Family Stress and Early Intervention for Families of Infants and Toddlers
With Complex Medical Needs

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ABSTRACT

Advances in medical technology have enabled children to survive with conditions that were once considered fatal; however, with their increased life expectancy these children may also experience chronic illnesses or severe disabilities. Part C early intervention is a home-based program that provides support for families of children aged 0-3 years with disabilities, with the purpose of assisting families in minimizing adverse effects of the child’s condition, and maximizing the child’s development. This mixed methods study was guided by the question: What do parents of children ages 0-3 with complex medical needs say about the relationship between early intervention services and parental levels of stress? Five follow-up questions addressed the change in the participants’ stress levels after 6 months of early intervention service, satisfaction with early intervention services, and additional supports available to the family. Participants included eight biological parents and one grandparent who were caring for a child with complex medical needs who were newly enrolled in early intervention services. Participants were given the Parenting Stress Index/Short Form (PSI/SF) at intake and again 6 months later. Paired samples t-tests were conducted for Total Stress and each of the subscales (PD, P-CDI, and DC). Semi-structured interviews, guided by the Family Support Scale (FSS) were conducted to determine additional supports. Results indicated a decrease in Total Stress scores and on two of the three subscales. Parents indicated an improvement in the child’s condition, access to information, and increased support and communication helped to reduce their overall stress levels. Findings indicate the need for further research including: the relationship between family stress and early intervention services, boundary ambiguity, and connection.
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DEDICATION

This work is dedicated to

a remarkable little girl named Sophia

and her loving family.
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Family Stress and Early Intervention for Families with Infants and Toddlers
With Complex Medical Needs

CHAPTER 1 – INTRODUCTION TO THE PROBLEM

Introduction

The Child and Adolescent Health Measurement Initiative (2012) identified an increasing prevalence of children with special health care needs (CSHCN). In 2001, 12.8% of children in the United States under the age of 18 were identified as CSHCN. By 2009-2010, the percentage had grown to 15.1% (Child Trends, 2012). In 2009-2010, children aged 0–5 comprised 20.8% of the CSHCN population nationwide; in the state in which this study was conducted, 18.8% of the population was identified as CSHCN (Child and Adolescent Health Management Initiative, 2012). Many of these children have complex medical needs and are eligible to receive Part C early intervention services.

Early intervention is a term used to describe services provided to children birth to 3 years of age who have developmental delays or are at risk for delays (Blann, 2005). Depending on the needs of the child and family, several therapists may be involved in the child’s care. As part of early intervention, each family is assigned a service coordinator who is responsible for overseeing the delivery of services (Blann, 2005). Early intervention is a federally funded program, currently being administered as Part C of the Individuals with Disabilities Education Act (IDEA, 2004; Blann, 2005).

Research indicates that having a child with special needs is stressful for parents (Hassall, Rose, & McDonald, 2005; Pelchat & Lefebvre, 2004). Research on grandparents raising children with special needs also indicates increased stress (Janicki,
The additional complications associated with a child who has complex medical needs increases parental stress (Enrione, Thomlinson, & Rubin, 2005; Hung, Wu, & Yeh, 2004; Wilson, Morse, & Penrod, 1998). Children with complex medical needs have been identified by many different terms. They have been referred to as technology-assisted (Odom & Chandler, 1990), technology-dependent (Heaton, Noyes, Sloper, & Shah, 2005), ventilator-assisted (Kuster & Badr, 2006), ventilator-dependent (Capen & Dedlow, 1998), children with complex health care needs (Townsley, Watson, & Abbott, 2004), children with special health needs (McIntosh & Runciman, 2008), children with chronic health conditions (Teague et al., 1993), terminally ill (Steele, 2002), chronically ill (Berge & Holm, 2007), and medically fragile (Kuster & Merkle, 2004). For the purpose of this study, the term complex medical needs is defined as an unstable life-threatening physical condition requiring involvement of a doctor, nurse, or other appropriately trained personnel (Müller, 2005) and/or need for medical interventions or assistive technology to support or replace the loss of a bodily function including ventilation, intravenous drug therapy, oxygen therapy, artificial nutrition, catheterization, tracheotomy, and suction machines (Heaton et al., 2005).

Investigations into parental stress for children with complex medical needs who are receiving home care have centered mainly on the role of home nurses. While early interventionists seek direction in order to successfully help parents navigate the difficult time period from birth to age 3, there is a paucity of literature to guide them. Nolan, Young, Hebert, and Wilding (2005) identified “dealing with family reactions to having a medically fragile family member” as a topic of interest to 65% of service coordinators of
children with complex healthcare needs (p. 168). It is important to explore the relationship between parental stress and involvement in early intervention services to meet the needs of the families being served by early intervention, and to avoid adding an increased and unnecessary burden to their already stressful lives. The purpose of this study was to examine the relationship between stress experienced by parents of infants and toddlers with complex medical needs and their family participation in home-based Part C early intervention services.

**Background**

Advances in medicine and technology have enabled children to survive with conditions once considered fatal; however, with their increased life expectancy, these children may also experience chronic illnesses or severe disabilities and require a lifetime of care (Berge & Holm, 2007). Beginning in the 1980s, federal health care policies changed to promote cost savings (Kirk & Glendinning, 2004) and to increase quality of life for children with complex medical needs (Kirk, 1998). Arguments were made that caring for the child at home would create normalization for the family (Toly, Musil, & Carl, 2012) and give parents a greater sense of control over their child’s care (Kirk, 1998). Society has increasingly shifted away from institutional care for children with complex medical needs and families are now expected to care for these children at home (Capen & Dedlow, 1998). Most parents have no previous medical training, but they are providing a level of care that is often intensive and specialized (Kirk & Glendinning, 2004), and many of these children require increased care 24 hours a day (Heaton et al., 2005).
Research has suggested the physical stress, financial strain, fatigue, and social isolation (Ratliffe, Harrigan, Haey, Tse, & Olsen, 2002) associated with caring for these children can adversely impact a parent’s physical (Kuster & Merkle, 2004) and mental health (Patterson, Leonard, & Titus, 1992). Research on grandparents caring for children with special needs has also revealed negative effects on physical and mental health (Janicki et al., 2000). Parents seek support from professionals, but the development of appropriate services in the community has not kept pace with the increased demand (Kirk & Glendinning, 2004), and there is limited information to guide professionals in their work with this population (Steele, 2002). The role of Part C early intervention, as a developmental service, in the care of children with complex medical needs is virtually uncharted territory. While the literature addressing early intervention for children with complex medical needs is very sparse, the need is rising. Oser and Cohen (2003) stated that since the creation of federally funded early intervention, there has been a greater than six-fold increase in the number of infants and toddlers receiving services. According to the 2009-2010 National Survey of Children with Special Health Care Needs, only 27% of the CSHCN population ages 0–2 years were receiving early intervention services nationwide compared to 47.3 % in the state in which this study was conducted (Child and Adolescent Health Management Initiative, 2012). The National Survey of Children with Special Health Care Needs has further indicated that in 2009-2010, 25% of CSHCN had family members who have cut back and/or stopped working because of the child’s health needs (Child and Adolescent Health Management Initiative, 2012).
Help is necessary to care for the child who has complex medical needs; however, Toly et al. (2012) report strangers in the home may disrupt family routines and interfere with the family’s ability to normalize their situation. Parents of children with complex medical needs commonly identify role conflict (particularly with health care professionals) as a source of stress (Ratcliffe et al., 2002). Ideally, early intervention services would provide support for families of children with medical needs thereby helping to alleviate stress; however, in reality this may not always be the case. McDowell, Saylor, Taylor, Boyce, and Stokes (1995) specifically identified participation in early intervention services as a potential source of parental stress.

**The Role of Stress**

The role of stress in parenting a child with complex medical needs is well documented in the literature (Enrione et al., 2005). Caring for a child with complex medical needs has been associated with parental anxiety (Pelchat, Lefbvre, Proulx, & Reidy, 2004), distress (Carnevale, Alexander, Davis, Rennick, & Troini, 2006), poor mental health outcomes (Kuster & Badr, 2006), sleep disruption (Heaton, Noyes, Sloper, & Shah, 2006) post-traumatic stress disorder (Santacroce, 2003), depression, and chronic sorrow (Hobdell, 2004). Janicki et al. (2000) found that grandparents who were fulltime caregivers for children with disabilities also experienced disrupted sleep, physical challenges, and were at an increased risk for depression.

Specific stressors identified by parents of children with complex medical needs include financial strain (Capen & Dedlow, 1998; Kingston, 2007; Odom & Chandler, 1990), uncertainty over changes in the child’s health status (Kuster & Badr, 2006), worry
over their own competence to provide medical care (Valkenier, Hayes, & McElheran, 2002), fear that the child would die (Carnevale et al., 2005), continuous care demands (Kuster & Badr, 2006), social isolation (Carnevale et al., 2005; Enrione et al., 2005), fatigue due to sleep disruption (Heaton et al., 2005; Teague et al., 1993), and a lack of respite care (Odom & Chandler, 1990; Teague et al., 1993; Valkenier et al., 2002). Grandparents who were fulltime caregivers for children with disabilities reported similar concerns including fear that professionals would deem them incompetent to care for the child, difficulty accessing services, isolation due to caregiving demands (Janicki et al., 2000) and financial strain (Ross & Aday, 2006).

Along with caregiver stress, a number of issues specific to professional health care providers have been identified as sources of stress for parents of children with complex medical needs. These included the type and amount of home care provided (Kirk, 1998), poor staff communication and preparation (Latour et al., 2011), failure to listen to parents (Steele, 2002), lack of privacy (Kirk, Glendinning, & Callery, 2005; Lindahl & Lindblad, 2011), loss of parental control (Lindahl & Lindblad, 2011; O’Brien & Wegner, 2002), disruption of usual family routines (O’Brien & Wegner, 2002), role conflict (Kirk et al., 2005; Odom & Chandler, 1990; Ratliffe et al., 2002), judgments made by nurses about the family’s lifestyle (Kirk et al., 2005; O’Brien & Wegner, 2002), disorganized services or problems accessing services (Townsley et al., 2004), professional incompetence, and lack of trust (Steele, 2002). Difficulties in accessing both formal and informal supports exist in the research on grandparents as caregiver as well (Hayslip & Kaminski, 2005; Janicki et al., 2000). Many of the resources currently offered
to grandparents focus on legal issues, school systems, health care, and economic issues but do not assist the grandparent with the child’s development or relationships (Brintnall-Peterson, Poehlmann, Morgan, & Shlafer, 2009). According to Kresak, Gallagher, and Kelley (2014), grandmothers raising grandchildren with disabilities reported professional services as “only sometimes helpful” (p. 12).

