
Organizational Support	4.29 (3.44)[a]	5.12 (3.88)[a]	8.49 (3.80)[b]	6.88 (4.57)[ab]	9.08*
Professional Support	9.94 (4.87)[a]	10.55 (4.57)[a]	11.90 (3.71)[a]	10.63 (4.40)[a]	1.34
Overall Support	31.18 (12.25)[a]	35.69 (12.61)[a]	45.69 (12.26)[b]	34.25 (13.47)[a]	9.33*

Note. Means with different superscripts significantly differed from one another. PIP = Pediatric Inventory for Parents; FSS = Family Support Scale.

*$p < .05$

Table 16

Correlations between Age and Hours of Care Differences with the PIP and FSS Measures

PIP-Frequency	Avg. Daily Hrs. Care	Avg. Weekly Hrs. Care	Child Age	Caregiver Age
Communication	-.33*	-.11	.35*	.13
Medical Care	-.38*	-.08	.33*	.22*
Emotional Distress	-.34*	-.14	.38*	.19*
Role Function	-.27*	-.08	.22*	.10
Overall	-.37*	-.12	.37*	.19*
PIP-Difficulty				
Communication	-.22*	-.03	.37*	.14
Medical Care	-.31*	-.04	.39*	.26*
Emotional Distress	-.25*	-.04	.37*	.20*
Role Function	-.24*	0	.22*	.08
Overall	-.28*	-.03	.37*	.19*
FSS				
Kinship	-.04	.06	.11	-.02
Spouse/Partner	-.26*	-.17*	.22*	-.11
Informal Support	.02	-.16*	.26*	.07
Organizational Support	-.09	-.10	.15	.02
Professional Support	-.07	.05	-.02	-.05
Overall	-.12	-.11	.21*	-.03

Note. PIP = Pediatric Inventory for Parents; FSS = Family Support Scale.
*$p < .05$

Study Aim 4: To Determine the Nature of the Relationship between Pediatric Parenting Stress (PPS) and Family support (SS) for Caregivers of Children with SHCN or DD

The fourth study aim was to determine the nature of the relationship between pediatric parenting stress and family support for this current sample. Pearson product moment correlations (*r*) were computed between caregiver participants' the Pediatric Inventory for Parents (PIP) and Family support (FSS) scales. Correlation coefficient reflects the size of an effect in the relationship between two variables. The range for *r*s is between +1 and -1, with values of ±.1 represent a small effect size, ±.3 a medium effect, and ±.5 a large effect (Field, 2013). As shown in Table 17, there were several strong associations between the PIP and FSS scores: (a) higher scores on the overall PIP-F and PIP-D, Communication (PIP-F and PIP-D), Medical Care (PIP-F and PIP-D) scales were significantly and positively associated with the total scale score on the FSS, *r*s ranging from .16 to .29, *p*s < .05; (b) higher scores on the Communication (PIP-F and PIP-D) as well as Medical Care (PIP-F and PIP-D) scales were significantly and positively associated with scores on the Informal and Program/Organizations subscales, *r*s ranging from .16 to .22, *p*s < .05, and (c) higher scores on the overall PIP-F and PIP-D, Communication (PIP-F and PIP-D), Medical Care (PIP-F and PIP-D), and Emotional Distress (PIP-F and PIP-D) scales were significantly, positively, and moderately associated with scores on the Spouse/Partner subscale, *r*s = ranging from .20 to .41, *p*s < .05. Notably, none of the PIP scales were significantly associated with the Kinship or Professional support scales on the FSS. In sum, these findings show that caregivers who experienced more frequent and difficult parenting stress in general also reported more available and helpful family support in general.

Table 17

Interscale Correlations Between the PIP and FSS Measures

	Total FSS	Kinship	Spouse/ Partner	Informal Support	Programs/ Organizations	Professional Support
PIP-Frequency						
Total	.19*	.02	.30*	.13	.14	.05
Communication	.21*	-.01	.27*	.18*	.19*	.06
Medical Care	.29*	.12	.41*	.23*	.19*	.08
Emotional Distress	.14	.05	.25*	.08	.09	.03
Role Function	.05	-.11	.13	.02	.07	.02
PIP-Difficulty						
Total	.15	-.01	.23*	.12	.13	.03
Communication	.16*	-.05	.21*	.16*	.17*	.02
Medical Care	.25*	.03	.32*	.22*	.20*	.04
Emotional Distress	.12	.04	.20*	.07	.09	.03
Role Function	.04	-.10	.14	.01	.04	.02

Note. PIP = Pediatric Inventory for Parents; FSS= Family Support Scale.
*$p < .05$

CHAPTER V

DISCUSSION

The purpose of the present study was to use a quantitative descriptive research design to examine the experiences of pediatric parenting stress and family support for a sample of caregivers of children with a broad range of special health care needs (SHCN) or developmental disabilities (DD). The study aims were to examine caregivers' reports about the occurrence of stressful caregiving-related events, the appraised difficulty of such stressors, and the perceived availability and helpfulness of family sources of support. I anticipated that knowledge gained from this study would expand scholars' and clinicians' understanding and knowledge about how to promote the well-being and functioning of caregivers, their children with SHCN or DD, and their families.

Present study findings were that (a) the PIP and FSS measures did not appear to have internal consistency reliability for the current sample of caregivers; (b) the existing PIP and FSS factor structures did not fit the present study data well; (c) the levels of pediatric parenting stress (both in frequency and difficulty) were higher overall for caregivers as compared to previous study samples of caregivers of children with a range of chronic illnesses; (d) levels of family support were lower overall for the present study sample as compared with previous samples of caregivers of children with developmental disabilities; (e) caregivers' experiences of pediatric parenting stress and family support differed significantly by several caregiver, child, and family factors (including child and caregiver gender, number of child diagnoses, type of child-caregiver relationship, household structure, type of insurance coverage, and caregiver education level) as well as survey format); and (f) the constructs of pediatric parenting stress and family support had

a positive, significant association. These study findings are discussed as they relate to the main study aims/research questions and followed by study strengths, limitations, and contributions.

Measurement of Pediatric Parenting Stress and Family Support

Present study results yielded strong internal reliability data for the Pediatric Inventory for Parents (PIP). While one FSS subscale and the total scale score had acceptable alphas, the remaining four FSS subscales (Kinship, Spouse/Partner, Informal Support, and Professional Support) had substantially lower alphas. The internal consistency of the FSS measure for this study sample could have impacted the study findings with regard to Type I or Type II errors. The relatively small number of items on the four FSS subscales with lower alphas (2 items, 4 items, 4 items, and 5 items respectively) and the short length of FSS measure (the current version has a total of 19 items) could have resulted in lower alpha values (Tavakol & Dennik, 2011).

The confirmatory factor analyses (CFA) conducted with the PIP and FSS measures failed to confirm the proposed factor structures for both of the measures with the present study caregiver sample. The exploratory factor analyses (EFA) for the PIP scales (PIP-Frequency and PIP-Difficulty) resulted in solutions with nine and eight factors respectively, which exceeded the original 4-factor structure (proposed by Streisand et al., 2001) or the comparative one-factor model (proposed by Vrijmoet-Wiersma et al., 2010). The factors for the PIP measure were derived theoretically rather than empirically (Streisand et al., 2001) and the PIP has been validated only, to date, with caregiver samples of children with single illness categories (such as pediatric cancer and Type 1 diabetes). The eight- and nine-factor solutions for the PIP-Frequency and PIP-

Difficulty subscales could suggest a more heterogeneous (rather than homogenous) construct of pediatric parenting stress for caregivers of children with SHCN or DD. This heterogeneity of underlying constructs, or factors, is likely due in part to the diversity of children's SHCN or DD represented in the present study. Given the broad range of conditions and disabilities, it is unlikely that all 42 of the PIP events had similar relevance for caregivers' experiences across the various SHCN or DD. That is, present study sample caregivers' experiences of stress frequency and difficulty likely varied more than the experiences measured with more homogeneous samples of caregivers.

Although the CFA for the Family Support Scale (FSS) measure revealed a poor fit for the five-factor structure, the EFA findings suggested a possible six-factor solution for the present study sample. The six factors and corresponding item loadings for the present study data are similar to the EFA factor solution in a previous examination of the psychometric properties of the FSS (Dunst et al., 1985), with the following factors: informal kinship, social organizations, formal kinship, nuclear family, specialized professional services, and generic professional services. For the present study data, it was initially surprising to determine that "family/child's physician" was the only item that had low communalities (with factor loadings below .40) across all of the six factors. The family/child's physician role is unique, however, and characterized in part by an ongoing partnership with the family and community to support personal health care (Donaldson et al., 1996). It is possible, therefore, that the family physician exists at the intersection of informal and formal support, making it more challenging to classify the item "family physician" under only one type of support.

The FSS measure comprised 19 items, which includes the item "neighbors" (added to the measure after 1988). A previous psychometric evaluation (conducted in 1998) served as a comparison for the present study sample. Although the factor structure did not match the proposed six factor-framework exactly, it holds potential as a possible framework for future psychometric evaluations of the FSS measure. Additionally, the changes that were made to the PIP and FSS measures in this study must be taken into consideration. The question stems for both of the measures were changed (with the lead authors' permission) to fit the current study and caregiver participant sample. Finally, response choice options on the FSS could have resulted the study findings. For the "N/A" option, there was no distinction as to whether participants selected that option to identify the type of support as being not available or as not needed. These issues must be taken consideration in examining the possible effects of measurement error upon the current study findings.

Comparison of Pediatric Parenting Stress and Family Support Experiences

To our knowledge, the present study is the first to include caregivers of children with a broad range of developmental disabilities in an examination of pediatric parenting stress (using the PIP measure) and caregivers with a broad range of special health care needs in an examination of family support (using the FSS measure). As such, the study hypotheses about the levels of pediatric parenting stress or family support for the present study sample were based upon findings in previously published studies that used the PIP or FSS measures.

Study results showed that caregiver participants reported more frequent and more difficult pediatric parenting stress in general as compared to caregivers of children with

chronic health conditions (Guilfoyle et al, 2012). The only exception in this comparison between study findings is that the present study sample reported less difficult overall stress and less difficult emotional distress/functioning relative to caregivers of children with cancer in the original PIP study that Streisand and colleagues conducted (Streisand et al., 2001). Neither of these sets of findings is surprising in terms of the extant literature on stress and support. It is of note that the top ten most prevalent diagnoses in the present study included ADHD/ADD, deformities, developmental disabilities, learning disorder, and intellectual disability. In a previous study examining parenting stress as measured by the Parenting Stress Index (PSI; Abidin & Abidin, 1990), caregivers of children with Attention-Deficit Hyperactivity Disorder (ADHD) or developmental disabilities (DD) reported higher levels of stress as compared to caregivers of children with HIV or asthma as well as caregivers of typically-developing children (Gupta et al., 2007). The negative impact upon psychosocial functioning for caregivers of children with cancer also has been well-documented (Kazak et al., 1997). Caregivers of children with cancer experience "one of the most severe stressors" (Kazak et al., 1997, p. 127), placing them at potential risk for post-traumatic stress (PTSS) symptoms, including but not limited to flashbacks, fears, and intrusive memories (Best, Streisand, Catania, & Kazak, 2007; Kazak et al., 2004). Therefore, the present study findings of lower overall difficulty and emotional-distress-related difficulty as compared to a sample of caregivers for children (Streisand et al., 2001) converges with existing clinical and research knowledge.

With regard to the Family Support Scale (FSS), the overall availability and helpfulness of social support for the present sample was significantly lower than a

previous studied sample of caregivers with developmental disabilities (Dunst et al., 1984). When examining the experiences of the present study sample, it is important to consider the larger ecological context for their caregiving experiences. Given the geographic location of the data collection sites serving Central and Southern Oregon, it is likely that some of the study participants reside in rural areas and had to travel outside of their communities to access services for their child. The health system in the state of Oregon is under-funded, which can directly impact the provision of high-quality health care (Oregon Health Authority, 2017).

Policies and statutes are part of the exosystemic level, and while more distal from the child and caregivers, can directly impact families' experiences and resources. Disparities in access to healthcare services for rural populations as compared to more urban or suburban populations continue to exist (Devoe et al., 2009; Farmer et al., 2005; Marcin et al., 2004; Skinner, 2007). In addition, research findings suggest that a higher prevalence of children with SHCN live in rural areas, where there is a higher incidence of poverty (Devoe et al., 2009). It is estimated that approximately half of Oregon's children residing in the state live below the federal poverty line (Oregon Health Authority, 2015) and approximately 16% of the state population lives in a rural setting (United States Department of Agriculture- Economic Research Service, 2017). Together, these social determinants of health factors can negatively impact the provision of and access to high-quality health and other related support services required to support children with SHCN (special health care needs) or DD (developmental disabilities) (Oregon Health Authority, 2015), potentially placing their overall health and well-being at further risk.

Key Child, Caregiver, and Family Correlates for Pediatric Parenting Stress and Social Support

The present study findings support a multi-dimensional conceptualization of pediatric parenting stress and social support (Monaghan et al., 2009; Streisand et al., 2005; White & Hastings, 2004), and provide convergent and discriminant validity information for the Pediatric Inventory for Parents (PIP) and Family Support Scale (FSS). Significant differences in experiences of pediatric parenting stress and family support were associated with the following child, caregiver, and family correlates: gender, age, number of diagnoses, household structure, type of insurance coverage, caregiver education level, as well as daily and weekly hours of care.

Gender- more specifically, caring for a male child and being a male caregiver - were associated with different experiences of pediatric parenting stress and family support for the present study sample. ***Male caregivers*** reported more frequent and difficult stressful events as well as more available and helpful social support in general as compared with female caregivers. Extant study findings have varied, but identify higher levels of stress for female caregivers, for male caregivers, and similar or correlated levels of stress for caregivers within the same family. It is of note that male caregivers (with a focus upon fathers) seem to be at greater risk for stress than female caregivers in particular caregiving circumstances. While fathers' greater involvement, specifically their perceived helpfulness, in caregiving has been associated with improved maternal, child, and family functioning, it can negatively impact their own functioning. For example, in a study of caregivers for children with Type 1 diabetes, fathers who perceived higher levels of involvement in caregiving for their children reported more stress and anxiety (Hansen et al., 2012). In a different study, fathers' holding primary caregiver roles have also reported higher levels of stress and increased risk for depression

(Bonner, Hardy, Willard, & Hutchinson, 2007). I speculated that male caregivers were involved in their children's care to a higher-than-typical degree by way of their decision to participate in the present study, which could affect their experience as well as endorsement of higher levels of stress.

Male caregivers also reported significantly more availability and helpfulness from the majority of the sources of support, except for Kinship, on the FSS measure relative to female caregivers. Although previous study findings suggest that male caregivers tend to report intrafamilial, in particular spousal, support to be the most beneficial (Crowley & Kazdin, 1998), male caregivers in the present study endorsed availability of and helpfulness from both intrafamilial and extrafamilial supports. A possible interpretation for the expanded endorsement of social support by this male caregiver subsample is that they were able to mobilize and use- in otherwise, access- various sources of support to meet their family's needs differently than the female caregiver subsample (Dunst et al., 1988). On the FSS measure, male caregivers endorsed the availability of all 19 sources of supports, with higher rates of availability (any item-level response scored as a "1" or higher) as compared with female caregivers. Given that study participants were already connected to and receiving support services from one of the four data collection sites, it was expected that they would report being connected to programmatic/ organizational and professional services. In addition to the availability of these two sources of support, male caregivers appeared to benefit from them more than female caregivers: a greater proportion of the subsample identified the programmatic/ organizational and professional services support as being "very helpful" (63% of male sample compared to 45% of female sample) to "extremely helpful" (39% of male subsample versus 28% of female

subsample) and, conversely, a smaller proportion of the male caregiver subsample identified these supports as being "not at all helpful" (2% of male subsample versus 14% of female subsample).

It would be important to gather information about additional factors, such as the typology (including onset, course, timeline) of the child's condition or disability, extent of the caregiving relationship, such as primary or secondary caregiver, relationship quality, such as with spouse/partner or with children, to better understand male caregivers' reported stress levels. Without additional information about other aspects of social support, such as the types of support (e.g., instrumental, emotional, etc.) received from various sources, it is not possible to reach further conclusions about their pattern of social support endorsement. In sum, the present study findings highlight the need for continued study of the experiences of male caregivers, including fathers, to better understand their experiences of stress and support in the caregiving context of child health and disability.

Caregivers of ***male children*** reported higher difficulty for role function-related stress as compared to caregivers of female children. To our knowledge, no PIP studies to-date have found differences in pediatric parenting stress related to child gender (e.g., Streisand et al., 2005). In the extant PIP literature, there are established associations between externalizing, internalizing, or comorbid diagnoses and increased levels of pediatric parenting (Hilliard et al., 2011; Taft et al., 2012). It is of note that, per present study caregivers' reports, male children accounted for the majority of externalizing (such as ADD/ADHD or ODD), internalizing (such as anxiety and depression), as well as multiple, or comorbid, diagnoses. It is possible that the prevalence of male children with

externalizing, internalizing, and comorbid diagnoses could affect caregivers' negotiation of roles in a variety of ways, including (but not limited to): missing time from work to address children's behavioral issues in other contexts, such at school; not being able to spend as much time with or to attend to the needs of other family members (including other children and spouse/partner) or oneself; and, more caregiver-child relationship strain, including difficulty with parenting style, including approach to child discipline. Additional information is needed about various factors, such as the typology (including onset, course, timeline) of the child's condition or disability, the extent or demands of the caregiving roles and relationship (such as primary versus secondary caregiving), caregiver relationship quality, such as with spouse/partner or with children, to determine possible associations with and explanations for caregivers' reported stress levels.

Age- more specifically, caring for an older child and being an older caregiver - were associated with different experiences of pediatric parenting stress and family support for the present study sample. Caregivers of ***older children*** reported higher frequency and difficulty of pediatric parenting stress relative to caregivers of younger children in the present study. In the extant literature, study findings are mixed. From a developmental perspective, children's and caregivers' needs, roles, and responsibilities change during the transition from childhood to adolescence to adulthood (American Academy of Pediatrics, 2002). Psychosocial challenges during this transition period can include health-related and other aspects of care, including increased independence and autonomy in managing medical regimens (Barakat et al., 2007). In a study with a sample comprising children of preschool as well as adolescent ages, caregivers of the older children reported higher PIP scores for communication-related stressors (Barakat et al.,

2007). In addition, adolescents with SHCN or DD are at-risk for having unmet needs. According to national survey data, fewer than one in five children (between the ages of 12 to 17 years) received care that met all of the six core outcomes as proposed by the Maternal and Child Health Bureau (NS-CSHCN, 11/12). Caregivers of older children reported significantly more overall social support, informal support, as well as spousal/partner support as compared with caregivers of younger children in the present study. One possible interpretation of this finding is that caregivers of older children have had the opportunity to acquire resources, including building experience in caregiving-both in general and specifically focused upon the children's SHCN or DD.

Being an ***older caregiver*** was associated with more frequent and difficult pediatric parenting stress (more specifically, overall, medical care-related, and emotional distress-related stressors). There have been varied findings in the extant literature about the relationship between caregiver age and stress. Some researchers have proposed younger caregivers as being at more risk for parenting stress due to the possible effects of less parenting experience and access to fewer family resources (Guilfoyle et al., 2012; Streisand et al., 2001). According to a national study, however, older caregivers were identified as having provided caregiving support for longer periods of time (thus, being more susceptible to impaired psychosocial functioning, such as depression, anxiety, and burnout) as well as having more complex caregiving roles and responsibilities, such as caring for other individuals (e.g., elderly parents) in addition to their child with SHCN or DD (National Alliance for Caregiving, 2009). The present study findings underscore the possibility that caregiver age may interact with the nature of and needs associated with children's SHCN and DD, such as time course of the condition or disability as well as

functional limitations, to place additional demands upon caregivers. In two previous studies, caregiver age effects were identified for older fathers but not older mothers (Vrijmoet-Wiersma et al., 2009; Vrijmoet-Wiersma et al., 2010), highlighting the importance of examining intersections of identities as well as experiences. There are multiple intersections of caregiver, child, and family factors, such as caregiver age/gender-child age/gender, that should be explored in future studies to better understand diverse identities in relation to stress and support.

The ***number of child diagnoses*** was associated with different experiences of pediatric parenting stress and family support for the present study sample. Consistent with the extant literature, caregivers of children with one diagnosis or multiple diagnoses reported significantly more frequent and difficult stress relative to caregivers of children with unknown diagnoses. This study finding is congruent with the extant literature. Children with comorbid diagnoses are more likely to have unmet needs, which has the potential to contribute to caregivers' stress (Farmer et al., 2004). A clinical implication for these findings is a conceptual distinction between the experiences of caregivers of children who do not yet have a diagnosis as compared to caregivers of children who have already received at least one diagnosis. Once a child has received a diagnosis, more formal services can be accessed and referrals for specialized support can be sought; however, when a caregiver does not yet have a known diagnosis, then it is possible that they are less likely to seek services (Bruhn & Rebach, 2014). The present study findings also highlight the possibility of a similar caregiving experience of stress and support for caregivers of children with one diagnosis or more than two diagnoses, which challenges the prevailing conceptualization of diagnostic comorbidity as a considerably different

caregiving experience. In other words, having only one or having multiple, comorbid diagnoses did not appear to distinguish caregiving experiences for this study sample.

Family structure- more specifically, the number of caregivers in the home- was associated with different experiences of pediatric parenting stress and family support for the present study sample. The present study findings support previous findings that different aspects of family structure are associated with family functioning; however, contrary to the extant literature, caregivers from two-caregiver households reported significantly higher stress frequency and difficulty when compared to households with one caregiver or other caregiver structures. Single, or lone, caregiver families have typically been identified as being at risk for more stress due to differential access to resources, such as economic, social, and instrumental resources (Lipman, Boyle, Dooley, & Offord, 2002), while caregivers residing in two-caregiver households have generally reported access to additional resources, such as finances related to higher combined income and time (Bruhn & Rebach, 2014). A possible explanation for these findings include increased resources available to both caregivers, including increased financial means and more time availability, as well as larger combined formal and informal social support networks. It is of note that the study sample comprised primarily two-caregiver households, more specifically, biological mothers and fathers of biological children. Previous studies have identified risk factors related to dyadic interactions between spouses/partners, such that levels of marital satisfaction or conflict, maternal perceptions of father's level of helpfulness in caregiving (Hansen et al., 2012), amongst other relationship factors, can affect caregivers' experiences of stress and support.

Caregivers' ***educational attainment*** levels were associated with different experiences of pediatric parenting stress and family support for the present study sample. The present study findings revealed an association between caregivers' educational attainment levels with stress and support, such that caregivers with bachelor's degrees reported higher scores on both the PIP and FSS measures. There have been mixed findings for the relationship between caregiver educational attainment and stress, with some study findings that suggest a negative relationship between the two constructs and other findings suggesting no relationship between the constructs. It is possible that various aspects of family contexts can affect the relationship between educational attainment and stress. Although higher educational attainment has the potential to facilitate increased caregiver knowledge about child health and disability, this knowledge might also increase aspects of the caregiving burden, such as the expectation of being an "expert" in the child's condition or disability. For example, in a study of caregiving coping for families of children with cancer, caregivers with bachelor's degrees or higher educational attainment were more likely to engage in active coping, such as problem-solving and seeking social support. In so doing, it is likely that their stress levels (per the PIP domains) were affected, such as time and emotion spent communicating with providers (Gage-Bouchard, 2017). As such, the positive relationship between caregivers' educational attainment levels and social support was in the expected direction and congruent with the extant literature.