While the body of research documenting parental stress for families of children with complex medical needs is expanding, the relationship between early intervention and parental stress has not been widely examined. There is a growing need to fill this gap in the literature. This study adds one piece to the puzzle that families and interventionists are now working together to solve.

**Research Questions**

This research was guided by the following question: What do parents of 0-3 year-old children with complex medical needs say about the relationship between early intervention and parental stress? Five follow-up questions were included to assist in further understanding the problem:

1. Do stress levels change after receiving 6 months of early intervention services?

2. Is there a relationship between the number of hours of early intervention services received and parental levels of stress?

3. How do various family members experience stress?

4. How do parents respond when asked about their satisfaction with the early intervention services provided to their child and family?

5. Are other supports available to the family?
**Study Design**

This study was conducted using the explanatory sequential design (Creswell, 2015), which is schematically represented in Figure 1. The explanatory sequential design is broken down into two distinct phases. The intent of the explanatory sequential design is to begin with the quantitative component of the study and then use the qualitative portion of the study to explain the quantitative results (Creswell, 2015). The strength in using this design is that each phase builds upon the other (Creswell, 2015), and the qualitative questions help explain how the quantitative findings occurred.

![Figure 1. Explanatory Sequential Design (Creswell, 2015). Used with permission.](image)

Onwuegbuzie and Leech (2006) stated that research questions in mixed methods studies dictate the research design. Greene (2007) stated “a mixed methods way of thinking … respects and actively embraces multiple philosophical and theoretical stances on knowledge and legitimizes diverse claims to know” (p. 23). The guiding question for this study was purposely framed to include both qualitative and quantitative language. Perhaps due to small sample sizes, much of the available literature regarding families of children with complex medical needs is based on qualitative data. While it is vital to obtain lived experiences from parents in their own words through interviews, it is also important to study parental stress quantitatively using a reliable assessment instrument.
because many parents who are undergoing stressful situations may not articulate their problems or needs (Lessenberry & Rehfeldt, 2004). In this study, reviewing the results from the quantitative Parenting Stress Index (Abidin, 2012) provided an excellent starting point for qualitative interviews because it offered the family members an opportunity to identify and discuss their stress, a topic of great interest to them, before leading into questions about family support.

Conceptual Framework

The Contextual Model of Family Stress (Boss, 2002) was chosen as the conceptual framework to guide this study. The Contextual Model of Family Stress is an adaptation of the original Family Stress Theory (Hill, 1949), which has been used by theorists and teachers for more than 50 years in a wide variety of situations involving families (McCubbin & Patterson, 1983). Boundary ambiguity is an important concept in the Contextual Model of Family Stress, and is defined by Boss (2002) as “not knowing who is in and who is out of one’s family” (p. 95). This concept drew particular attention for its potential to create stress for families, thereby making it highly relevant to this study. The Contextual Model of Family Stress is explained further in Chapter 2.

Definition of Terms

Complex medical needs - An unstable life-threatening physical condition requiring involvement of a doctor, nurse, or other appropriately trained personnel (Müller, 2005) and/or need for medical interventions or assistive technology to support or replace the loss of a bodily function including ventilation, intravenous drug therapy,
oxygen therapy, artificial nutrition, catheterization, tracheotomy, and suction machines (Heaton et al., 2005).

Early intervention - A federally funded program, currently being administered as Part C of the Individuals with Disabilities Education Act (IDEA, 2004; Blann, 2005).

Family stress - An actual or perceived imbalance between a demand and resource capabilities (McCubbin & McCubbin, 1993).

Individual Family Service Plan (IFSP) - A legal document that specifies which services the child will receive, who will deliver them, how often, and in which setting (Blann, 2005).

Parental stress - Reactions to a stressful event, such as having a chronically ill child, including uncertainty, anxiety, depressive symptoms, and posttraumatic stress (PTS) (Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, & Egeler, 2008).

Resources - Emotional, social, and financial assistance provided by family, friends, and the community (Sands & Goldberg-Glen, 2000).

Social support - The degree to which various individuals, groups, and agencies have been helpful (Dunst, Jenkins, & Trivette, 1984).

Stressor - A life event that affects the family unit and either produces, or has the potential to produce, change in the family’s social system (McCubbin & McCubbin, 1993, p. 66).

**Summary**

The number of children with special health care needs is rising in this country (Child Trends, 2012). Consequently, the need for early intervention services is also rising
Among this population are children with complex medical needs. Caring for a child with complex health care needs is stressful for families (Enrione et al., 2005). Parents and grandparents seek support from professionals to assist in this caregiving role, but to date the information available to guide early intervention service providers on how to care for these children has not kept pace with the need (Steele, 2002). This study explored the relationship between early intervention and family stress with the purpose of guiding practice to avoid increased and unnecessary stress for families already confronted with a stressful parenting situation.
CHAPTER 2 – REVIEW OF THE LITERATURE

Introduction

A review of the literature was conducted to establish conceptual links between parental stress, the experience of having a child who has complex medical needs, and participation in early intervention services. Few studies combined all three of these variables (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; McDowell et al., 1995); however, the relationship between parental stress and having a child with complex medical needs is well documented (Pelchat et al., 2004; Carnevale et al., 2006). The following section outlines stressors that parents and grandparents of children with complex medical needs must manage, paying particular attention to those stressors that involve a relationship with health care professionals. First, the Contextual Model of Family Stress (Boss, 2002) is introduced and discussed as a conceptual framework to guide this study. The role of parents and grandparents as caregivers for the child who has complex medical needs is also examined. Differences in how mothers, fathers, and grandparents cope are explored. The role of support in the form of family, spouse/partner, informal kinship, social organizations, and professional services (Cooley, 1994; Dunst et al., 1984) as a buffer against stress is explored. Finally, early intervention is introduced and described.

Conceptual Framework

The conceptual framework supporting this research was the Contextual Model of Family Stress (Boss, 2002). A visual representation of this model is presented in Figure 2. The Contextual Model of Family Stress is an adaptation of the original Family
Stress Theory, developed by Reuben Hill in 1949 as a framework for studying families separated by war (Hill, 1949). In the original theory, three variables were used to determine whether or not an event would become a crisis for a family. The event itself (1), interacting with the resources of the family (2), and the meaning the family made of the event (3), all worked together to determine whether the family would treat the event as though it were a threat (Hill, 1949). By 1958, the theory had evolved slightly and the three original variables had been renamed A, B, and C, while the crisis event was referred to as X (Boss, 2002). Hill’s ABC-X model of family stress has been used by theorists and researchers for more than 50 years in a wide variety of situations involving families (McCubbin & Patterson, 1983).

**Contextual Model**

The Contextual Model of Family Stress is an adaptation of the original ABC-X model in which the four components have moved from a linear to a circular framework, and two additional layers representing internal and external contexts form rings that surround the family core. The ABC elements have remained intact in the contextual model; however, the X was split in two parts. One half of the X was labeled stress and the other was labeled crisis. Within the stress portion, the left side indicated low stress while the right side, which was situated closer to the crisis “breaking” point, indicated high stress.

The external context ring is the outermost layer of the model. It is comprised of components over which the family has no control. It includes elements of the environment in which the family is embedded such as history, culture, economics, and
The purpose of the external context ring is to identify “the time and place in which a particular family finds itself” (Boss, 2002, p. 40).

The internal context lies just inside the external context ring, between the external context and the family core. The internal context ring consists of elements over which the family does have control and can change. It is comprised of structural, psychological, and philosophical dimensions that include the family’s boundaries, values, beliefs, and perceptions. The purpose of the internal context ring is to help “understand and assess what that family is experiencing and what changes are possible” (Boss, 2002, p.46).

Figure 2. Contextual Model of Family Stress (Boss, 2002). Used with permission.

**Stress.** Within the Contextual Model of Family Stress, the word stress is defined simply as change (Boss, 2002). The two words, stress and change, may be used interchangeably. Stress is not assigned a value such as good or bad; it is simply an event.
Families may experience stress in a wide variety of ways ranging from mild to drastic, but whether the stress elevates to crisis status is left for the family to determine. How the family does this is based upon other elements in the theory such as internal and external contexts.

Boss (2002) developed a system for classifying stressors according to: (a) source (internal vs. external); (b) type (normative vs. catastrophic, developmental vs. situational, predictable vs. unexpected, ambiguous vs. clear, volitional vs. non-volitional); (c) duration (chronic vs. acute); and (d) density (cumulative vs. isolated). She believed the type of stress experienced by a family was highly correlated to how well the family handled the situation and how likely or unlikely a family would escalate into crisis. The stress of having a child with complex medical needs would be classified as internal (coming from within the family), catastrophic (not foreseen), ambiguous (facts about the situation may remain unclear), non-volitional (not freely chosen), chronic (lasting over a long period of time), and cumulative (with numerous stressors piled up over time).

**Boundary Ambiguity.** The concept of boundary ambiguity is unique to the Contextual Model of Family Stress. Boundary ambiguity is defined as “not knowing who is in and who is out of one’s family” (Boss, 2002, p. 95) and is “an outcome of an incongruence between physical and psychological presence in the family” (Boss, 2002, p.95). Boundary ambiguity is an important concept because of its potential to create stress for families.

When families are living with a situation that creates ambiguous loss, defined by Boss (2002) as “ambiguity regarding a family member’s presence or absence in the
family system” (p. 94), it places families at high risk for boundary ambiguity. Boundary ambiguity falls within Category C in the Contextual Model of Family Stress. It is derived from the family’s interpretation or perception of ambiguous loss and is a risk factor for managing stressors poorly (Boss, 2002).

Berge and Holm (2007) defined two dimensions of boundary ambiguity. These were role ambiguity and membership ambiguity. These two dimensions were applied to the family with a chronically ill child and specifically defined. Role ambiguity referred to the internal family boundaries that defined who was responsible for what, while membership ambiguity referred to external boundaries that defined the difference between the family and the outside world.

Families with a child who has complex medical needs may experience boundary ambiguity in a number of ways. The child who has complex medical needs may require a number of external people coming into the home to provide necessary medical care. This intrusion into the family by health care providers may be one source of boundary ambiguity (Berge & Holm, 2007; Mu, Tomlinson, Huckabay, & Heims, 2009; Ratliffe et al., 2002). Similarly, parents caring for a child who has complex medical needs may be simultaneously fulfilling the roles of parent and nurse by providing medical care in the home. They may begin to wonder where one set of responsibilities begins and the other ends. Where such blurring occurs, it is possible for role ambiguity to exist (Berge & Holm, 2007).