Higher levels of educational attainment are associated with increased health literacy as well as access to support services, both of which are key protective factors for health and well-being (DeWalt et al., 2004). From an ecological perspective, it is likely

that a caregiver who has completed postsecondary studies has access to more resources, including a broader network and more likelihood of earning a higher income. It is noteworthy that the present study sample represented an above average level of education as compared to average educational attainment in the state of Oregon (U.S. Census, 2010), thus possibly limiting the generalizability of the study findings.

Caregivers' ***insurance coverage*** was associated with different experiences of pediatric parenting stress and family support for the present study sample. Caregivers from families with private or other insurance reported higher levels of both PIP and FSS. This study finding was inconsistent with the findings in previous studies, which have indicated a higher level of pediatric parenting stress for families with no insurance or Medicaid insurance relative to those with additional forms of coverage, such as private insurance coverage. Insurance coverage has been identified as a key factor associated with caring for children with SHCN or DD. For the present study, insurance coverage was conceptualized as a proxy variable for socioeconomic status- similar to previous studies. Medicaid coverage in Oregon is provided to individuals and families who reside below the federal poverty level (State of Oregon, 2017). In a study of the state's Medicaid program (Baicker & Finklestein, 2011), enrollees reported financial security and improvements in self-reported health after receiving health insurance coverage. Medicaid coverage, therefore, can be conceptualized as a factor that could mitigate the financial costs associated with increased services required to address child health or disability, thus alleviating some of the risk to caregiver psychosocial functioning. Previous national study data suggest that families with private insurance have more financial burden, such as higher out-of-pocket costs (NS-CSHCN, 11/12). The associated

financial demands of accessing health and other services for children with SHCN or DD is a considerable part of the caregiving burden (Davidoff, 2004; Parish et al., 2008). Caring for children with SHCN or DD can, therefore, result in "income poverty" and "asset poverty" (p. 241) that can increase as caregivers and children age, for example families' planning for educational costs and retirement savings. Given the higher stress levels associated with older caregiver and child age in the present study, this "financial vulnerability" appears to be particularly relevant in understanding families' experiences (Bruhn & Rebach, 2014, p. 56). In light of the impact of caregiving on caregivers' employment levels and future career trajectories, financial difficulty for these families can become a compounded risk that builds over time.

Average hours of caregiving were associated with different experiences of pediatric parenting stress and family support for the present study sample. Caregivers reported levels of ***daily and weekly care hours*** were negatively correlated with certain aspects of pediatric parenting stress and family support. Caregivers in the present study reported a wide range of daily and weekly hours of care: 0 to 16 hours for daily care, and 0 to 60 hours for weekly care. Given the average number of daily and weekly hours of care reported by study participants, it was determined likely that many of the study participants held primary caregiver roles for their children, and as such were able to provide the majority of caregiving support directly to their children. The negative relationship between daily and weekly hours of care and stress suggest that they were able to establish a match between their caregiving needs in the face of potential caregiving stress. Another possible interpretation is that caregivers who spent more time with their children were able to establish strong relationships, thus mitigating some of the

caregiving stress and the need for additional social support. The negative association between stress and spousal/partner support and informal support suggests that positive appraisals of the proximal microsystemic relationships can foster caregiving health and well-being. These findings are congruent with the extant literature, which suggests that informal support is often reported by caregivers as being more beneficial than formal support, including professional services.

Contrary to the extant literature, there were no significant associations between ***child and caregiver race and ethnicity***, PIP, or FSS levels. Previous findings consistently suggest that caregivers and children with ethnic minority identities experience higher levels of stress and lower levels of access to resources in the context of child health and disability (Streisand et al., 2001). It is important to note that, in the present study sample, there was an overrepresentation of caregivers and children with ethnic minority identities (28% and 31% of the present sample respectively) as compared with the overall demographic profile of approximately 13% of the Oregon population (U.S. Census, 2015). In light of this critical finding, it is important to note that there is a lack of representativeness and thus limited generalizability from this present study sample to the general population of the community, region, and state. There are several possibilities for this overrepresentation of ethnic diversity in the present study sample: this subsample of caregivers was aware of the availability of and had established connection with support services, which could demonstrate a more resource-based help-seeking process than other caregivers with similar cultural identities; caregivers were required to have English language proficiency to participate in the study, which could indicate that language issues are not a barrier to care; the participating agencies could be

offering services that are perceived by caregivers as being culturally-sensitive and appropriate, also decreasing the impact of this possible barrier to care; although families potentially travelled from around the region, their connection with services could have affected their overall caregiving experience by alleviating their experiences of stress and bolstering support; ethnic minority families might have considerable informal support systems that bolster support differently than formal support systems; and, finally, child/family physicians provide the majority of referrals to two of the data collection sites, which implies a connection to professional services that preceded study participation. I speculate that the lack of significant differences in stress or support for caregivers and children with ethnic minority identities might be associated some of the other correlates for this study sample, such as the reported levels of stress and support related to the caregiver educational attainment, age of the child and the caregiver, insurance status, and household structure, amongst others.

In sum, the present study findings were similar to those in previous studies examining the experiences of stress and social support for caregivers of children with special health care needs or developmental disabilities: higher levels of reported stress, fewer family resources, and increased need for professional or specialized supports (Britner, Morog, Pianta, & Marvin, 2003; Kazak, 1987, 1989).

Relationship between Pediatric Parenting Stress and Family support

Per the extant literature, I hypothesized that there would be a strong, negative association between scores on the Pediatric Inventory for Parents (PIP) and the Family Support Scale (FSS); that is, I predicted that caregiver participants who reported higher levels of available and helpful family support would report lower levels of pediatric

parenting stress. Surprisingly, the study findings revealed a positive correlation between PIP scores and FSS scores overall; higher levels of family support were associated with higher levels of pediatric parenting stress. The high level of social support in the face of high levels of stress for the present study sample reported could reflect an active, problem-focused coping; however, this relationship between the constructs should be interpreted with caution. Given the cross-sectional methodology of the present study, it is not possible to determine causality or temporality in the relationship between stress and support.

As previously mentioned, the FSS measure is conceptualized as representing the availability and helpfulness of informal and formal sources of social support for caregivers and their families. The present study findings support the existing literature with regard to the potential impact of multifaceted social support spanning families' ecology. According the ecological model, the most proximal levels of the ecology are likely to exert the greatest influence upon the caregiver; however, all ecological levels have the potential to exert bidirectional influences upon one another. Notably, the informal support network, including spousal/partner, reflect key microsystemic and mesosystemic ecological levels or context that are most proximal to the caregiver. The caregiver and family are important pieces of the microsystem for the child with SHCN or DD.

When examining the relationship between pediatric parenting stress and family support for this current sample, conclusions drawn from the study findings that a positive, significant correlation between PPS and FSS for this caregiver participant sample should be examined with caution. There are several factors that were not included in this study

that would be necessary to fully examine the complexity of the relationship between stress and support. For example, without accounting for factors (such as the types of and timeline for access to services, the severity of the SHCN or DD, time since diagnoses, etc.), it is not possible to determine definitive conclusions about the possible aspects of the relationship between the factors of stress and support.

In sum, caregivers' access to and receipt of high-quality social support (in other words, helpful support that meets their families' needs) is central within the context of "resource-based, family-centered assessment and intervention practices" (Dunst et al., 1994, p. 156). As proposed by the Maternal and Child Health Bureau, family-centered care underlies best practices and support best outcomes in serving this caregiver population and their families, highlighting the bidirectional influences between various ecological levels that affect overall health and well-being (Lindeke, Leonard, Presler, & Garwick, 2002).

Limitations of the Present Study

There were several limitations of the present study. One of the key limitations of the present study was possible informant bias due to the reliance on individual caregiver self-reported data on the PIP and FSS measures (rather than expanding data sources to multiple agents, e.g., service providers, teachers, as well as multiple types of data, e.g., observational). The reliance on self-reported data is also subject to a self-presentation bias and shared variance. Another key limitation of the study was the cross-sectional design, which did not allow for any determination of causality in the relationship between pediatric parenting stress and social support. Additional limitations were related to eligibility and participation requirements or criterion, such as limiting participation to

caregivers proficient in the English language and administering measures only in the English language, the request that caregivers limit their report of information to one child per household, and the non-random, convenience sampling (such that participants were already connected to support services at the agencies that served as data collection sites). The majority of the present study sample was female, European-American, well-educated, insured, and partnered caregivers, which limits the information gathered about and, thus, possible generalization to the experiences of other caregivers' experiences. Due to the possible sensitive nature of the information gathered via the three study measures (Pediatric Inventory for Parents, Family support, as well as the Demographic and Medical Information form), participants were invited to provide responses to questions at their own discretion, which may have directly affected the level of missing data. There was possible measurement bias or error due to the possible differing interpretations of response options on the PIP and FSS measures, which could have affected the accuracy of participants' responses. Finally, due to the private and confidential nature of the study participation, it was not possible to verify that all of the eligibility or participation criteria had been satisfied (e.g., only one caregiver per family, only one study packet completed per participant) or the specific context of study participation (e.g., in-clinic, at home).

Adapting the PIP and FSS measures to more diverse populations, e.g., limited current study only to English-speaking participants, would be an important focus in future research. Selection bias and possible skewed sample is important to consider given the number of social service agencies in the Eugene/Springfield community, which results in a community that is very socialized toward receipt of services and thus might

not be truly representative of full breadth of experiences for families of children with SHCN or DD. Additional, it was not possible to determine accurate participation rate out of the possible participating families, such as identifying potential differences between families who opted to participate versus those who did not do so. Finally, the mixed methodology across and within sites- with highest response rate concentrated at one of the four sites (where only electronic data was collected) could have affected the study findings.

As addressed through this section, there are several factors that were not accounted for in this study that could expand the understanding of pediatric parenting stress and family support. Future studies should an examination of the following factors: time since diagnosis, number of children in the home with SHCN or DD, type of services currently being accessed, psychosocial typology of the condition to consider onset, severity, and timeline (per Rolland and Walsh, 2006), assessment of caregiver health and well-being, amongst other factors.

Strengths and Contributions of the Present Study

To our knowledge, the present study is the first to use both the Pediatric Inventory for Parents (PIP) and Family Support Scale (FSS) measures together to explore caregiver stress (pediatric parenting stress) and social support (family support). I hoped that study findings would provide new knowledge about the types of stress and supports that caregivers of children with SHCN or DD experience, and ultimately, illuminate avenues that may be targeted to increase the health-related and other resources that these families can access across contexts of care. Study contributions include psychometric measurement data for the PIP and FSS measures that have not previously used with

caregivers with a broad range of SHCN or DD. The study extends the psychometric evaluation of the two measures, for which there is a dearth of existing studies. To my knowledge, there are no studies that examine the constructs of pediatric parenting stress and social support for a broad range of SHCN or DD. In addition, few of the existing studies recruited participants from multiple sites for inclusion in the present study sample.

Directions for Future Research and Clinical Practice

Directions for future research and clinical practice include continued and further study of diverse caregivers of children with SHCN or DD to expand the existing literature and knowledge base for serving these families. Assessing multiple family caregivers and family members using different forms of data will advance research on parenting stress and support with these families. For example, assessing specific aspects of caregiver, child, and family psychosocial functioning, such as relationship quality between caregivers, parenting style, symptoms of anxiety or depression, and child behaviors across contexts, would provide important contextual information in service provision to the families of children with SHCN or DD. Some of the ways in which this information could inform the provision of services is that couples therapy and family therapy could be offered alongside other health-related support services. In addition, parents or caregivers could be offered parent training and other skills training, e.g., medication management, behavior management, to support their caregiving. Within the school setting, information about caregiver and family functioning as it relates to stress and support could be applied to the development of school-related supports, such as IEP and 504 planning for children with comorbid SHCN or DD. Psychoeducation about the symptoms of anxiety or

depression for caregivers, their children, and other family members would be a critical component of family-centered care. In addition, assessing caregiver well-being, given the possibility of longitudinal impacts of caregiving stress would be an important clinical practice. Given the brief administration time for both the PIP and FSS measures, these measures could be used for continuous monitoring and assessment of pediatric parenting stress and family support. The findings from the PIP and FSS could also be applied to tailor treatment plans for children with SHCN or DD, their caregivers, and families. Longitudinal examination of pediatric parenting stress and social support will help scholars identify how stress and social support change over time, with the child's and family's development, and access and engagement with services. In addition, scholars must examine diverse caregivers and how gender, age, and race/ethnicity influence caregiving experiences. The intersections of these cultural and personal identities could directly impact the experiences of stress and support. Future research should examine interactions of some of these covariates; e.g., social economic status, household structure, and family density (e.g., households with more than one child with special health care needs, multiple caregivers). For families who have access to financial and other resources, including time and social capital, the stress related to caregiving for their children with SHCN or DD might be perceived as being much greater in comparison to families of lower socioeconomic status, for whom limited resources could not only impact the access to healthcare services but other aspects of their lives, including adequate food, good education systems, transportation services. Therefore, privileged or marginalized identities and social location could be related to and shape the perception of experiences of stress and support by caregivers and their families as well as by

stakeholders in their ecologies, such as family members, service providers (health, school), and community members. In addition, future research studies should expand upon the current study to improve assessment and measurement of the constructs of stress and support for the diverse caregiver population with children who have SHCN or DD.