Coping. How a family copes with stress is often tied to the family’s resources or strengths at the time of the crisis; however, the word coping does not exist in Hill’s
original ABC-X model (Boss, 2002). The concept of coping was introduced by McCubbin and others in 1979 (Boss, 2002). In the Contextual Model of Family Stress, coping is a systematic process that falls into Category B in the family core as well as the internal context ring. Boss (2002) is cautious to note that coping is a term used to define both adaptive and maladaptive individual and family behavior. With that in mind, she has defined “family coping” as:

… the process of managing a stressful event or situation by the family as a unit with no detrimental effects on any individual in that family. Family coping is a cognitive, affective, and behavioral process by which individuals and their family systems as a whole manage, rather than eradicate, stressful events or situations. (Boss, 2002, p. 79)

Families of children with complex medical needs display many different forms of coping. Much has been written about denial as a coping strategy (Bingham, Correa, & Huber, 2012). Families with a child who has complex medical needs may very well be in denial, particularly when they first learn of their child’s condition and are dealing with ambiguous loss. Boss (2002) stated that denial can be a healthy coping mechanism, providing a “type of respite ” (p. 129) for family members when the trauma is simply too much to manage. Conversely, Rehm and Bradley (2005) found that for parents whose children had both medically fragile status and developmental delays, denial was not an option “because the continuous and intensive caregiving required to sustain their children was a constant reminder to parents …” (p. 813).
Studies of families with children who have chronic illnesses (McCubbin, 1988; Young & McCubbin, 2002) have identified positive coping behaviors including communication with health care personnel and other parents, receiving support from extended family, and relying on support from their marital partner (Mu et al., 2009). Rehm and Bradley (2005) studied the concept of normalization for families with children who had both medically fragile status and developmental delays. They found that parents of these children sometimes reframed their experiences with their children as positives in their lives but did not consider those experiences normal, nor would they have chosen the experience if they did not have a child with these types of special needs. The object of an early intervention program is to assist in the development of the child, thereby potentially decreasing levels of parental stress (McDowell et al., 1995).

**Parental Stress**

Ratliffe et al. (2002) reviewed and analyzed literature pertaining to the stress experienced by families of children with complex medical needs. They were able to divide the stressors into four main themes: (a) role conflict, (b) financial burden, (c) care burden, and (d) independence/isolation. These four categories provide a broad base from which to examine current literature on the stress experienced by parents of children with complex medical needs.

**Role Conflict**

Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch (1995) used the term “caregiving career” (p. 16) to describe the evolving process of caring for an ill family member. Although Aneshensel et al. (1995) studied families caring for elderly people with
dementia, many of the concepts are applicable to parents proving in-home care for a child who has complex medical needs. Unlike an occupational career, parents do not place themselves in this role by choice and sometimes do not even know they are in it until they are well established. For most, the launching of their caregiving career was unexpected and unplanned. Unlike an occupational career choice, the direction and duration of the caregiving career is not decided by the parent but rather is driven by the medical needs of the child. Due to the informal nature of this work, parents are not afforded the same rights, privileges, and recognition as those who choose caregiving as a career (Aneshensel et al., 1995).

Parents who are caring for a child with complex medical needs may begin to wonder where the lines are drawn between being a parent and a nurse, because they may be simultaneously fulfilling both duties by providing medical care for their child in the home. Parents caring for a child who has complex medical needs in the home adopt a number of roles including financial planner, personnel manager, and respiratory, occupational, and physical therapist (Murphy, 1997). As parents increasingly shift into the role of health care provider, blurring between roles occurs (Berge & Holm, 2007) which may lead to conflicts regarding who is in charge of providing care for the child (Kingston, 2007), discipline, and scheduling (Capan & Dedlow, 1998). Family caregivers learn to manage the necessary medical equipment for their child before they leave the hospital, therefore they become the experts on their child’s care (Capan & Dedlow, 1998). While parents rely on support from health care professionals to help them manage the care of their child at home, the process of building a relationship with these
professionals is not always easy. Grandparents providing care for a child with disabilities fear that professionals will not see them as capable to care for the child (Janicki et al., 2000). An optimal relationship is based on mutual trust, and parents initially may be apprehensive about relinquishing control of their child’s care (McIntosh & Runciman, 2008). Kirk et al. (2005) stated that parents perceived professionals as not only lacking experiential knowledge about the child and family, but also not placing value on that form of knowledge. Information sharing is one area where the balance of power as the expert frequently shifts back and forth between parents and health care professionals, creating the potential for both increased partnership and elevated stress (McIntosh & Runciman, 2008).

Fighting to get appropriate services established for their child may place additional demands on parents’ (Valkenier et al., 2002) and grandparents’ (Janicki et al., 2000) limited time and energy. Parents resent the effort they must expend to coordinate and advocate for services for their child (Ray, 2002), and grandparents face anxiety as they attempt to access supports (Janicki et al., 2000). Steele (2002) found parents felt “they almost had to explode in rage before anyone would listen to them” (p. 423). Townsley et al. (2004) stated that many families were frustrated by limited access to services and duplication of assessments and reviews while trying to access services. In addition to their other duties, these parents felt they had to coordinate their child’s services in spite of having a named person assigned to this responsibility. Unfortunately, the type and amount of support services received by parents is variable and dependent on funding sources, often leaving parents to advocate for the services needed by their child.
and family (Kirk, 1998). Studies on grandparents raising grandchildren further identified regulatory hurdles such as difficulty in obtaining services due to ambiguous guardianship and legal situations as sources of stress (Janicki et al., 2000).

Parents often voiced concerns over the qualifications and competency of the professionals (mainly nurses) providing care for their child in the home (Capan & Dedlow, 1998; Kingston, 2007). Competence involves a mixture of technical skills, strong clinical reasoning, and communication skills, and is a prerequisite to trust (Steele, 2002). The potential for communication between parents and health care professionals to become a source of stress cannot be overstated. Latour et al. (2011) described communication as “an influencing factor for distress among parents” (p. 323). Parents may already be skeptical about receiving services because they feel no one can take care of their child the same way they can and therefore worry about leaving their child in someone else’s hands (Carnevale et al., 2005). A further concern leading to doubts about professional competence are reports of nurses falling asleep at night when they are supposed to be caring for the child (Kingston, 2007). Although these instances are not the norm, the fact that it does happen causes fear and stress for parents. In one extreme example of mistrust, a parent was quoted by Carnevale et al. (2005) as saying, “Right now, I’m fearful whenever they offer me services, because they’re always poisoned services” (p. e56).

Parents’ view of the home may change or be lost in the presence of various pieces of medical equipment (Ontonello et al., 2007) and health care providers (Capan & Dedlow, 1998). Parents report a feeling of invasion, lack of privacy (Capan & Dedlow,
1998), and a loss of parental control (Lindahl & Lindblad, 2011) caused by the presence of health care professionals in the home. Parents worry whether their parenting skills will come under scrutiny, about keeping up with their housekeeping, and about being unprepared when health care staff arrive if they are dressed too comfortably (Capan & Dedlow, 1998). Nurses agreed the medical equipment and need for trained caregivers in the home affected family experiences (O’Brien & Wegner, 2002).

**Financial Burden**

The relationship between financial strain and caregiver stress for families with a child who has complex medical needs is well documented in the literature (Teague et al., 1993; Vrijmoet-Wiersma et al., 2008). The cost of caring for a child with complex medical needs at home can be staggering and may remain hidden within families (Wang & Barnard, 2004). Patterson et al. (1992) found that family caregivers who reported more financial burden also experienced more physical illness. Parents reported paying for supplies, medical equipment, and care as a major source of family stress (Ratliffe et al., 2002). Heyman et al. (2004) translated the costs to families of children who were gastrostomy-tube (g-tube) dependent to those whose children were not and found the total annual cost to the family whose child is g-tube dependent was more than twice that of the family whose child was not. Many mothers have to leave work to care for their child with complex medical needs at a time when their family expenses are rising (Kirk, 1998); however, some parents rely on health insurance through their employers to access care for their child and may feel trapped in that situation (Capan & Dedlow, 1998). Costs may include nursing care, medications, equipment, transportation (Kingston, 2007), in-home
therapy, cleaning services, and increased heating and electrical bills (O’Brien, 2001). The process of understanding insurance policies and their restrictions, accessing coverage, and appealing inappropriate claim denials is time consuming, frustrating, and has been reported as a significant source of stress for parents (Capen & Dedlow, 1998).

**Care Burden**

Family relationships change as a result of having a child with special health care needs (Ray, 2002); however, Teague et al. (1993) reported 65% of caregivers indicated that “caring for their child was the best aspect of the situation in which they found themselves” (p. 231). While most parents are happy to have their children home and feel the benefits outweigh the problems of caring for their child with complex medical needs, some aspects of caregiving may negatively impact the entire family (Murphy, 1997). Greater caregiving burden is associated with increased physical illness for parents (Patterson et al., 1992) and grandparents (Janicki et al., 2000). How well a parent is able to perform the duties of caregiver for their child is dependent on several factors including, the family’s economics, environment, composition, control, available resources (Capen & Dedlow, 1998), and level of functioning, as well as the child’s status (Toly et al., 2012). Grandparents’ ability to care for the child with disabilities was closely correlated to availability of helpful sources of support, particularly informal supports (Kresak et al., 2014). According to Vrijmoet-Wiersma et al. (2008), parents of children with cancer who displayed the highest levels of strain at diagnosis continued to display high levels of strain even after their child’s treatment ended. Capen and Dedlow (1998) found a successful caregiver is one who is committed, demonstrates competence in the
care of the child, and has appropriate financial and community resources. The absence of any one of these can lead to stress and failure (Capen & Dedlow, 1998).

Due to the extraordinary demands placed on the family by the child with special health care needs, relationships with friends, partners, and extended family may become strained (Ray, 2002). Many families have additional children who also need attention (Caplan & Dedlow, 1998). Finding the time for family activities is difficult (O’Brien, 2001), and siblings may feel left out or less important to the parents than the child with medical needs (Murphy, 1997). Grandparents caring for grandchildren with disabilities similarly identified decreased participation in family events or activities due to the needs of the child with a disability (Kresak et al., 2014).

Having a child with a chronic illness is associated with higher divorce rates (Ray, 2002). According to O’Brien (2001), while most parents stressed the importance of maintaining a relationship with their partner, they also acknowledged their relationship had been affected by having a child with special health care needs. Ontonello et al. (2007) reported that some of the parents in their study had separated as a result of the psychological burden associated with caring for children who were ventilator-dependent. While parents of children with special health care needs were aware of their increased risk for divorce, some also felt the experience of co-parenting a child with a chronic illness had brought them closer as a couple (Ray, 2002). Ross and Aday (2006) studied African American grandparents raising their grandchildren and found that because married grandparents had to divide their time between a spouse and a grandchild, their stress loads were higher than those of unmarried grandparents.
Sleep disruption is commonly reported by parents of children with complex medical needs (Heaton et al., 2006) and grandparents of children with disabilities (Janicki et al., 2000). Sleep disruption may occur due to alarms going off and the need to administer medications or treatments during the night (Kirk & Glendinning, 2004). Some families felt the need to rearrange their sleep schedules and be constantly vigilant in case they needed to respond to their child at night (Heaton et al., 2006). Exhaustion was identified by parents as limiting their ability to work and socialize (Heaton et al., 2006) and contributing to heightened emotional responses (O’Brien & Wegner, 2002).

Every parent must learn to care for their child; however, basic care for an infant with complex medical needs is stress inducing. Odom and Chandler (1990) found the following:

… holding or bathing an infant who is attached to a ventilator or IV may require parents to make substantial and nontrivial adjustments other parents do not experience. Learning to feed an infant who requires a gastrostomy tube or who has had a tracheotomy will initially place greater and possibly stressful demands on parents. (p. 50)

Care for children with complex medical needs may include medication and feeding administration, tracheostomy care, tracheostomy-tube changes, suctioning, GT care, as well as equipment monitoring and troubleshooting (Kingston, 2007). Parents have reported their engagement in the caregiving routine is not done by choice, but rather becomes automatic because they simply have to do it. They have no alternative. They may not even realize how hard they are working until the workload changes or they have
another child who is healthy and by comparison easier to care for (Ray, 2002). Often parents reported the technical aspects of caregiving were the most difficult. Performing procedures that caused the child discomfort such as suctioning airways and giving injections was contrary to the nurturing and protective role parents wanted to fulfill, placing parents in great distress (Kirk, 1998; Wilson et al., 1998). Parents noted that while they were performing the same procedures as home nurses, they had different feelings about it. For parents there was no removal from the intensity and emotion that was part of everyday, routine care for the child. Parents expressed fears about harming their child during a procedure and the guilt that would cause them; therefore, they may have held themselves to higher standards of care than would be expected of others (Kirk et al., 2005).

**Independence/Isolation**

Caring for a child with complex medical needs can be socially isolating (Kirk, 1998). Lindahl and Linblad (2011) have identified a clear risk that the child, their siblings, and the parents may be confined to the home and this risk increases over time. Grandmothers raising grandchildren with disabilities are also at increased risk for social isolation (Kresak et al., 2014). Murphy (1997) reported that parents who do not regularly leave their home within the first 6 months after initiating home care tend to become increasingly isolated. This exclusion from society may arise from a number of different factors. Often, children with complex medical needs use large pieces of specialized equipment such as a ventilator, oxygen, batteries, suction machine, feeding pump, and wheelchair which may make it difficult to leave the home (Ratcliffe et al., 2002). Even if
the parent has a car, is able to drive, and can afford gas, some family vehicles are not adequate for transporting the child and his or her equipment (Capan & Dedlow, 1998). Grandparents identified transportation and physical demands (such as having to carry the child up and down many stairs) as barriers to accessing available services (Janicki et al., 2000).

As mentioned previously, sleep deprivation is associated with caring for a child with complex medical needs and can limit parents’ (Heaton et al., 2005) and grandparents’ (Janicki et al., 2000) ability to work and socialize. Preparing the child for an outing often constitutes a major expedition and parents may simply be too exhausted to leave home. When parents are not caring for their child, they may use these occasions to catch up on their sleep (Heaton et al., 2005).

Finding someone to care for the child with complex medical needs is a continuous problem for parents, and the need for respite care is well documented in the literature (Parra, 2003; Valkenier et al., 2002). Grandparents caring for children with disabilities reported never being able to leave the child with someone else (Janicki et al., 2000). Locating, training, and trusting a caregiver is a process that takes time. Parents of children with complex medical needs do not have the luxury of doing anything spontaneous outside their home. Everything must be meticulously planned (Ratliffe et al., 2002). Over time, support from friends and family may decrease (Ratliffe et al., 2002; Ray, 2002). For parents of children with special needs, the child’s grandparents may be too old to help with care for the child and may be in need of care themselves (Ray, 2002). Friends and family members may be fearful of the child’s condition and uncomfortable in
the child’s presence (Ray, 2002). Grandparents who are caregivers of children with disabilities report being shunned by their peers who are no longer in the caregiver role (Janicki et al., 2000). Parents of children who are fed home enteral nutrition stated their child’s limited ability to participate in recreational activities is a significant restraint (Enrione et al., 2005). When families do take their child in public, they often feel conspicuous due to the child’s appearance, vocalizations, behavior, or machinery and equipment. Parents are sensitive to the reactions their children receive, which may include being stared at, questioned, shunned, discriminated against, and given unequal treatment by others (Rehm & Bradley, 2005). Parents and grandparents find support from other parents helpful (O’Brien, 2001; Kresak et al., 2014); however, it is difficult to gain access to other families who share their experience, which leads to a strong sense of isolation (Ray, 2002; Kresak et al., 2014).

**Gender Differences**

Mothers and fathers may respond differently to various stressors associated with having a child with a chronic illness; however, as Latour et al. (2011) pointed out, in many of the studies on parental stress, fathers have either been underrepresented or not represented at all. Pinelli (2000) found conflicting information in the literature, with some studies reporting gender differences in coping, family functioning, and stress experienced by parents of a chronically ill child while others found no difference. Her study illustrated this conflict with results that showed similarities and differences between mothers and fathers. Knafl and Zoeller (2000) stated that parents were more alike than different in their responses to their child’s chronic illness.
Steele (2002) found that while both mothers and fathers were deeply affected by their child’s illness, mothers were more vocal and displayed more emotion than fathers, who tended to want action rather than talking. Latour et al. (2011) stated that fathers wanted honest information from health care professionals even when they did not know some of the answers, whereas mothers more often related honesty to certainty. Steele (2002) found that while both parents sought knowledge about their child’s illness, mothers required more information than fathers. Fathers asked questions for a certain length of time and then stopped, while mothers continued seeking answers. Two factors may have contributed to this situation. First, mothers took on the role of information gatherer and shared what they learned with their partner, thereby reducing the need for fathers to investigate. Second, a number of children in Steele’s (2002) study had diseases that were transferred through maternal genes. These mothers were often guilt ridden and driven by an interest in the genetic aspects of the illness (Steele, 2002).

The intensity of a parent’s role in management of the child’s illness was sometimes a source of stress. Mothers reported stress related to the work of managing the child’s illness and the impact it was having on the family (Knafl & Deatrick, 2002) and experienced higher levels of anxiety than fathers (Pinelli, 2000). Grandmothers similarly reported higher caregiver stress than grandfathers (Ross & Aday, 2006). Knafl and Zoeller (2000) discovered that within families, parents typically had a shared view of the impact of a seriously ill child on their family; however, when there were differences it was the mother who emphasized the negative aspects of the chronic illness. Steele (2002) found that mothers tended to be more firm in the medication and feeding schedule than
fathers. Even when given permission by professionals to be somewhat flexible, mothers tended to adhere to the regimen, and this became a source of conflict and stress for fathers (Steele, 2002).

While both mothers and fathers acknowledged the need to care for themselves in order to care for their child, parents overall tended to neglect their own needs (Steele, 2002). Grandparents also reported focusing more attention on their grandchildren’s needs than on themselves (Janicki et al., 2000). Mothers, in particular, placed the needs of others above their own, perhaps because fathers were more likely than mothers to incorporate needs such as exercise into their daily routines (Steele, 2002). Ross and Aday (2006) reported that married custodial grandmothers did not receive much support from their spouses. Lee, Miles, and Holditch-Davis (2005) found that fathers’ support of mothers with an infant who has complex medical needs decreased over time. In addition, these researchers found that mothers of female infants received more support than mothers of male infants. One reason may be the loss of a traditional father-son relationship created a need for fathers to withdraw from the situation in order to cope (Lee et al., 2005). Fathers reported supporting mothers in caring for their ill child; however, they did not want the illness to become the entire focus of family life (Knafl & Deatrick, 2002). Clark and Miles (1999) found that fathers felt they needed to remain in control and be strong in order to support mothers. These fathers achieved control by working and keeping up with routines; therefore, they hid their own emotional distress and feelings of helplessness (Clark & Miles, 1999). Carnevale et al. (2005) reported more mothers than fathers sought kinship with other families living with a similar experience.
Grandparents

According to a report by the U.S. Census Bureau (2014) grandparents raising grandchildren is a growing trend in the United States. In 1970, about 3% of children lived in grandparent maintained households but by 2012 the percentage had grown to 6%. In 2012, 20% of children living with a grandparent had no parent present (U.S. Census Bureau, 2014). In the state in which this study was conducted, 4,691 grandparents were living with grandchildren, and of these households 5.6% had no parent in the home (AARP, 2014). Grandparents become the primary caregivers for their grandchildren due to a number of different circumstances, including neglect related to parental substance abuse, abandonment, emotional and physical abuse, parental death, mental and physical illness, incarceration, teen pregnancy, and parents’ work/school schedule (Ross & Aday, 2006).

Grandparents who are raising their grandchildren often experience stress related to fulfilling the parental role (Ross & Aday, 2006). Grandparents whose grandchildren have special needs may experience greater levels of stress and report less satisfaction with family quality of life than grandparents raising grandchildren without disabilities (Kresak et al., 2014). Although much of the available literature has focused on increased stress in grandparents who have assumed the parental role (Kresak et al., 2014; Ross & Aday, 2006), Harrison, Richman, and Vittimberga (2000) compared parental stress in grandparents versus parents raising children with behavioral problems and found grandparents reported lower levels of stress than either single parents or married parents.
Sources of stress for grandparents raising children with disabilities are similar to those reported in the literature for parents of children with special needs. They include caregiving challenges and strains, increased financial demands (Ross & Aday, 2006), social isolation (Kresak et al., 2014), an absence of needed supports (Janicki et al., 2000) or obstacles in accessing supports such as medical and legal services (Hayslip & Kaminski, 2005), and a concern over their own ability to care for the child (Ross & Aday, 2006). Research suggests when grandparents lack adequate support, their stress levels are high (Ross & Aday, 2006; Sands & Goldberg-Glen, 2000).