Finally, the role of cultural values, traditions and norms should be measured quantitatively and qualitatively to get a more comprehensive picture of how caregiving for child health or disability, stress, and support are experienced across diverse families (Rolland, 2006). The measures could be supplemented by other cultural assessments measures, such as the completion of a cultural interview, to provide culturally-informed care. Rolland (2006) proposed that understanding of cultures could support efforts toward engagement and collaboration with providers involved in their children's and families' care.

Summary and Conclusions

The present study examined the experiences of pediatric parenting stress and family support for a sample of caregivers with children representing a broad range of special health care needs or developmental disabilities. The relationship between these two constructs had not been measured using the Pediatric Inventory for Parents and Family Support Scale Measures in previous studies. Results revealed that stress and support experiences are related to several child, caregiver, and family correlates, highlighting the need to examine the health and well-being outcomes within the context of diverse families. Study findings underscored the impact of caregiver education, family insurance coverage, household structure, child diagnoses, amongst other aspects, on psychosocial functioning. Strengths of the present study included expanding the study of

stress and support to a sample of caregivers of children representing a broad range of special health care needs or developmental disabilities, psychometric instrumentation for two existing measures, and multi-centric data. Limitations of the present study included (but are not limited to) mono-operational bias, possible measurement error due to the measures used, and geographical restriction. Implications and recommendations include ongoing clinical assessment of caregivers' stress and support to inform interventions and inclusion of various correlates in the relationship of stress and support. The overarching study aims were to examine caregivers' reports about the occurrence of stressful caregiving-related events, the appraised difficulty of such stressors, as well as the perceived availability and helpfulness of family sources of support. It was anticipated that achieving the study aims would expand scholars and clinicians' understanding and knowledge about bolstering families' adaptation to the stress and support associated with caregiving for children with SHCN or DD. In sum, the overarching goal for the current study was to promote well-being and health in these families. Further examination of the experiences of stress and support for caregivers of children with special health care needs or developmental disabilities is needed.

APPENDIX A

PERMISSION LETTERS

May 27, 2015

Research Compliance Services
5237 University of Oregon
Eugene, OR 97403-5237

To whom it may concern,

The purpose of this letter is to confirm that the Oregon Health & Science University's Child Development and Rehabilitation Center (CDRC), which is located on the University of Oregon campus at 901 18th Avenue, Eugene, Oregon 97403, gives permission to Christine Ngo to recruit participants for her dissertation research. Ms. Ngo has our authorization to administer surveys to caregivers who agree to participate in her proposed dissertation study and our clinic staff will work with her in this effort.

Sincerely,

Marianne Taylor

Marianne Taylor, RN, MS
Associate Director, CDRC-Eugene Clinical Programs

April 5, 2016

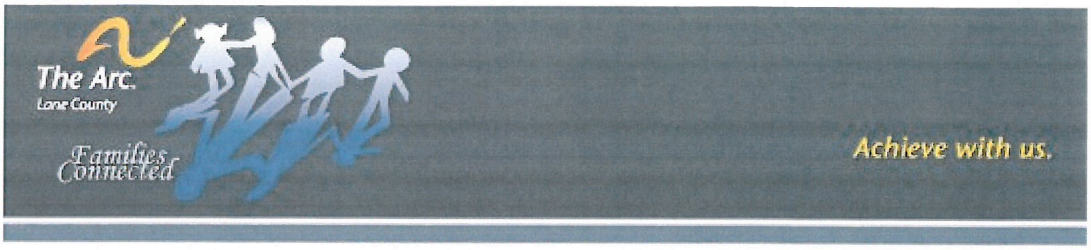
Research Compliance Services
5237 University of Oregon
Eugene, OR 97403-5237

To whom it may concern,

The purpose of this letter is to confirm that the HEDCO Clinic, which is located on the University of Oregon campus at 1655 Alder Street- Suite 170, Eugene, Oregon 97403, gives permission to Christine Ngo to recruit participants for her dissertation research. Ms. Ngo has our authorization to administer surveys to caregivers who agree to participate in her proposed dissertation study.

Sincerely,

Lalla Pudewell
Clinic Manager, HEDCO Clinic



May 6, 2016

Research Compliance Services
5237 University of Oregon
Eugene, OR 97403-5237

To Whom It May Concern:

The purpose of this letter is to confirm The Arc Families Connected, which is located at 4181 E. Street, Springfield, Oregon 97478, provides permission to Christine Ngo to recruit participants for her dissertation research.

The Arc Families Connected will publish information about her study in the program's monthly newsletter sent to families. The Arc Families Connected will also offer study information to families at the program's monthly dinner night and provide study packets to potential participants. These packets will include a cover letter that informs participants their participation is voluntary.

Sincerely,

Laura Dahill

Laura Dahill
Director, The Arc Families Connected

541-343-5256 (office)
541-343-4387 (fax)

The Arc Families Connected
4181 E Street, Springfield, OR 97478

www.arcfamiliesconnected.com
email: info@arclane.org

Early Childhood CARES

University of Oregon • 299 East 18th Avenue • Eugene, OR 97401
(541) 346-2578 • (800) 925-8694 • Fax (541) 346-6189
http://earlychildhoodcares.uoregon.edu/

April 7, 2016

Research Compliance Services
5237 University of Oregon
Eugene, OR 97403-5237

To whom it may concern,

The purpose of this letter is to confirm that Early Childhood CARES, which is located at 299 East 18th Avenue, Eugene, Oregon 97401, will assist Christine Ngo to recruit participants for her dissertation research. Early Childhood CARES will publish information about her study in the program's monthly newsletter to parents. Early Childhood CARES will also distribute packets of information about the study to parents of children in the Circle of Friends Classroom. These packets will include a cover letter from Early Childhood CARES indicating this study is not associated with Early Childhood CARES and that parent participation is completely voluntary.

Sincerely,

Valerie Close
Co-Director, Early Childhood CARES

APPENDIX B

STUDY MEASURES: DEMOGRAPHIC AND
MEDICAL INFORMATION FORM

DEMOGRAPHIC AND MEDICAL INFORMATION

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOUR CHILD (WHO IS BEING SEEN AT THE CDRC TODAY), YOURSELF, AND YOUR FAMILY.

THE INFORMATION THAT YOU SHARE IN THIS QUESTIONNAIRE WILL BE HELPFUL IN UNDERSTANDING YOUR RESPONSES FOR THE 2 OTHER QUESTIONNAIRES.

PLEASE SKIP ANY QUESTIONS THAT YOU DO NOT WISH TO ANSWER.

****NOTE: THE PAGES OF THIS QUESTIONNAIRE ARE DOUBLE-SIDED.****

Part I. DEMOGRAPHIC INFORMATION

1. What is your child's sex?

- O Male
- O Female
- O Other (please describe): _____

2. What is your child's birth year (e.g. 2002)? _____

3. What is your child's race? (Please check all that apply.)

- O African-American or Black
- O American Indian or Alaska Native
- O Asian
- O Caucasian or White
- O Hispanic, Latino, or Spanish Origin
- O Native Hawaiian or other Pacific Islander
- O Two or more races
- O Other- not listed (please specify): _____

4. How are you related to your child? (Please check the best answer and circle your role, if applicable.)

- O Biological parent (mother or father)
- O Step-parent (stepmother or stepfather)
- O Foster parent (mother or father)

- O Adoptive parent (mother or father)
- O Grandparent (grandmother or grandfather)
- O Sibling (sister or brother)
- O Other family member (please specify): _____
- O Other (please specify): _____

→ Please turn this double-sided page over to complete page 2 (on the back of this page) →

5. What is your sex?

- O Male
- O Female
- O Other (please describe): _____

6. What is your birth year (e.g. 1975)**? _____**

7. What is your race? (Please check all that apply.)

- O African-American or Black
- O American Indian or Alaska Native
- O Asian
- O Caucasian or White
- O Hispanic, Latino, or Spanish Origin
- O Native Hawaiian or other Pacific Islander
- O Two or more races
- O Other- not listed (please specify): _____

8. What is your current employment status? (Please check the best answer.)

- O Employed for wages
- O Self-employed
- O Out of work and looking for work
- O Out of work but not currently looking for work
- O A homemaker
- O A student
- O Retired
- O Unable to work
- O Other (please describe): _____

9. What is the highest level of school or degree that you have completed? (Please check the best answer. If currently enrolled in studies, please mark the previous grade or highest degree received.)

- O No schooling completed
- O Nursery school to 8th grade
- O 9th, 10th, or 11th grade
- O 12th grade, no diploma
- O High school graduate- high school diploma or equivalent (e.g., GED)
- O Some college credit, but less than 1 year
- O 1 or more years of college, no degree
- O Associate degree (e.g., AA, AS)
- O Bachelor's degree (e.g., BA, BS, AB)
- O Master's degree (e.g., MS, MA, MS, MEng, MEd, MSW, MBA)
- O Professional degree (e.g., MD, DDS, DVM, LLB, JD)
- O Doctorate degree (e.g., PhD, EdD)

Part II. MEDICAL INFORMATION

10. What is your child's diagnosis or diagnoses? (If your child has multiple diagnoses, please check all that apply. If you do not know your child's diagnosis or diagnoses, please check the "Do not know" box at the end of the list below.)

✔ PLEASE CHECK ALL THAT APPLY	✔ PLEASE CHECK ALL THAT APPLY
☐ **Adjustment Disorder**	☐ **Intellectual Disability**
☐ **Anxiety**	☐ **Learning Disorder**
☐ **Arthritis**	☐ **Medical condition- *OTHER*, e.g., asthma, heart murmur, Neuroblastoma, vision problems**
☐ **Ataxia**	☐ **Motor delays or problems, e.g., dyspraxia**
☐ **Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)**	☐ **Musculoskeletal problems, e.g., ligamentous laxity, low tone**
☐ **Attachment Disorder**	☐ **Obesity**

☐ **Autism**	☐ **Obsessive Compulsive Disorder (OCD)**
☐ **Behavior problems- *OTHER***	☐ **Oppositional Defiant Disorder (ODD)**
☐ **Bowel problems, e.g., constipation, encopresis, enuresis**	☐ **Pica**
☐ **Cerebral Palsy**	☐ **Post-traumatic Stress Disorder (PTSD)**
☐ **Child Abuse/Neglect**	☐ **Prematurity**
☐ **Contractures**	☐ **Scoliosis**
☐ **Deformities**	☐ **Seizures**
☐ **Developmental Delay**	☐ **Sensory issues**
☐ **Depression or other mood disorder**	☐ **Social Pragmatic Disorder**
☐ **Dysarthria (speech)**	☐ **Speech/communication problems, e.g., Articulation Disorder**
☐ **Dysgraphia (writing)**	☐ **Tourette's Syndrome**
☐ **Dysphagia (feeding)**	☐ **Torticollis**
☐ **Failure to Thrive**	☐ **Traumatic Brain Injury (TBI)**
☐ **Fetal Alcohol Syndrome or effects**	☐ **Visual-motor coordination**
☐ **Genetic Disorder**	☐ **Do not know**
☐ **Hearing problems**	☐ **Do not know**

→ Please turn this double-sided page over to complete page 4 (on the back of this page) →

10. (cont'd.) Does your child have any diagnosis or diagnoses that are not listed on the previous page? (Please provide additional information below.)