The Role of Support

Social support as a buffer against stress has received much attention and has been negatively correlated with illness and family care strain for parents of children with complex medical needs (Kuster & Badr, 2006; Tak & McCubbin, 2002; Teague et al., 1993). Cooley (1994) looked at social support as a “community-based, family centered system” (p. 118) that included three subsystems: natural supports, informal supports, and formal supports. Families caring for a child with complex medical needs may require support from all three levels, but each family’s need for support may be different (Cooley, 1994). These three categories will provide a broad base from which to examine current literature on the sources of support available to families of children with complex medical needs.

Natural Supports

Natural supports include people in or close to the immediate family circle such as spouses, extended family members, friends, neighbors, and church members (Cooley,
Although these relationships were considered by Cooley as the family’s first and most important line of defense, they were also the most vulnerable to being disrupted or usurped by formal support systems (Cooley, 1994). One of the obstacles to receiving help from family and friends was that parents may not have known or had the energy to specifically explain what they needed (Ray, 2002).

The majority of parents recognize the importance of maintaining the quality of their spousal relationship although finding the time and energy to do so is difficult (O’Brien, 2001). Parents in a study by Heims et al. (1997) reported they looked to their partners as best friends and the strongest of all support systems to get them through their child’s health crisis. This mutual dependence served to provide an alliance that was sometimes needed to confront the health care system (Heims et al., 1997). Support manifested itself in various ways. Some fathers felt it was their role to be strong in order to support mothers (Clark & Miles, 1999), others offered support by praising the mother’s involvement with the child (Knafl & Deatrick, 2002), and still others tended to show support and comfort by avoiding talk, thereby respecting the other’s independence (Steele, 2002). It was not uncommon for friends and extended family members to rally around the parents of a child with complex medical needs in the acute phase of an illness and drift away over time (Ray, 2002). Lee et al. (2005) also found mothers perceived less support from fathers over time, particularly if the infant with complex medical needs was a boy.
Informal Supports

Informal support is the term Cooley (1994) used to describe support systems “specific to the issue of caregiving for a family member with a disability” (p. 118). These are important resources that may help the family feel less isolated. These supports include chance meetings with other families who have lived the same experience, support groups, informal networking, and formal parent-to-parent programs (Cooley, 1994). O’Brien (2001) identified the relationship with other parents who had children with similar needs as helpful to combat feelings of isolation and important sources of information on the latest treatments, health care providers, and strategies for coping; however, within the same family the need for informal support may vary. Grandparents raising a child with a disability who had access to informal support reported increased satisfaction with quality of life (Kresak et al., 2014). Patterson et al. (1992) reported that informal support contributed to caregiver health but only modestly. Ray (2002) found a longing for contact with an informal support network was more common among mothers than fathers. Only one father in Ray’s study stated an interest in meeting a family living with a similar experience. O’Brien (2001) identified four barriers to parents being able to attend support groups: time of day the meetings were held, child’s health status, lack of child care for either the ill child or siblings, and difficulty transporting the child to meetings. A lack of respite care was also identified as a barrier for custodial grandparents to attend support groups (Janicki et al., 2000).
Formal Supports

According to Cooley (1994), formal supports are the layer of support most removed from the family circle and should be only one part of a continuum of services for the family. Cooley (1994) identified financial and health insurance benefits, service coordination, early intervention programs, respite care, and other state-supported services as being formal supports. Cooley (1994) warned parents against relying too heavily on formal supports, saying, “Families who are surrounded by empty rings of natural and informal support and have only formal supports are destined to remain dependent on those formal supports and are at high risk for social isolation and demoralization” (p. 118). Pelchat and Lefebvre (2004) similarly advised that nurses should encourage parents “not to exclude any source of potential support” (p. 128).

A number of studies have indicated the type and amount of support services parents receive at home are variable, can be fragmented, and are largely dependent on how the services are funded (Kirk, 1998; Noyes, Hartmann, Samuels, & Southall, 1999). In addition, grandparents raising grandchildren may encounter difficulty receiving services due to their guardianship status (Janicki et al., 2000). McDowell et al. (1995) reported that early intervention participants who perceived an increase in support and resources experienced a reduction in parental stress. Similarly, Sands and Goldberg-Glen (2000) reported a negative correlation between receipt of community services and stress for grandparents raising grandchildren. Patterson et al. (1992) reported increased nursing hours as a protective factor for families over informal supports. Margalit & Kleitman
(2007) correlated the support and empowerment received from professionals with decreased levels of stress.

McIntosh and Runciman (2008) explored partnerships between families and professionals and found that trusting relationships with parents were built on critical listening, respect, and empathizing with parents and children. Similarly, Enrione et al. (2005) stated that support services need to be a collaborative team effort, and professionals must understand the caregivers’ experience to offer appropriate support services to meet their needs. Parents are reassured when they feel that health care professionals are accessible, know their child and family, and value their expertise (Kirk & Glendinning, 2004).

**Early Intervention**

Early Intervention is a federally funded program, currently being administered as Part C of the Individuals with Disabilities Education Act (IDEA, 2004; Blann, 2005). Part C early intervention is a discretionary program in that individual states can choose whether to participate. Presently, all states and eligible territories are offering Part C services including the state in which this study was conducted (Oser & Cohen, 2003).

The primary purpose of early intervention services is to assist parents in minimizing adverse effects of the child’s condition (Jones, 2009) and maximizing the child’s development (Oser & Cohen, 2003). Depending on the needs of the child and family, services may include occupational therapy, physical therapy, speech therapy, special education, vision therapy, deaf education, nutrition, and social work (Nolan et al., 2005). Early intervention programs also offer guidance and support to the family
members caring for the child to address the family’s needs, priorities, and concerns. Services such as family training and counseling may be written into the Individualized Family Service Plan (IFSP) to assist parents with strategies that will further develop their competence in meeting the needs of their child. The service coordinator is responsible for directing family members to additional services in the community such as parent-focused groups, as necessary (Blann, 2005).

An IFSP is a legal document specifying which services the child and family will receive, who will deliver them, how often, and in which setting. The IFSP is reviewed every 6 months at a minimum, and rewritten every year until the child leaves the program (Blann, 2005). The focus of Part C early intervention is on the family and supporting caregivers to meet the needs of their child (Blann, 2005). In addition to identifying the services to be provided, the IFSP identifies the family’s concerns, priorities, and resources. Desired outcomes to address the family’s concerns are written into the plan along with specific goals to help the child and family reach those outcomes (Blann, 2005).

Parents are the experts on their own child, and although the child may receive multiple services through Part C early intervention, the family is ultimately responsible for carrying out the plan when therapists are not present (Crawford, 2002). The Individuals with Disabilities Education Act (IDEA) acknowledges the importance of family involvement and requires parents to be members of the multidisciplinary team during the process of determining eligibility for Part C early intervention services, provide informed consent for participation in services, and participate in developing
appropriate outcomes for the child (IDEA, 2004; Blann, 2005). The role of professionals in Part C early intervention is to assess, support, and monitor the child within the context of the family (Crawford, 2002), providing services that fit into their everyday routines, in a natural environment (Blann, 2004). For a child with complex medical needs, the most natural environment is typically the home (Toly et al., 2012).

Planning an intervention program for a child with complex medical needs may be a more complicated course than would be expected for a child whose medical needs are not a primary concern (Ahmann & Lipsi, 1991). Several factors must be considered including the child’s respiratory condition, neurologic status, tolerance for positioning and activity, and scheduling of medications and/or other treatments, as well as the effect of the medication on the child’s state and endurance (Ahmann & Lipsi, 1991). As part of early intervention, each family is assigned a service coordinator who is responsible for overseeing the delivery of services and ensuring the family has access to additional resources in the community as necessary (Blann, 2003). In the case of a child with complex medical needs, the service coordinator will need to obtain documentation of the child’s medical status and coordinate care among multiple providers (Ahmann & Lipsi, 1991).

**Summary**

A review of the literature combining parental stress, children with complex medical needs, and early intervention services has both confirmed an established link between parental stress and having a child with complex medical needs, and identified a gap with regard to participation in early intervention services. Specific stressors that
parents of children with complex medical needs must manage include role conflict, financial burden, care burden, and independence/isolation (Ratcliffe et al., 2002). Gender differences may contribute to parental stress, as mothers and fathers respond differently to various stressors associated with having a child with a chronic illness (Steele, 2002). Grandparents caring for children with special needs experience similar stressors, including caregiving challenges and strains, increased financial demands, and social isolation (Ross & Aday, 2006). Social support in the form of family, spouse/partner, informal kinship, social organizations, and professional services acts as an important buffer against stress (Cooley, 1994). While research has focused primarily on home nursing, Part C early intervention has the potential to provide support to parents of children with complex medical needs, thereby helping to alleviate stress (McDowell et al., 1995).

The Contextual Model of Family Stress offers a solid conceptual framework to support continued research (Boss, 2002). Boundary ambiguity, a concept unique to the Contextual Model of Family Stress (Boss, 2002) is important because of its potential to create stress for families. Families with a child who has complex medical needs may experience boundary ambiguity in a number of ways, including role conflict with professionals who provide services to their child in the home.
CHAPTER 3 – METHOD

Introduction

This mixed methods study was designed to explore the relationship between participation in early intervention services and stress levels for family members of children with complex medical needs. In this chapter, the explanatory sequential design (Creswell, 2015) used to study the problem is introduced, eligibility criteria for study participation are discussed, and the instruments used to measure stress and guide interviews with family members are introduced. Finally, procedures to analyze data from the instruments are discussed.

The Mixed Methods Research Paradigm

One definition of mixed methods research is “a type of research design in which the findings of quantitative and qualitative methods/approaches are integrated in order to gain a fuller understanding of the phenomenon under investigation” (Tashakkori & Newman, 2010, p. 514). Researchers have combined methods of data collection since the 1930s; however, in 1959 when Campbell and Fiske introduced a multitrait, multimethod approach researchers became interested in using multiple methods in a single study (Creswell, 2008). By the 1970s, the integration of research techniques within a single study was being described as a new style of research (Seiber, 1973). In recent years, mixed methods designs have gained popularity and are being used across disciplines (Simpson, 2011). Applications for mixed methods research include nursing, psychology, education, sociology, library and information science, information systems, and political
science (Terrell, 2012) to generate new theories or expand current ones, as well as to test theoretical understandings in a single study (Tashakkori & Newman, 2010).