_____

_____

_____

_____

_____

_____

_____

11. Before today, has your child received any support services for his or her special health care needs or developmental disabilities?

- O No.
- O Yes. If so, which of the following services has your child received? (Please check all that apply.)

✔ PLEASE CHECK ALL THAT APPLY	✔ PLEASE CHECK ALL THAT APPLY
☐ **Speech-language therapy**	☐ **Occupational therapy**
☐ **In-school services, e.g., special education, IEP, 504 plan**	☐ **Physical therapy**
☐ **Educational services in the community, e.g. tutoring**	☐ **Social skills training**
☐ **Primary care services (e.g., your child's doctor)**	☐ **Organizational skills training**
☐ **Mental health services**	☐ **Developmental Disabilities Services (DDS)/Supplemental Security Income (SSI)**

Have you received information from any sources that are not listed above? (Please provide additional information below.)

_____

_____

_____

_____

_____

_____

12. On an average day in the life of your family, how many hours is your child typically in your care?

_____ waking hours per day

13. During an average week in the life of your family, how many hours do you typically spend on activities and services related to meeting your child's special health care needs or developmental disabilities (e.g., attending medical appointments, contacting service providers, completing necessary paperwork, attending school conferences about accommodations)**?**

_____ hours per week

14. What type of insurance coverage does your family have? (Please check the best answer.)

- O Care Coordination Organization (CCO)- OHP/Medicaid insurance
- O Private insurance
- O None
- O Other (please describe): _____

15. What is the child's family history? (Please provide information about the child's biological parents and siblings.)

Relationship to Child		**Age/ Birth Year**	**Living in the home?** (check if "yes")	**Any known health problems?** (please provide additional information below)
1) *Mother- biological*				
2) *Father- biological*				
3) *Siblings* (please circle which)				
Brother	Sister			
Brother	Sister			
Brother	Sister			
Brother	Sister			

Brother	Sister			

Relationship to Child	**Age/Birth Year**	**Any known health problems?** (please provide additional information below)

→ Please turn this double-sided page over to complete page 6 (on the back of this page) →

Please list any other individuals living in the home (e.g., foster child, family friend). In addition, if the child is an adoptive or foster home, make sure to list all adults and children living in the home

APPENDIX C

CONSENT FORM

University of Oregon Department of Counseling Psychology
Informed Consent for Participation as a Subject in

"Experiences of pediatric parenting stress and family support for caregivers of children with special health care needs or developmental disabilities"

Investigator: Christine L. Ngo
Type of consent: Participant Consent Form

INSTRUCTIONS

I) PLEASE READ THIS CONSENT FORM FOR AN OVERVIEW OF THIS STUDY
II) IF YOU WISH TO PARTICIPATE, PROCEED WITH COMPLETING THE 3 ATTACHED QUESTIONNAIRES
III) PLACE YOUR COMPLETED QUESTIONNAIRES INTO THE ENVELOPE, SEAL IT, AND SUBMIT
THE ENVELOPE TO THE CDRC FRONT DESK STAFF. THE STAFF MEMBER WILL THEN PROVIDE YOU
WITH YOUR GIFT CARD.
IV) IF YOU WOULD LIKE TO TAKE THE STUDY PACKET WITH YOU AND RETURN IT BY MAIL, PLEASE TAKE
ONE OF THE PRE-ADDRESSED, PRE-STAMPED ENVELOPES FROM THE STUDY BASKET. ONCE
SENT, CONTACT RUTH WARWICK, SUPPORT STAFF SUPERVISOR (541.346.2608 OR WARWICK@OHSU.EDU) WITH YOUR ENVELOPE NUMBER. RUTH WILL THEN SUBMIT YOUR SEALED
ENVELOPE TO THE RESEARCH TEAM AND ENSURE THAT YOUR GIFT CARD IS AVAILABLE FOR PICK-UP
FROM THE CDRC FRONT DESK. FOR YOUR PRIVACY AND CONFIDENTIALITY, PLEASE DO NOT INCLUDE
YOUR RETURN ADDRESS ON THE ENVELOPE.
V) CONTACT THE RESEARCH TEAM WITH ANY QUESTIONS OR CONCERNS ABOUT THE STUDY
VI) KEEP THIS COPY OF THE CONSENT FORM FOR YOUR RECORDS AND FOR FUTURE REFERENCE

Introduction

I would like to invite you to participate in a research study. I am interested in learning more about the experiences of stress and family support for caregivers of children with special health care needs or developmental disabilities.

I would like to work with you because you are a caregiver of a child who has special health care needs or developmental disabilities.

You are welcome to contact me or my faculty advisor with any questions that you might

about the study. Our contact information is listed at the end of this form (under the "Contacts and Questions" section).

Purpose of Study:

- The purpose of this study is to learn about what caregivers, such as yourself, experience as you care for your children- more specifically, your experiences of stress and support.
- Any caregiver (including biological, adoptive, or foster parents or legal guardians): 1) whose child is between the ages of 0 to 21 years of age, has special health care needs or developmental disabilities, and who is receiving services at the CDRC; 2) has legal custody of the child (who is a patient at the CDRC); and 3) is able to read and write in the English language is welcome to participate in this study.
- I would like to invite *only one* caregiver from your family to participate in the study.

Description of the Study Procedures:

- If you agree to participate in this study, you will complete 3 questionnaires about: (1) your family's demographic and medical information; (2) pediatric parenting stress for you as a caregiver; and (3) sources of support for your family. The 3 questionnaires will take approximately 15 to 20 minutes in total to complete.

Risks/Discomforts of Being in the Study:

- I do not think that my study will pose many risks. There are, however, a few possible risks that I would like to mention:
    - For many families, in particular those attending the clinic for a testing or an assessment session, today's visit to the CDRC could be experienced as being stressful. Completing a measure about stress might be difficult for some caregivers to do in this context.

    - Possible risks for psychological risk are due to the nature of the information gathered in the questionnaires. For example, it could be upsetting to reflect upon negative or difficult experiences that you have had thus far in caring for your child with special health care needs or developmental disabilities.
    - Please do not hesitate to contact my faculty advisor or myself with any questions or concerns that you might have about the study.

Benefits of Being in the Study:

- The purpose of this study is to offer caregivers of children with special health care needs or developmental disabilities the opportunity to share about their experiences of stress as well as their sources of support.
- This information has the potential to increase your own awareness following further reflection about your experiences to-date in caring for your child.
- The experiences of your family can also help (1) to inform general knowledge about stress and social support for families of children with special health care needs and developmental disabilities, which can be important when providing human services, (2) to provide useful information to the CDRC- Eugene Programs location in serving families in the future.

Payments:

- You will receive a $10 gift card as a token of appreciation for your time, help, and participation in this study.

Costs:

- There is no financial cost to you for participating in this research study.

Confidentiality:

- Your responses on the questionnaires and participation in the study are *private* and *confidential*. Neither you nor your family members' names will be associated with the study. In any report that I might publish, I will not include any information that will make it possible to identify you or your family. I will keep research records in a locked file, and I will secure all electronic information by using passwords to protect the files.
- Access to study records will be limited to me and my faculty advisor; however, please note that the Institutional Review Board and internal University of Oregon auditors may review the research records to ensure that I am adhering to ethical standards. Additionally, CDRC providers will receive a summary of the final group results at the end of the study.

Voluntary Participation/Withdrawal:

- Your participation is voluntary. If you decide not to participate, your decision will not have a negative effect on your current or future relationship with Oregon Health & Science University, the Child Development and Rehabilitation Center, the University of Oregon, or me.
- You are free to withdraw from the study at any time for any reason. If you wish to withdraw from participation, please discard the study packet in the nearest shredder or waste bin.

Contacts and Questions:

- I, Christine Ngo, am the primary investigator/researcher conducting this study. If you have questions or concerns, or if you would like more information about this research, please do not hesitate to contact me directly at (541) 632-4012 or ngo@uoregon.edu. Dr. Krista Chronister, my faculty advisor and the co-investigator for the study, can be reached at (541) 346-2415 or kmg@uoregon.edu.
- If you have any questions about your rights as a research participant, you may contact Research Compliance Services, University of Oregon at (541) 346-2510 or ResearchCompliance@uoregon.edu.

Copy of Consent Form:

- Please keep this copy of the consent form for your records and for future reference.

Your Statement of Consent:

- If you agree to participate in this study, you will complete the questionnaires, place them in the attached envelope, and then submit the sealed envelope to the CDRC front desk staff. Should you wish to return the study packet by mail, please use one of the pre-addressed, pre-stamped envelopes from the study baskets.

APPENDIX D

QUESTIONNAIRE INSTRUCTIONS COVERSHEET

Experiences of Pediatric Parenting Stress and Family Support for Caregivers of Children with Special Health Care Needs or Developmental Disabilities

Dear Caregiver:

Thank you for your interest in this study. The purpose of the study is to learn more about the experiences of stress and support for the caregivers of children who have special health care needs or developmental disabilities.

There are 3 attached questionnaires to complete: i) the demographic and medical information questionnaire, ii) the Pediatric Inventory for Parents (Streisand et al., 2010) questionnaire, and iii) the Family Support Scale (Dunst, Trivette, & Jenkins, 2007) questionnaire. Your responses on the questionnaires and participation in the study will be *private* and *confidential*. Neither you nor your family will be associated with the questionnaires. Please do not write any of your family members' names on the questionnaires.

Please complete the entire set of questionnaires to the best of your ability. You may skip any questions that you do not wish to answer. If you would like to comment on any of your answers or the questions, feel free to write in the margins of the questionnaires. All of your comments will be read and taken into account.

Once you have completed the questionnaires, seal them into the attached envelope and submit your packet to the CDRC front desk staff. The staff member will then provide you with a gift card.

Thank you,

Christine L. Ngo
Doctoral Student, Counseling Psychology
5251 University of Oregon
Eugene, Oregon 97403-5251

APPENDIX E

IRB REVIEW AND EXEMPT DETERMINATION- AMENDMENT

UNIVERSITY OF OREGON

DATE: November 16, 2016 IRB Protocol Number: 07162015.017

TO: Christine Ngo, Principal Investigator
Department of Counseling Psychology

RE: Protocol entitled, "Experiences of Pediatric Parenting Stress and Family Support for Caregivers of Children with Special Health Care Needs and Developmental Disabilities"

Notice of IRB Review and Exempt Determination-Amendment
as per Title 45 CFR Part 46.101 (b)(2)

The amendment submitted on November 06, 2016 to the above protocol has been reviewed by the University of Oregon Institutional Review Board and Research Compliance Services. This is a minimal risk research protocol that continues to qualify for an exemption from IRB review under 45 CFR 46. 101(b)(2) for research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior.

Please note that you will not be required to submit continuing reviews for this protocol, however, you must submit any changes to the protocol to Research Compliance Services for assessment to verify that the protocol continues to qualify for exemption. This exempt determination will expire September 20, 2020. Should your research continue beyond expiration date, you will need to submit a new protocol application.

The purpose of this Amendment is to:

- Include fifth data collection site
- Add researchers; Kyndl Woodlee and Fallon Baraga

Your responsibility as a Principal Investigator also includes:

- Obtaining written documentation of the appropriate permissions from public school districts, institutions, agencies, or other organizations, etc., prior to conducting your research
- Notifying Research Compliance Services of any change in Principal Investigator
- Notifying Research Compliance Services of any changes to or supplemental funding
- Retaining copies of this determination, any signed consent forms, and related research materials for five years after conclusion of your study or the closure of your sponsored research, whichever comes last.

As with all Human Subject Research, exempt research is subject to periodic Post Approval Monitoring review.

If you have any questions regarding your protocol or the review process, please contact Research Compliance Services at ResearchCompliance@uoregon.edu or (541)346-2510.

Sincerely,

COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS ● RESEARCH COMPLIANCE SERVICES
677 E. 12· Ave., Suite 500, 5237 University of Oregon, Eugene OR 97401-5237
T 541-346-2510 F 541-346-5138 **http://rcs.uoregon.edu**

REFERENCES CITED

Abidin, R. R., & Abidin, R. R. (1990). Parenting Stress Index (PSI). Charlottesville, VA: Pediatric Psychology Press.

Alderfer, M. A., Labay, L. E., & Kazak, A. E. (2003). Brief report: does posttraumatic stress apply to siblings of childhood cancer survivors?. *Journal of Pediatric Psychology*, *28*(4), 281-286. doi: 10.1093/jpepsy/jsg016

American Psychological Association (2010). *Public Interest Directorate, Family Caregiver Briefcase*. Retrieved from: http://www.apa.org/pi/about/publications/caregivers/

American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*(Supplement 3), 1304-1306.

Andersen, R. M. (1968). *Behavioral Model of Families' Use of Health Services*. Research Series No. 25. Chicago, IL: Center for Health Administration Studies, University of Chicago.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter?. *Journal of Health and Social Behavior*, *36*(1), 1-10. doi: 10.2307/2137284

Andersen, R., & Aday, L. A. (1978). Access to medical care in the US: realized and potential. *Medical Care 16*(7), 533-546.

Baicker, K., & Finkelstein, A. (2011). The effects of Medicaid coverage- learning from the Oregon experiment. *New England Journal of Medicine*, *365*(8), 683-685.

doi: 10.1056/NEJMp1108222

Barakat, L. P., Alderfer, M. A., & Kazak, A. E. (2005). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of pediatric psychology*, *31*(4), 413-419. doi: 10.1093/jpepsy/jsj058

Barakat, L. P., Patterson, C. A., Tarazi, R. A., & Ely, E. (2007). Disease related parenting stress in two sickle cell disease caregiver samples: preschool and adolescent. *Families, Systems and Health*, 25(2), 147-161. doi: 10.1037/1091-7527.25.2.147

Barakat, L. P., Patterson, C. A., Weinberger, B. S., Simon, K., Gonzalez, E. R., & Dampier, C. (2007). A prospective study of the role of coping and family functioning in health outcomes for adolescents with sickle cell disease. *Journal of Pediatric Hematology/Oncology, 29*(11), 752-760. doi: 10.1097/ MPH.0b013e318157fdac

Barakat, L. P., Patterson, C. A., Daniel, L. C., & Dampier, C. (2008). Quality of life among adolescents with sickle cell disease: mediation of pain by internalizing symptoms and parenting stress. *Health and Quality of Life Outcomes, 6*(60). doi: 10.1186/1477-7525-6-60

Baum, L. S. (2004). Internet parent support groups for primary caregivers of a child with special health care needs. *Pediatric nursing*, *30*(5), 381-401.

Bennett, D. S. (1994). Depression among children with chronic medical problems: a meta-analysis. *Journal of Pediatric Psychology*, *19*(2), 149-169. doi: 10.1093/jpepsy/19.2.149

Bentler, P. M. (1990). Comparative fit indexes in structural models. *Psychological bulletin*, *107*(2), 238-246. doi: 10.1037/0033-2909.107.2.238

Berge, J. M., Patterson, J. M., & Rueter, M. (2006). Marital satisfaction and mental health of couples with children with chronic health conditions. *Families, Systems, & Health*, *24*(3), 267-285. doi: 10.1037/1091-7527.24.3.267

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: care, health, and cost. *Health affairs*, *27*(3), 759-769. doi: 10.1377/hlthaff.27.3.759

Best, M., Streisand, R., Catania, L., & Kazak, A. E. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology*, *26*(5), 299-307. doi: 10.1093/jpepsy/26.5.299

Bethell, C. D., Read, D., Blumberg, S. J., & Newacheck, P. W. (2008). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal*, *12*(1), 1-14. doi: 10.1007/s10995-007-0220-5

Bonner, M. J., Hardy, K. K., Willard, V. W., & Hutchinson, K. C. (2007). Brief report: Psychosocial functioning of fathers as primary caregivers of pediatric oncology patients. *Journal of Pediatric Psychology*, *32*(7), 851-856. doi: 10.1093/jpepsy/jsm011

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *The Annals of Family Medicine*, *2*(6), 576-582. doi: 10.1370/afm.245

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., Visser, S., & Kogan, M. D. (2011). Trends in the prevalence of

developmental disabilities in US children, 1997–2008. *Pediatrics*, *127*(6), 1034-1042.

Britner, P. A., Morog, M. C., Pianta, R. C., & Marvin, R. S. (2003). Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis. *Journal of Child and Family Studies*, *12*(3), 335-348.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by design and nature*. Cambridge, MA: Harvard University Press.

Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(4), 238-245. doi: 10.1111/j.1741-1130.2006.00085.x

Bruhn, J. G., & Rebach, H. M. (2014). *The sociology of caregiving*. New York, NY: Springer Publishing Company.

Centers for Disease Control and Prevention. (2011). National Center on Birth Defects and Developmental Disabilities (NCBDDD): NCBDDD 10 years of Service. Retrieved from: www.cdc.gov/ncbddd/AboutUs/10-year-recap.html.

Chen, A. Y., & Newacheck, P. W. (2006). Insurance coverage and financial burden for families of children with special health care needs. *Ambulatory Pediatrics*, *6*(4), 204-209. doi:10.1016/j.ambp.2006.04.009

Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Health*, *11*, 588-594.

Chou, K. R. (2000). Caregiver burden: a concept analysis. *Journal of pediatric nursing*, *15*(6), 398-407. doi: 10.1053/jpdn.2000.16709

Churchill, S. S., Villareale, N. L., Monaghan, T. A., Sharp, V. L., & Kieckhefer, G. M. (2010). Parents of children with special health care needs who have better coping skills have fewer depressive symptoms. *Maternal and child health journal*, *14*(1), 47. doi: 10.1007/s10995-008-0435-0

Chwalisz, K., & Obasi, E. (2008). Promoting health and preventing and reducing disease. In S. D. Brown & R. W. Lent (Eds.), *Handbook of counseling psychology* (4th ed.) (pp. 516-534). Hoboken, NJ: John Wiley & Sons, Inc.

Cohen, L., Vowles, K., & Eccleston, C. (2010). Parenting an adolescent with chronic pain: An investigation of how a taxonomy of adolescent functioning relates to parent distress. *Journal of Pediatric Psychology*, 35(7), 748-757. doi: 10.1093/jpepsy/jsp103

Cohen, S., & McKay, G. (1984). Social support, stress and the buffering hypothesis: A theoretical analysis. *Handbook of psychology and health*, *4*, 253-267.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, *38*(8), 809-828. doi: 10.1093/jpepsy/jst049

Craig, W. M. (1998). The relationship among bullying, victimization, depression, anxiety, and aggression in elementary school children. *Personality and individual differences*, *24*(1), 123-130. doi: 10.1016/S0191-8869(97)00145-1

Crnic, K., & Stormshak, E. (1997). The effectiveness of providing social support for families of children at risk. In M. J. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 209-225). Baltimore, MD: Paul H. Brookes Publishing Co.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, *16*(3), 297-334. doi: 10.1007/BF02310555

Crowley, M. J., & Kazdin, A. E. (1998). Child psychosocial functioning and parent quality of life among clinically referred children. *Journal of Child and Family Studies*, *7,* 233–251.

Cuellar, N. G. (2002). A comparison of African American & Caucasian American female caregivers of rural, post-stroke, bedbound older adults. *Journal of Gerontological Nursing*, *28*(1), 36-45. doi.org/10.3928/0098-9134-20020101-08

Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Wiley series on personality processes. Social support: An interactional view* (pp. 319-366). Oxford, England: John Wiley.

Davidoff, A. J. (2004). Insurance for children with special health care needs: patterns of coverage and burden on families to provide adequate insurance. *Pediatrics*, *114*(2), 394-403. doi:10.1542/peds.114.2.394

DeVoe, J. E., Tillotson, C. J., & Wallace, L. S. (2009). Children's receipt of health care services and family health insurance patterns. *The Annals of Family Medicine*, *7*(5), 406-413. doi: 10.1370/afm.1040

DeWalt, D. A., & Hink, A. (2009). Health literacy and child health outcomes: a systematic review of the literature. *Pediatrics*, *124*(Supplement 3), 265-274.

doi: 10.1542/peds.2009-1162

Dunst, C. J. (1985). Rethinking early intervention. *Analysis and Intervention in Developmental Disabilities*, 5, 165-201. doi: 10.1016/S0270-4684(85)80012-4

Dunst, C. J., Trivette, C. M., & Deal, A. M. (Eds.) (1994). *Supporting and Strengthening families. Vol 1.: Methods, Strategies, and Practices*. Northampton, MA: Brookline Books.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). Family Support Scale: Reliability and validity. *Journal of Individual, Family, and Community Wellness*, 1, 45–52.

Dunst, C. J., Trivette, C. M., & Jodry, W. (1997). Influences of social support on children with disabilities and their families. In M. J. Guralnick (Ed.), The effectiveness of early intervention (pp. 499-522). Baltimore, MD: Paul H. Brookes Publishing Co.

Easters Seals & the National Alliance for Caregiving (2007). *Caregiving in Rural America*. Retrieved from: http://www.easterseals.com.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*(4286), 129-136. doi: 10.1126/science.847460

Engel, G. L. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry*, *137*(5), 535-544. doi: 10.1093/med/9780190628871.003.0002

Engel, G. L. (1997). From biomedical to biopsychosocial: Being scientific in the human domain. *Psychosomatics*, *38*(6), 521-528. doi: 10.1016/S0033-3182(97)71396-3

Fairbrother, G., Kenney, G., Hanson, K., & Dubay, L. (2005). How do stressful family environments relate to reported access and use of health care by low-income

children?. *Medical Care Research and Review*, *62*(2), 205-230. doi: 10.1177/1077558704273805

Family caregiver briefcase. (2011, March). *American Psychological Association*. Retrieved from: http://www.apa.org/pi/about/newsletter/2011/03/caregiver-briefcase.aspx

Farmer, J. E., Marien, W. E., Clark, M. J., Sherman, A., & Selva, T. J. (2004). Primary care supports for children with chronic health conditions: identifying and predicting unmet family needs. *Journal of Pediatric Psychology*, *29*(5), 355-367. doi: 10.1093/jpepsy/jsh039

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191. doi: 10.3758/BF03193146

Field, A. (2013). Discovering statistics using IBM SPSS statistics. Chicago, IL: Sage.

Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *The Canadian Journal of Psychiatry*, *45*(4), 369-375. doi: 10.1177/070674370004500406

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American psychologist*, *55*(6), 647. doi: 10.1037/0003-066X.55.6.647

Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, *55*, 745-774. doi.org/10.1146/annurev.psych.55.090902.141456

Folkman, S., & Moskowitz, J. T. (2007). Positive affect and meaning-focused coping during significant psychological stress. In *The Scope of Social Psychology: Theory and Applications* (pp. 193-208). New York, NY: Psychology Press.