Over the years, the term paradigm shifted from describing a specific source of data and a researcher’s conceptualization of a field of study to the researcher’s overarching epistemological view (Lederman & Lederman, 2013). Debates about the match between a researcher’s worldview and his or her methods of conducting research continued for decades (Creswell, 2008). Questions arose as to whether mixed methods research was even possible because methodology was so closely tied to paradigms; thus using mixed methods was linked to mixing paradigms (Creswell, 2011). From these “paradigm wars” (Terrell, 2012, p. 255), mixed methods studies emerged. Researchers are beginning to use multiple paradigms in a single study, perhaps employing different paradigms in different phases of the study, thereby linking paradigms to research design (Creswell, 2011). While some view mixed methods as a third paradigm along with qualitative and quantitative, arguments have been made against defining mixed methods as anything more than a combination of different types of data collection (Lederman & Lederman, 2013). Terrell (2012) identified mixed methods studies as products of the “pragmatist paradigm” (p. 256) while Lederman and Lederman (2013) suggested that combining research methods could be done for pragmatic reasons. Pragmatism places emphasis on the importance of research questions, the value of experiences, and the practical consequences of understanding real world phenomena (Creswell, 2011). Tashakkori and Newman (2010) contend mixed methods research is often based on the
premise that the research question dictates the method of inquiry rather than the paradigm.

It is now generally accepted in the scientific community that both qualitative and quantitative research methods have much to offer (Simpson, 2011). In fact, according to Terrell (2012) it is commonly believed in the social science world that no major problem should be studied exclusively with one research method, and many granting agencies now require a mixed methods approach (Simpson, 2011). Although there is a basic assumption that using a combination of qualitative and quantitative methods provides a better understanding of the problem than either method by itself (Creswell, 2008), several criteria must be met to justify using a mixed methods approach. A mixed methods study is appropriate when one type of data (either qualitative or quantitative) is not enough to answer a research question or address the complexity of a research problem. Mixed methods studies are not parallel strands of research. The two types of research, when seen as complimenting rather than competing with one another, have the potential to promote creativity and give insights that may not be gained from separate studies (Mengshoel, 2012). Each should build upon the other to extend, elaborate, or make better sense of the two data sets (Creswell, 2008). Such is the case in this study, where the stories from individual family members were needed to explain the results of the parental stress surveys. Application of the explanatory sequential design (Creswell, 2015), is schematically represented in Figure 3.
Figure 3. Application of the Explanatory Sequential Design (Creswell, 2015).

**Parameters of the Study**

**Setting**

This study was conducted in a metropolitan area in a western state. Participants were given the option to be interviewed in their homes or another setting of their choice. With two exceptions, one mother wished to meet for coffee at a local Starbucks, and another mother wished to meet at a local park, the participants were interviewed in their homes. All participants completed the pre and post parental stress measures within their homes.

**Participants**

Study participants consisted of a purposive sample of eight biological parents and one grandparent who met the definition of parent for the purposes of this study because she had legal guardianship and was acting in a parental role. All participants: (a) agreed to participate in the study, (b) were residing fulltime and were involved with care giving activities for a child aged 0-3 who met this study’s definition of having complex medical
needs, and (c) had been receiving Part C early intervention services for less than a month. Eligible participants were flagged for contact upon enrollment in early intervention services and contacted by a developmental specialist, who is a provider of Part C services and acts as the service coordinator. Recruitment continued for 6 months after the first participant was enrolled. Fifteen participants were originally enrolled in this study.

Between completion of the first and second stress survey, one couple moved out of state and three more participants were lost to contact because they did not return calls to complete the second stress survey. One grandmother completed both the first and second survey; however, she did not return calls to schedule an interview and was withdrawn from the study. The data from her stress surveys was not used in the statistical analysis because there was evidence of defensive responding and without an interview to explain those results her data could not be included.

**Enrollment Procedure**

The Research Integrity Office, Human Subjects Research and Institutional Review Board (IRB) approved all procedures involved in this study before they were implemented. When recruitment began five agencies in the area were providing Part C early intervention services; however, two were very small agencies that were not taking children with complex medical needs. A meeting was held with representatives from the three agencies serving children with complex medical needs to discuss the study, to engage their interest in recruiting participants, and to allow access to the Individual Family Service Plan (IFSP) of any family agreeing to participate. The process for entry into Part C services is multi-layered. Before the IFSP is written, the child is evaluated to
determine eligibility for services. To maintain confidentiality, upon eligibility in Part C early intervention services, and with permission from the qualifying agency, family members whose children met the medical criteria for eligibility in the study were approached by a developmental specialist regarding their willingness for future contact. Upon completion of their IFSP, the researcher placed a phone call to family members who agreed and asked them to participate in the study. Enrollment consisted of a brief meeting, no longer than 20 minutes unless the participant had questions, during which family members were given information about the study and asked to complete consent forms. In families where more than one family member was participating, each was asked to sign a research consent form before completing any research instruments. The Parental Stress Index-Short Form (PSI/SF; Abidin, 2012) was introduced at this time. Participants had the option of completing it then, or having it picked up at a later date. One father chose to complete the protocol outside the enrollment meeting. All other participants completed the first protocol during the enrollment meeting.

Upon completion of the second PSI/SF, as a token of appreciation for their time, families were given a bag of stress relief items such as herbal mint tea, dark chocolate, bath bubbles, and a stress ball. The bag included a list of community resources for families in stressful situations and flyers for financial resources available to families of children with disabilities. One bag was given to each household.

**Data Collection**

Following completion of the consent forms, participants were given a demographic survey concerning child and family characteristics (one per family), and
each individual was given the PSI/SF (Abidin, 2012). Upon enrollment, participants were informed they would be completing the PSI/SF twice (once at enrollment in the study and 6 months later), and may be asked to participate in one face-to-face interview.

The first 6 months of caring for a child with complex medical needs has been described by Murphy (1997) as critical. Parents in her study stated “it took four to six months to be able to comfortably leave the house, resume normal sexual activity with spouses and to generally resume other family and work-related activities without major anxiety” (p. 118). Ray further stated it was 6 months “before the technical aspects of care became the most taken-for-granted part of their child’s care” (p. 426). The role of time in the process of adapting to a child’s complex medical status has been well documented in the literature (Heims et al., 1997), and many studies have used a 6 month time frame to document changes in parental stress (McDowell et al., 1995; Pelchat et al., 2004). This study used a 6 month time frame to assess changes in stress levels based on timelines described in the literature.

**Instruments Used**

Due to the extraordinary demands placed on family members caring for a child with complex medical needs, the PSI/SF rather than the PSI/full-length test was used to measure parental stress and be respectful of the families’ time. The 36-item PSI/SF is a derivative of the PSI/full-length test. The PSI/SF generates a score for Total Stress and three subscales. A Total Stress score is used to assess the overall level of parenting stress. According to Abidin (2012), the Parental Distress (PD) subscale is used to assess “the level of stress a parent reports as a function of personal factors directly related to
parenting” (p. 3). Parental-Child Dysfunctional Interaction (P-CDI) subscale assesses “the extent to which the parent perceives the child as not meeting expectations and finds that interactions with the child are not reinforcing his or her parenting role” (Abidin, 2012, p. 3). Finally, the Difficult Child (DC) subscale “assesses the temperament or behavioral characteristics of the child that influence the parent-child relationship” (Abidin, 2012, p. 3).

The primary interpretive framework for the PSI/SF is percentiles. The normal range for scores is within the 16th to 84th percentiles. Scores in the 85th to 89th percentiles are considered high, and scores in the 90th percentile or higher are considered “clinically significant” (Abidin, 2012, p. 59). According to Abiden (2012), “Parents who obtain a Total Stress score in the 91st percentile or higher are experiencing clinical levels of stress. These individuals should be referred for closer diagnostic study and for professional assistance” (p. 60). The initial PSI/SF was not scored until completion of the second PSI/SF and families were offered a list of community resources for families in stressful situations as part of a stress relief bag they received as a token of appreciation for their time when they completed the second PSI/SF.

Use of the PSI/SF to measure stress for families with a child who has complex medical needs is documented in the literature (Hung et al., 2004), along with use of the PSI/SF to measure parental stress in grandparents (Ross & Aday, 2006). The PSI/SF has also been used to compare parental stress in grandparents versus parents (Harrison et al., 2000). Reliability for this assessment tool is reported at 0.90 for total stress (Abidin, 2012). Validity for the PSI/SF by itself does not exist at this time; however, because it is
a derivative of the full-length PSI, Abidin (2012) reported “it is likely that it will share in the validity of the full-length PSI” (p. 61).

The Family Support Scale (FSS; Dunst et al., 1984) is a 19-item self-report measure. Rather than producing a score or rating, for the purpose of this study the FSS was used to guide semi-structured interviews with family members to determine the support systems available to the family, which resulted in transcribed interview data. Wengraf (2001) defined an interview as “a research interview, designed for the purpose of improving knowledge” (p. 3) and stated semi-structured interviews must be particularly well prepared to be successful. The FSS was designed with the purpose of identifying sources of support for families of young children. This tool breaks support into five categories: kinship, spouse/partner support, informal support, programs/organizations, and professional services. These categories fall closely in line with natural supports, informal supports and formal supports (Cooley, 1994) as discussed in the literature review, making this tool a good fit to guide interviews with family members in this study. The FSS has been used to measure family support in studies of families with children with complex medical needs (Kuo, Robbins, Lyle, Barrett, Burns & Casey, 2013). Studies on parental stress in families of children with special needs have used the FSS along with the PSI/SF (Macias, Saylor & Spratt, 2007), and the FSS has been used to measure support for grandparents raising children with disabilities (Kresak et al., 2014).
**Research Questions**

This research was guided by the following question: What do parents of 0-3 year-old children with complex medical needs say about the relationship between early intervention and parental stress? Follow-up questions include:

1. Do stress levels change after receiving 6 months of early intervention services? To answer this question a paired samples t-test was conducted on Total Stress scores as measured by the PSI/SF taken at intake and again after 6 months of service. Paired samples t-tests were also conducted for each of the subscales (PD, P-CDI, and DC) as measured by the PSI/SF taken at intake and again after 6 months of service.

2. Is there a relationship between the number of hours of early intervention services received and parental levels of stress? To answer this question a Pearson product-moment correlation coefficient was conducted to look at the relationship of differences in stress scores as measured by the PSI/SF after 6 months of early intervention services and the number of hours of service on the families’ IFSP.