Fujijura G. T., & Yamaki K. (2000). Trends in demography of childhood poverty and disability. *Exceptional Children*, 66, 187-199. doi: 10.1177/001440290006600204

Gage-Bouchard, E. A. (2017). Culture, Styles of Institutional Interactions, and Inequalities in Healthcare Experiences. *Journal of Health and Social Behavior*, *58*(2), 147-165. doi: 10.1177/0022146517693051

Guilfoyle, S., Baldassano, R., & Hommel, K. (2012). Pediatric parenting stress in inflammatory bowel disease: Application of the Pediatric Inventory for Parents. *Child: Care, Health and Development,* 38(2), 273-279. doi: 10.1111/ j.1365-2214.2010.01200.x

Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *Journal of Developmental and Physical Disabilities*, *19*(4), 417-425. doi: 10.1007/s10882-007-9060-x

Halfon, N., Houtrow, A., Larson, K., & Newacheck, P. W. (2012). The changing landscape of disability in childhood. *The Future of Children*, *22*(1), 13-42. doi: 10.1353/foc.2012.0004

Hansen, J., Weissbrod, C., Schwartz, D., & Taylor, W. (2012). Paternal involvement in pediatric Type 1 diabetes: Fathers' and mothers' psychological functioning and disease management. *Families, System, & Health,* 30(1), 47-59. doi: 10.1037/ a0027519

Hawker, D. S., & Boulton, M. J. (2000). Twenty years' research on peer victimization and psychosocial maladjustment: A meta-analytic review of cross-sectional studies. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, *41*(4), 441-455. doi: 10.1111/1469-7610.00629

Hilliard, M. E., Monaghan, M., Cogen, F. R., & Streisand, R. (2011). Parent stress and child behavior among young children with Type 1 diabetes. *Child: Care, Health and Development*, *37*(2), 224-232. doi: 10.1111/j.1365-2214.2010.01162.x

Homer, C. J., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P., Van Cleave, J., & Perrin, J. M. (2008). A review of the evidence for the medical home for children with special health care needs. *Pediatrics*, *122*(4), 922-937. doi: 10.1542/peds.2007-3762

Inkelas, M., Raghavan, R., Larson, K., Kuo, A. A., & Ortega, A. N. (2007). Unmet mental health need and access to services for children with special health care needs and their families. *Ambulatory Pediatrics*, *7*(6), 431-438. doi: 10.1016/ j.ambp.2007.08.001

Kaiser, H.F. (1960). The application of electronic computers to factor analysis. *Educational and Psychological Measurement, 20,* 141-151. doi: 10.1177/ 001316446002000116

Kazak, A. E., Alderfer, M., Rourke, M. T., Simms, S., Streisand, R., & Grossman, J. R. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of pediatric psychology*, *29*(3), 211-219. doi: 10.1093/jpepsy/jsh022

Kazak, A.E., Barakat, L.P., Meeske, K., Christakis, D., Meadows, A.T., Casey, R., Penati, B. and Stuber, M.L. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of consulting and clinical psychology*, *65*(1), pp.120-129. doi: 10.1037/ 0022-006X.65.1.120

Keller, D., & Honig, A. S. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry*, *74*(3), 337. doi: 10.1037/0002-9432.74.3.337

Kochenderfer, B. J., & Ladd, G. W. (1996). Peer victimization: Cause or consequence of school maladjustment?. *Child development*, *67*(4), 1305-1317. doi: 10.2307/1131701

Kuhlthau, K., Hill, K. S., Yucel, R., & Perrin, J. M. (2005). Financial burden for families of children with special health care needs. *Maternal and child health journal*, *9*(2), 207-218. doi: 10.1007/s10995-005-4870-x

Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of pediatrics & adolescent medicine*, *165*(11), 1020-1026. doi: 10.1001/archpediatrics.2011.172

Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of gerontology*, *46*(4), 181-189. doi: 10.1093/geronj/46.4.P181

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

Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European journal of personality*, *1*(3), 141-169. doi: 10.1002/per.2410010304

Lewin, A. B., Storch, E. A., Silverstein, J. H. , Baumeister, A. L., Strawser, M. S., & Geffken, G. (2005). Validation of the Pediatric Inventory for Parents in mothers

of children with type 1 diabetes: An Examination of parenting stress, anxiety, and childhood psychopathology. *Families, Systems, & Health,* 56-65. doi: 10.1037/1091-7527.23.1.56

Lindeke, L. L., Leonard, B. J., Presler, B., & Garwick, A. (2002). Family-centered care coordination for children with special needs across multiple settings. *Journal of Pediatric Health Care*, *16*(6), 290-297. doi: 10.1067/mph.2002.121917

Lipman, E. L., Boyle, M. H., Dooley, M. D., & Offord, D. R. (2002). Child well-being in single-mother families. *Journal of the American Academy of Child & Adolescent Psychiatry*, *41*(1), 75-82. doi: 10.1097/00004583-200201000-00014

Logan, D. E., Radcliffe, J., & Smith-Whitley, K. (2002). Parent factors and adolescent sickle cell disease: associations with patterns of health service use. *Journal of Pediatric Psychology*, *27*(5), 475-484. doi: 10.1093/jpepsy/27.5.475

Looman, W. S., O'Conner-Von, S. K., Ferski, G. J., & Hildenbrand, D. A. (2009). Financial and employment problems in families of children with special health care needs: implications for research and practice. *Journal of Pediatric Health Care*, *23*(2), 117-125. doi: 10.1016/j.pedhc.2008.03.001

Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (2005). Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*, *115*(6), 1562-1568. doi: 10.1542/peds.2004-1262

Marcin, J. P., Ellis, J., Mawis, R., Nagrampa, E., Nesbitt, T. S., & Dimand, R. J. (2004). Using telemedicine to provide pediatric subspecialty care to children with special

health care needs in an underserved rural community. *Pediatrics*, *113*(1), 1-6. doi: 10.1542/peds.113.1.1

McManus, B. M., Carle, A. C., & Rapport, M. J. (2014). Classifying infants and toddlers with developmental vulnerability: Who is most likely to receive early intervention?. *Child: care, health and development*, *40*(2), 205-214.

McPherson, M., Arango, P., & Fox, H.B. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*, pp.137-140. doi: 10.1542/peds.102.1.137

McPherson, M., Weissman, G., Strickland, B. B., van Dyck, P. C., Blumberg, S. J., & Newacheck, P. W. (2004). Implementing community-based systems of services for children and youths with special health care needs: How well are we doing?. *Pediatrics*, *113*(Supplement 4), 1538-1544.

Mednick, L., Gargollo, P., Oliva, M., Grant, R., & Borer, J. (2009). Stress and coping of parents of young children diagnosed with bladder exstrophy. *Journal of Urology, 181*(3), 1312-1316. doi: 10.1016/j.juro.2008.10.051

Melamed, B. G., & Ridley-Johnson, R. (1988). Psychological preparation of families for hospitalization. *Developmental and Behavioral Pediatrics*, 9, 96-102. doi: 10.1097/00004703-198804000-00010

Mitchell, S.J., Hilliard, M.E., Mednick, L., Henderson, C., Cogen, F.R., & Streisand, R. (2009). Stress among fathers of young children with type 1 diabetes. *Families, Systems, & Health, 27*, 314-324. doi.org/10.1037/a0018191

Monaghan, M. C., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2009). Nighttime caregiving behaviors among parents of young children with Type 1 diabetes:

Associations with illness characteristics and parent functioning. *Families, Systems, & Health*, *27*(1), 28. doi: 10.1037/a0014770

Monaghan, M., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2011). Supporting parents of very young children with Type 1 diabetes: Results from a pilot study. *Patient Education and Counseling*, *82*(2), 271-274. doi.org/10.1016/j.pec.2010.04.007

Muller-Godeffroy, E., Treichel, S., & Wagner, V.M. (2009). Investigation of quality of life and family burden issues during insulin pump therapy in children with type 1 diabetes mellitus- a large-scale multicentre pilot study. *Diabetic Medicine, 26*, 493-501. doi: 10.1111/j.1464-5491.2009.02707.x

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: care, health and development*, *33*(2), 180-187. doi: 10.1111/j.1365-2214.2006.00644.x

Muthén, L.K. and Muthén, B.O. (1998-2015). Mplus User's Guide. Seventh Edition. Los Angeles, CA: Muthén & Muthén.

National Alliance for Caregiving (2009). *Caregiving in the U.S.* Retrieved from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.

Neff, J. M., & Anderson, G. (1995). Protecting children with chronic illness in a competitive marketplace. *The Journal of the American Medical Association, 274*(23), 1866-1869. doi: 10.1001/jama.1995.03530230052030

Newacheck, P. W., Hughes, D. C., Hung, Y. Y., Wong, S., & Stoddard, J. J. (2000). The unmet health needs of America's children. *Pediatrics*, *105*(Supplement 3), 989-997.

Newacheck, P. W., Inkelas, M., & Kim, S. E. (2004). Health services use and health care expenditures for children with disabilities. *Pediatrics*, *114*(1), 79-85.

Newacheck, P. W., & Kim S. E. (2005). A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs. *Archives of Pediatric & Adolescent Medicine,* 159*(1)*, 10-17. doi: 10.1001/archpedi.159.1.10

Newacheck, Strickland, Shonkoff, Perrin, McPherson, McManus, Lauver, Fox, & Arango (1998). An epidemiologic profile of children with special health care needs. *Pediatrics*, *102*(1), 117-123. doi: 10.1542/peds.102.1.117

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York, NY: McGraw-Hill.

O'Connor, M., Howell-Meurs, S., Kvalsvig, A., & Goldfeld, S. (2015). Understanding the impact of special health care needs on early school functioning: A conceptual model. *Child: care, health and development*, *41*(1), 15-22. doi: 10.1111/cch.12164

Odell, S., Sander, E., Denson, L. A., Baldassano, R. N., Hommel, K. A. (2011). The contributions of child behavioral functioning and parent distress to family functioning in pediatric inflammatory bowel disease. *Journal of Clinical Psychology in Medical Settings*, 18(1), 39-45. doi: 10.1007/s10880-011-9228-5

Ohleyer, V., Freddo, M., Bagner, D. M., Simons, L. E., Geffken, G. R., Silverstein, J. H., & Storch, E. A. (2007). Disease-related stress in parents of children who are overweight: relations with parental anxiety and childhood psychosocial functioning. *Journal of Child Health Care*, *11*(2), 132-142. doi: 10.1177/1367493507076065

Olweus, D. (1993). Victimization by peers: Antecedents and long-term outcomes. In K. H. Rubin & J. B. Asendorpf (Eds.), *Social withdrawal, inhibition, and shyness in childhood*, (pp. 315-341). New York, NY: Psychology Press.

Orsmond, G. I., Lin, L. Y., & Seltzer, M. M. (2007). Mothers of adolescents and adults with autism: Parenting multiple children with disabilities. *Intellectual and Developmental Disabilities*, *45*(4), 257-270. doi:10.1352/1934-9556(2007) 45%5B257:MOAAAW%5D2.0.CO;2

Oswald, D. P., Bodurtha, J. N., Willis, J. H., & Moore, M. B. (2007). Underinsurance and key health outcomes for children with special health care needs. *Pediatrics*, *119*(2), e341-e347. doi: 10.1542/peds.2006-2218

Parish, S. L., Magaña, S., & Cassiman, S.A. (2008). It's just that much harder: Multilayered hardship experiences of low-income mothers with disabilities raising their children. *The Journal of Women and Social Work*, 23, 51-65. doi: 10.1177/ 0886109907310463

Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional children*, *68*(2), 151-170. doi: 10.1177/001440290206800201

Patterson, J. M. (1988). Families experiencing stress: I. The Family Adjustment and Adaptation Response Model: II. Applying the FAAR Model to health-related issues for intervention and research. *Family Systems Medicine*, *6*(2), 202-237.

Patterson, J. M. (2002). Understanding family resilience. *Journal of clinical psychology*, *58*(3), 233-246. doi: 10.1002/jclp.10019

Patton, S., Dolan, L., Smith, L., Thomas, I., & Powers, S. (2011). Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of young children with type 1 diabetes mellitus. *Journal of Clinical Psychology in Medical Settings*, 18(4), 345-352. doi: 10.1007/s10880-011-9256-1.

Pearson, K. (1900). On the criterion that a given system of deviations from the probable in the case of a correlated system of variables is such that it can be reasonably supposed to have arisen from random sampling. *Philosophical Magazine Series, 5*(302), 157-175. doi: 10.1080/14786440009463897

Preston, A., Storch, E. A., Lewin, A., Geffken, G. R., Baumeister, A. L., Strawser, M. S., & Silverstein, J. H. *(*2005). Parental stress and maladjustment in children with short stature. *Clinical Pediatrics, 44*, 327-31. doi: 10.1177/000992280504400407

Quittner, A. L., Espelage, D. L., Opipari, L. C., Carter, B., Eid, N., & Eigen, H. (1998). Role strain in couples with and without a child with a chronic illness: associations with marital satisfaction, intimacy, and daily mood. *Health Psychology*, *17*(2), 112. doi: 10.1037/0278-6133.17.2.112

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M. & Walter, S. D. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC pediatrics*, *4*(1), 1. doi: 10.1186/1471-2431-4-1.

Rietveld, M. J., Hudziak, J. J., Bartels, M., Beijsterveldt, C. V., & Boomsma, D. I. (2004). Heritability of attention problems in children: longitudinal results from a study of twins, age 3 to 12. *Journal of Child Psychology and Psychiatry*, *45*(3), 577-588. doi: 10.1111/j.1469-7610.2004.00247.x

Rigby, K., & Slee, P. (1999). Suicidal ideation among adolescent school children, involvement in bully—victim problems, and perceived social support. *Suicide and life-threatening behavior*, *29*(2), 119-130.

Risdal, D., & Singer, G. H. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research & Practice for Persons with Severe Disabilities*, *29*(2). doi.org/10.2511/rpsd.29.2.95

Rolland, J. S. (1984). Toward a psychosocial typology of chronic and life-threatening illness. *Family systems medicine*, *2*(3), 245. doi: 10.1037/h0091663

Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family process*, *26*(2), 203-221. doi: 10.1037/h0089735

Rolland, J. S. (1987). Family illness paradigms: Evolution and significance. *Family Systems Medicine*, *5*(4), 482. doi: 10.1037/h0089735

Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New York, NY: Basic Books.

Rolland, J. S., & Walsh, F. (2006). Facilitating family resilience with childhood illness and disability. *Current opinion in pediatrics*, *18*(5), 527-538. doi: 10.1097/ 01.mop.0000245354.83454.68

Rommelse, N. N., Franke, B., Geurts, H. M., Hartman, C. A., & Buitelaar, J. K. (2010). Shared heritability of attention-deficit/hyperactivity disorder and autism spectrum disorder. *European Child & Adolescent Psychiatry*, *19*(3), 281-295. doi: 10.1007/s00787-010-0092-x

Saloviita, T., Itälinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX

model. *Journal of Intellectual Disability Research*, *47*(4-5), 300-312. doi: 10.1046/j.1365-2788.2003.00492.x

Sanders, L. M., Thompson, V. T., & Wilkinson, J. D. (2007). Caregiver health literacy and the use of child health services. *Pediatrics*, *119*(1), 86-92. doi: 10.1542/ peds.2005-1738

Schafer, J. L., & Graham, J. W. (2002). Missing data: our view of the state of the art. *Psychological methods*, *7*(2), 147. doi: 10.1037/1082-989X.7.2.147

Schumacker, R. E., & Lomax, R. G. (2004). *A beginner's guide to structural equation modeling*. New York, NY: Psychology Press.

Seligman, M., & Darling, R. B. (1997). *Ordinary families: Special children*. New York, NY: Guilford Press.

Seltzer, M. M., Almeida, D. M., Greenberg, J. S., Savla, J., Stawski, R. S., Hong, J., & Taylor, J. L. (2009). Psychosocial and biological markers of daily lives of midlife parents of children with disabilities. *Journal of Health and Social Behavior*, *50*(1), 1. doi: 10.1177/002214650905000101

Singer, G. H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American journal on mental retardation*, *111*(3), 155-169. doi:10.1352/ 0895-8017(2006)111%5B155: MOCSOD%5D2.0.CO;2

Skinner, A. C., & Slifkin, R. T. (2007). Rural/urban differences in barriers to and burden of care for children with special health care needs. *The Journal of Rural Health*, *23*(2), 150-157. doi: 10.1111/j.1748-0361.2007.00082.x

Smith, A. M., & Grzywacz, J. G. (2014). Health and well-being in midlife parents of children with special health needs. *Families, Systems, & Health*, *32*(3), 303. doi: 10.1037/fsh0000049

Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, *71*(2), 257-261. doi:10.1037/0002-9432.71.2.257

Steiger, J. H. (1990). Structural model evaluation and modification: An interval estimation approach. *Multivariate behavioral research*, *25*(2), 173-180. doi: 10.1207/s15327906mbr2502_4

Stoneman, Z., & Gavidia-Payne, S. (2006). Marital adjustment in families of young children with disabilities: Associations with daily hassles and problem-focused coping. *Journal Information*, *111*(1). doi: 10.1352/0895-8017(2006)111%5B1:MAIFOY%5D2.0.CO;2

Storch, E., Keeley, M., Merlo, L., Jacob, M., Correia, C., & Weinstein, D. (2008). Psychosocial functioning in youth with glycogen storage disease type 1. *Journal of Pediatric Psychology, 33*(7), 728-738. doi: 10.1093/jpepsy/jsn017

Streisand, R., Braniecki, S., Tercyak, K. P., & Kazak, A. E. (2001). Childhood illness-related parenting stress: the pediatric inventory for parents. *Journal of Pediatric Psychology*, *26*(3), 155-162. doi: 10.1093/jpepsy/26.3.155

Streisand, R., Tercyak, K., & Kazak, A. E. (2003). Pediatric-specific parenting stress and family functioning in children treated for cancer. *Children's Health Care, 32*, 245-256.

Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. S. (2005). Pediatric parenting stress among parents of children with type 1 diabetes: The Role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology, 30*, 513-521.

Streisand, R., Mackey, E.R., Elliot, B.M., Mednick, L., Slaughter, I.M., Turek, J., & Austin, A. (2008). Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: opportunities for education and counseling. *Patient Education and Counseling*, *73*(2), 333-338. doi: 10.1016/ j.pec.2008.06.014

Swearer, S. M., Song, S. Y., Cary, P. T., Eagle, J. W., & Mickelson, W. T. (2001). Psychosocial correlates in bullying and victimization: The relationship between depression, anxiety, and bully/victim status. *Journal of Emotional Abuse*, *2*(2-3), 95-121. doi: 10.1300/J135v02n02_07

Szilagyi, P. (2012). Health Insurance and Children with Disabilities. *The Future of Children, 22*(1), 123-148. doi: 10.1353/foc.2012.0000

Taft, T. H., Ballou, S., & Keefer, L. (2012). Preliminary evaluation of maternal caregiver stress in pediatric eosinophilic gastrointestinal disorders. *Journal of pediatric psychology*, *37*(5), 523-532. doi: 10.1037/0022-006X.54.4.416

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International journal of medical education*, *2*, 53. doi: 10.5116/ijme.4dfb.8dfd

Taylor, S.E. (2011). "Social support: A Review". In M.S. Friedman. *The Handbook of Health Psychology* (pp. 189–214). New York, NY: Oxford University Press.

Thoits, P. A. (1986). Social support as coping assistance. *Journal of consulting and clinical psychology*, *54*(4), 416. doi: 10.1037/0022-006X.54.4.416

Trainor, A. A. (2010). Diverse Approaches to Parent Advocacy During Special Education Home- School Interactions Identification and Use of Cultural and Social Capital. *Remedial and Special Education*, *31*(1), 34-47.

Tucker, L. R., & Lewis, C. (1973). A reliability coefficient for maximum likelihood factor analysis. *Psychometrika, 38,* 1–10. doi: 10.1007/BF02291170

Tukey, J. W. (1949). Comparing individual means in the analysis of variance. *Biometrics*, 99-114. doi: 10.2307/3001913

Turchi, R. M., Gatto, M., & Antonelli, R. (2007). Children and youth with special healthcare needs: there is no place like (a medical) home. *Current opinion in pediatrics*, *19*(4), 503-508. doi: 10.1097/MOP.0b013e32825a67b4

Twyman, K. A., Saylor, C. F., Saia, D., Macias, M. M., Taylor, L. A., & Spratt, E. (2010). Bullying and ostracism experiences in children with special health care needs. *Journal of Developmental & Behavioral Pediatrics*, *31*(1), 1-8. doi: 10.1097/DBP.0b013e3181c828c8

Twyman, K., Saylor, C., Taylor, L. A., & Comeaux, C. (2010). Comparing children and adolescents engaged in cyberbullying to matched peers. *Cyberpsychology, behavior, and social networking*, *13*(2), 195-199. doi: 10.1089/cyber.2009.0137

U.S. Department of Health and Human Services, Administration for Children and Families (2000). Administration on Intellectual and Developmental Disabilities. Retrieved from: https://www.govtrack.us/congress/bills/106/s1809

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (2012). *Child and Adolescent*

Health Measurement Initiative, "Fast Facts: 2011/12 National Survey of Children's Health." Retrieved from: http://www.childhealthdata.org/learn/NSCH

U.S. Department of Health and Human Services, Health Resources and Services Administration. (2015). *Maternal & Child Health Topics, Children with Special Health Care Needs*. Retrieved from: https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2016). *Healthy People 2020, Disability and Health*. Retrieved from: https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health

Uchino, B (2006). "Social support and health: A review of physiological processes potentially underlying links to disease outcomes". *Journal of Behavioral Medicine, 29*(4), 377–387. doi: 10.1007/s10865-006-9056-5

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research & Practice for Persons with Severe Disabilities*, *29*(2). doi: 10.2511/rpsd.29.2.144

Ward, B. W., Ridolfo, H., Creamer, L., & Gray, C. (2015). The 1994-1995 National Health Interview Survey on Disability (NHIS-D): A bibliography of 20 years of research. *Review on Disability Studies, 11*(2), 1-22.

Weitlauf, A. S., Vehorn, A. C., Taylor, J. L., & Warren, Z. E. (2014). Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism*, *18*(2), 194-198. doi: 10.1177/1362361312458039

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*(3), 181-190. doi: 10.1111/j.1468-3148.2004.00197.x

Wiltshire, J., Cronin, K., Sarto, G. E., & Brown, R. (2006). Self-advocacy during the medical encounter: use of health information and racial/ethnic differences. *Medical care*, *44*(2), 100-109. doi: 10.1097/01.mlr.0000196975.52557.b7

Witt, W. P., Kasper, J. D., & Riley, A. W. (2003). Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination. *Health services research*, *38*(6), 1441-1466.

Wood, D. (2003). Effect of child and family poverty on child health in the United States. *Pediatrics*, *112*(Supplement 3), 707-711.

Van Cleave, J., & Davis, M. M. (2006). Bullying and peer victimization among children with special health care needs. *Pediatrics*, *118*(4), 1212-1219. doi: 10.1542/peds.2005-3034

Van Dyck, P. C., Kogan, M. D., McPherson, M. G., Weissman, G. R., & Newacheck, P. W. (2004). Prevalence and characteristics of children with special health care needs. *Archives of pediatrics & adolescent medicine*, *158*(9), 884-890. doi: 10.1001/archpedi.158.9.884

Vaux, A. (1988). *Social support: Theory, research, and intervention*. New York, NY: Praeger Publishing.

Vrijmoet-Wiersma, C. M. J., Egeler, R. M., Koopman, H. M., Bresters, D., Norberg, A.

L., & Grootenhuis, M. A. (2010). Parental stress and perceived vulnerability at 5 and 10 years after pediatric SCT. *Bone Marrow Transplantation*, *45*(6), 1102-1108. doi:10.1038/bmt.2009.309.

Vrijmoet-Wiersma, C. M. J., Hoekstra-Weebers, J. M., de Peinder, W., Koopman, H. M., Tissing, W. E., Treffers, P. A., Bierings, M. B., Jansen, N. C. A., Grootenhuis, M. A., & Egeler, R. (2010). Psychometric qualities of the Dutch version of the Pediatric Inventory for Parents (PIP): A multi-center study. *Psycho-Oncology*, *19*(4), 368-375. doi:10.1002/pon.1571.

Vrijmoet-Wiersma, C. M. J., Ottenkamp, J., van Roozendaal, M., Grootenhuis, M. A., & Koopman, H. M. (2009). A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease. *Cardiology in the Young, 19*, 608-614. doi:10.1017/S1047951109991831.