3. How do various family members experience stress? The results of the PSI/SF at enrollment in the study and 6 months later were scored after collection of the second PSI/SF. These results were shared with each participant and discussed as part of the semi-structured interviews to gain the participants’ perspective on the changes in their stress scores. The interview data were coded and categorized. These categories were compared to determine relevance to each other and compared to existing literature to determine whether similarities or differences existed in the stress experienced by mothers, fathers, and grandmothers.
4. How do family members respond when asked about their satisfaction with the early intervention services provided for their child and family? During the interviews, family members were asked about their satisfaction with each service on the child’s IFSP and about their experience with the program overall.

5. Are other supports available to the family? Using the FSS to guide semi-structured interviews, family members were asked questions about their access to resources from family and kin, spouse/partner support, informal support, programs/organizations, and professional services.

**Data Analysis**

Stress was measured using the PSI/SF (Abidin, 2012), which was administered to participants within one month of initiating early intervention services and 6 months later. A paired samples t-test was run on the Total Stress scores and each of the three subscales (PD, P-CDI, and DC) as measured by the PSI/SF given at enrollment and 6 months later to determine if there was a difference in the mean scores at intake and after receiving 6 months of early intervention services. Due to the population being studied, there was expected to be a small n. It was understood from the beginning of this study there was a good chance, due to the small population being studied, there may be a difference, but even with a large effect size it could be missed. Cohen’s d was used to calculate the effect size.

For each participant, a change score was calculated by subtracting the Total Stress score on the PSI/SF at 6 months from the Total Stress score on the PSI/SF at intake. Each score was transformed by adding the number 30 so all scores were
positive numbers. A Pearson product-moment correlation coefficient was calculated on these change scores as one variable and the number of hours of early intervention services the family was receiving per month as the other variable to look at the direction of this relationship.

Semi-structured research interviews were conducted using the FSS (Dunst et al., 1984) as a guide to determine the family’s support system. Additional questions were asked regarding the parent/grandparents’ satisfaction with each individual service listed on their IFSP (Bailey et al., 2004) and about their overall experience with the program. In families where more than one family member participated in the study, I followed Knafl and Zoeller’s (2000) recommendation to interview fathers and mothers separately to increase the opportunity for each family member to freely express his or her views.

With parental consent, interviews were audio recorded for transcription at a later date. These interviews were conducted in homes, a park, or coffee shop with parents and grandparents caring for children with complex medical needs. Consequently, a lot of background noise and interruptions existed during the interview due to the parents or grandparent having to attend to the child. Having the interviews audio taped and transcribed at a later date ensured the family members’ words were being fully captured. The audio recordings were transcribed by hand and yielded 171 typed pages.

Interview transcripts were analyzed by hand using the constant comparison method devised by Glaser and Strauss, in which interview data is coded and compared to
existing categories to determine relevance, then compared to other data within that
category to determine relationships between categories (Schwandt, 2007). As new
categories and relationships between categories were identified, these were compared to
the Contextual Model of Family Stress (Boss, 2002). To analyze interview data regarding
the families’ support systems, the qualitative comparative analysis method developed by
Charles Ragin in 1997 was employed. In this model a table is constructed in which all of
the variables appearing in the data are listed along with the corresponding participants
and situational variables (Leech & Onwuegbuzie, 2008). Comparisons are then made
within groups, and commonalities are combined. Eventually unnecessary variables are
identified and eliminated (Leech & Onwuegbuzie, 2008). According to Leech and
Onwuegbuzie (2008), this method of qualitative data analysis may be used to reanalyze
data collected by other researchers and to build theory. Although this study did not use
data collected by other researchers, it did employ the FSS (Dunst et al., 1984) as a tool to
guide semi-structured interviews and built upon the Contextual Model of Family Stress
(Boss, 2002) as a conceptual framework.

Trustworthiness, Credibility, and Dependability

Trustworthiness is a term originated by Yvonna Lincoln and Egon Guba in 1985
to describe a set of criteria, similar to the traditional criteria used to evaluate quantitative
procedures, which could be used to judge the scientific quality of a qualitative research
study. The term trustworthiness was defined as “that quality of an investigation (and its
findings) that made it noteworthy to audiences” (Schwandt, 2007). Credibility and
dependability are two of the criteria Lincoln and Guba developed. Later criteria began to
involve and emphasize the role of the researcher (Lichtman, 2013). Trustworthiness was established in this study through credibility, dependability, and transparency of the researcher’s role.

Credibility, parallel to internal validity in quantitative research, ensures a good fit between a participant’s view of their experiences and the researcher’s representation of these views (Schwandt, 2007). Credibility was established in this study through multiple contacts with each family and through a process known as member checking. Once the interviews were transcribed, each participant was given a copy of their interview for review. Each participant was asked about quotes that would be used as data to ensure what they said was indeed being analyzed and interpreted correctly by the researcher.

Dependability, parallel to reliability in quantitative research, refers to measures the researcher takes to ensure the research process was logical, traceable, and documented (Schwandt, 2007). Several procedures helped establish dependability in this study. Each interview was audio taped and transcribed verbatim. A member of my research committee initially read one-third of the interview transcriptions and coded them independently. She later read all the transcriptions to compare existing themes and search for new categories. Meetings were held every two weeks during the qualitative analysis phase to discuss findings and ensure agreement in our understanding of the data. As each new concept emerged from the interviews, it was compared to the Contextual Model of Family Stress (Boss, 2002), which was chosen to provide this study’s structural framework. Finally, a table was constructed, which delineated the categories along with
the corresponding participants and situational variables for comparison with the Contextual Model of Family Stress (Boss, 2002).

**Researcher’s Role**

One criticism of qualitative research is researcher bias. Several definitions of this type of bias exist. Bias has been described by Schwandt (2007) as “individual preferences, predispositions, or predilections that prevent neutrality or objectivity” (p. 20) and by Lichtman (2013) as “a preference that inhibits impartial judgment” (p. 21). Striving to obtain objectivity or impartial judgment is not necessarily seen as important, or even desirable, in qualitative research where the role of the researcher is considered vital to the process (Litchman, 2013). In this mixed methods study it was important to identify and define my role as a researcher for several reasons, but primarily because transparency of my role as researcher was a significant factor in establishing this study’s trustworthiness.

I have worked in the field of early childhood since graduating with an associate degree in Early Childhood Education in May, 1989. In Canada, where I was born, raised, and educated, integration of children with special needs into classrooms and child care settings was the norm. As a child care teacher for many years, I had children with varying needs in my classroom among their peers with typical development. When I moved to the USA in October, 2000, I was unable to work for several years due to my immigration status, so I returned to school. In December, 2005, I completed a Bachelor of Science in Early Childhood Education. In December, 2007, I earned a Master’s of Education in
Early Childhood Special Education. Along the way my love for children with special needs grew and strengthened.

Upon graduating with my Master’s degree, I began work as a developmental specialist with the state’s Part C early intervention services. In this setting I was able to put my years of training into practice; however, it soon became very clear to me there was much I did not know. In 2008 I met a child who would change my life forever. Sophia had complex medical needs. She had a tracheotomy tube, which had to be suctioned frequently, and was fed by a gastronomy tube attached to a continuous pump. She was also classified as deaf-blind. Through my work with Sophia and her family I was introduced to a program that works with children who have dual sensory impairments, and I attended my first Western Regional Early Intervention Conference. During this conference I was exposed to new ideas I could use to work with Sophia and others like her, and found I had a passion for children with complex medical needs and/or sensory impairments. I returned from this conference with renewed enthusiasm and determination I would put these new-found tools to use. It was also in 2008, knowing I had much more to learn, that I enrolled in the doctoral program in Special Education and Disability Studies. My motivation for obtaining a PhD in special education was to gain knowledge that would help me do my job better. Having been a student in the doctoral program for several years, many things have changed. The motivation for completing this program has not been one of them.

As a developmental specialist, part of my job is to provide service coordination to the family members of children on my caseload. The more I have worked with families of
children with complex medical needs, the more I have discovered the importance of this role. As excited as I was about providing developmental services for the children on my caseload, I quickly realized if parents’ needs were not being met I could not expect great outcomes for the child. It was through a desire to meet the needs of these parents that I chose family stress and early intervention as the topic for my study.

Qualitative research requires the researcher to become the primary instrument in data collection and analysis. Qualitative data are filtered through the lens of the researcher based on his or her knowledge, skill, background experiences, and worldview (Lichtman, 2013). My background as a developmental specialist and passion for working with families of children with complex medical needs would naturally prohibit me from conducting this research from the perspective of an unbiased observer; however, for this study, and as a condition of my employment, several measures were put in place to reduce researcher bias. Efforts were made to involve families from outside the state’s early intervention services, where I worked, but no families from these community agencies participated in the study. Families who met this study’s qualifying criteria were not assigned to my caseload for the period of time from the beginning of recruitment until the end of data collection, thereby ensuring I would not enroll families in the study who were on my own caseload. Families were approached about the study by their developmental specialists and I was given their contact information only if they expressed an interest in participating in the study, and after their IFSP was written.

For the participants to honestly answer their stress surveys and feel comfortable participating in interviews it was necessary for me to develop a trusting relationship with
them. During our initial meeting I explained the study, disclosed I was a developmental specialist, and told them my purpose for this study, which was to gain information I hoped would help me do my job more effectively. Although it was not possible to remove all researcher bias from this study, measures such as member checking and discussing the interview data with a committee member were put into place to ensure my bias did not interfere with an accurate interpretation of the qualitative data.

Summary

This mixed methods study explored the relationship between participation in early intervention services and stress levels for family members of children with complex medical needs. The explanatory sequential design (Creswell, 2015), which was chosen to study the problem, includes both quantitative and qualitative phases, with each phase building upon the other. In this study the qualitative questions helped explain how the quantitative findings occurred.

Participants in this study included eight biological parents and one grandparent who met this study’s definition of parent because she had legal guardianship and was acting in the parental role for a child with complex medical needs. Five of the parents were mothers and three were fathers. All were residing fulltime and were involved with caregiving activities for a child aged 0-3 who met this study’s definition of complex medical needs and had been receiving Part C early intervention services for less than one month. The setting for this study was primarily the family home. Families were initially informed about the study by their developmental specialist and I was given their contact information if they expressed an interest in participating.
The instrument used to measure parental stress was the PSI/SF, which was given at enrollment in the study and 6 months later. Follow-up interviews were conducted to help explain the differences in PSI/SF scores. The FSS was used to guide semi-structured interview questions to determine which supports were available to the family in addition to early intervention services. Interview data was first transcribed by hand and coded using the constant comparison method. Data from the questions on family supports were transferred to a table and analyzed using the qualitative comparative analysis method.

Trustworthiness was established in this study through multiple contacts with participants, member checks to ensure participants’ views were accurately represented, and collaboration with a member of my committee to discuss data analysis. Because researcher bias can be an issue in qualitative research, transparency of my role as researcher was an important aspect of this study. In the following chapter I report the results of data analysis.
CHAPTER FOUR – FINDINGS

Introduction

Even under ideal conditions, parenting can be a stressful job. Research indicates that having a child with special needs increases parental stress (Hassall, Rose, & McDonald, 2005; Pelchat & Lefebvre, 2004) and that stress is even further increased when the child has complex medical needs (Enrione, Thomlinson, & Rubin, 2005; Hung, Wu, & Yeh, 2004). With support, parents’ stress levels can be managed or reduced. Support comes in a number of different forms, from many different sources, and is unique to each family. There may even be differences for individuals within families. What one person may find helpful and supportive, another may not. Thus it was important to hear from each participant what support looked like.

One source of support for families of children with complex medical needs is Part C early intervention. All participants in this study had infants or toddlers who were medically eligible and receiving services from early intervention under the Individuals with Disabilities Education Act. Part C early intervention is a comprehensive program with the primary purpose of assisting families in minimizing adverse effects of the child’s condition (Jones, 2009) and maximizing the child’s development (Oser & Cohen, 2003).

In this study, I examined the stress experienced by eight parents and one grandparent (who was acting in the parental role) of children with complex medical needs who had been enrolled in Part C early intervention services for less than a month. I used a mixed methods design that incorporated pre and post stress survey results along with
parent interviews to help explain those results. I investigated several means of support including those from family and kin, informal support systems, and formal support systems. The goal of this study was to examine the relationship between stress experienced by family members of infants and toddlers with complex medical needs and their participation in home-based Part C early intervention services.

In this chapter I report the findings of my data analysis. This research was guided by the following question: What do parents of 0-3 year-old children with complex medical needs say about the relationship between early intervention and parental stress? Follow-up questions included:

1. Do stress levels change after receiving 6 months of early intervention services?

2. Is there a relationship between the number of hours of early intervention services received and parental levels of stress?

3. How do various family members experience stress?

4. How do family members respond when asked about their satisfaction with the early intervention services provided for their child and family?

5. Are other supports available to the family?

Statistical analysis of the scores from the pre and post parental stress surveys was used to answer the first question. Although the second question was written to be answered quantitatively, the small number of participants made statistical significance impossible for this question; however, a Pearson product-moment correlation coefficient was run to show the direction of the relationship. The third, fourth, and fifth questions
were answered using data collected from semi-structured interviews with the family members.

The Contextual Model of Family Stress (Boss, 2002) was chosen to guide and inform this study. Analysis of the interview data revealed several categories not present in this model; thus, theory development became an important and ongoing part of qualitative data analysis. The Parental Stress Model for Families of Children with Complex Medical Needs Who Are Receiving Early Intervention (Young, 2015) contains some primary elements from the Contextual Model of Family Stress (Boss, 2002); however, during data analysis it continued to evolve to more fully represent these families’ stories.

**Participants**

Study participants were eight parents and one grandparent of children with medical disabilities. Of the eight parents, five were mothers and three were fathers. All were the children’s biological parents. One grandparent was included in the study because she had legal guardianship of two children receiving early intervention services and was acting in the parental role. All participants met the inclusionary criteria of caring for a child aged 0-3 who met the study’s definition of having complex medical needs, and had been receiving early intervention services for less than a month at the time of enrollment in the study. To maintain confidentiality participants were first approached about the study by their developmental specialists, who were providing direct early intervention services to the family. When the family members indicated their interest, I contacted them to provide additional information.
To protect the identity of study participants, no real names are used. Instead participants are referred to as Anne, Gordon, Antonia, Carlos, Becky, Gary, Diane, Jody, and Maggie. Their children’s names are also pseudonyms. Table 1 details participants’ demographic information.

Anne and Gordon are a Caucasian, married couple. Gordon works fulltime to support the family and Anne is a part-time student who stays home to care for their son who developed epilepsy as a result of a hypoxic-ischemic event (oxygen deprivation to the brain) shortly after he was born. The family began receiving early intervention services when Marcus was 1 month old. Marcus is Anne’s first child and was 3 months old at initial data collection. Gordon also has a 6 year-old son from a previous relationship who lives in the home.

Antonia and Carlos are a young, married couple of Latin descent. Carlos works fulltime to support the family, and Antonia stays home to care for their three children. At the time of initial data collection, their son, Carlito, was 3 months old. He was diagnosed with DiGeorge syndrome on his first day of life and had his first heart surgery at 1 month of age. Carlito has two older sisters, 3 and 5 years-old, living in the home. The family began receiving early intervention services when Carlito was approximately 2 months old.

Becky and Gary are a Caucasian, married couple. At the time of initial data collection Becky was on maternity leave from her fulltime teaching job and Gary was finishing up nursing school. Their daughter Rachel, the first child for both of them, was born with a cleft lip and palate, resulting in feeding issues and poor growth. She was only
4 weeks old when the family enrolled in the study and began receiving early intervention services when she was 19 days old.

Diane is a retired, married, grandmother of African American descent. Diane is the primary caregiver and legal guardian for her twin grandsons who were born with a chromosomal condition that causes an assortment of medical complications requiring heart surgery and supplemental oxygen for one child and gastrostomy tube placement for both. A gastrostomy tube, also commonly referred to as a g-tube, is a tube placed directly into the stomach through a small, surgical opening. This is used when children are not capable of safely managing their food orally. At the time of initial data collection the boys were 9 months old and were newly released from a hospital in a southern part of the state, about 8 hours drive from where the family lived. The family had been receiving early intervention services for seven days. The boys live with Diane and her husband along with an adult aunt and their 8 year-old sister who is also in Diane’s legal care. The mother has been deemed unable to care for her children due to an intellectual disability. The mother does not live in the home but sees the children regularly. This was the only family in the study receiving in-home nursing support. The nurse was providing services in the home 24 hours per week.

Jody is a Caucasian, married woman. Her husband works fulltime, and she stays home to care for their three children. At 4 months of age their youngest daughter Ashley was diagnosed with an atrial septal defect (ASD), a hole in the wall (septum) that separates the heart’s two upper chambers (atria). Ashley required heart surgery and experienced poor weight gain in her first year of life. Ashley was 10 months old at the
Table 1

Participant Demographics

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Education</th>
<th>Employment</th>
<th>Family Income</th>
<th>Child</th>
<th>Diagnosis</th>
<th># in Home</th>
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</thead>
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<td>18-25</td>
<td>Married</td>
<td>Some College</td>
<td>PT Student</td>
<td>20,000-35,000</td>
<td>Marcus</td>
<td>Epilepsy</td>
<td>4</td>
</tr>
<tr>
<td>Gordon</td>
<td>26-35</td>
<td>Married</td>
<td>Some College</td>
<td>Employed FT</td>
<td>20,000-35,000</td>
<td>Marcus</td>
<td>Epilepsy</td>
<td>4</td>
</tr>
<tr>
<td>Antonia</td>
<td>18-25</td>
<td>Married</td>
<td>High School</td>
<td>Unemployed</td>
<td>Under 20,000</td>
<td>Carlito</td>
<td>DiGeorge syndrome</td>
<td>5</td>
</tr>
<tr>
<td>Carlos</td>
<td>18-25</td>
<td>Married</td>
<td>High School</td>
<td>Employed FT</td>
<td>Under 20,000</td>
<td>Carlito</td>
<td>DiGeorge syndrome</td>
<td>5</td>
</tr>
<tr>
<td>Becky</td>
<td>26-35</td>
<td>Married</td>
<td>Advanced Degree College</td>
<td>Teacher</td>
<td>35,000-50,000</td>
<td>Rachel</td>
<td>Cleft lip &amp; palate</td>
<td>3</td>
</tr>
<tr>
<td>Gary</td>
<td>26-35</td>
<td>Married</td>
<td>College Graduate Some College</td>
<td>FT Student</td>
<td>35,000-50,000</td>
<td>Rachel</td>
<td>Cleft lip &amp; palate</td>
<td>3</td>
</tr>
<tr>
<td>Diane</td>
<td>&gt;45</td>
<td>Married</td>
<td>Some College</td>
<td>Retired</td>
<td>35,000-50,000</td>
<td>Twins</td>
<td>Chromosomal disorder</td>
<td>5</td>
</tr>
<tr>
<td>Jody</td>
<td>26-35</td>
<td>Married</td>
<td>Some College</td>
<td>Unemployed</td>
<td>20,000-35,000</td>
<td>Ashley</td>
<td>Atrial septal defect</td>
<td>5</td>
</tr>
<tr>
<td>Maggie</td>
<td>18-25</td>
<td>Single</td>
<td>High School</td>
<td>Unemployed</td>
<td>Under 20,000</td>
<td>Aiden</td>
<td>VACTERL</td>
<td>6</td>
</tr>
</tbody>
</table>
time of initial data collection, and the family had been receiving early intervention services for approximately three weeks.

Maggie is a Caucasian, single mother of two boys: a 7 month-old and a 3 year-old. She lives with her parents in a rural area approximately 30 minutes drive from the nearest major city and stays home with her children. During this study the boys’ father was in military training. Aiden, her youngest son, was born with VACTERL, an association of birth defects affecting multiple structures in the body with each letter representing the first letter of one of the more common findings seen in affected children. These include vertebral defects, anal atresia, cardiac defects, tracheo-esophageal abnormalities, renal (kidney) anomalies, and limb abnormalities (NORD, 2012). Aiden is reliant upon a g-tube for his nutrition, must be fed a prescription formula, and is on daily medications to control severe vomiting. At the time of initial data collection the family had been receiving early intervention services for 15 days.

Conceptual Framework

The Parental Stress Model for Families of Children with Complex Medical Needs Who Are Receiving Early Intervention

The Contextual Model of Family Stress (Boss, 2002) was originally chosen as the theory to guide this study because of the unique concept of boundary ambiguity and its potential to create role strain between service providers and parents. Shortly into data analysis it was discovered that while Family Stress Theory in general, and the Contextual Model of Family Stress (Boss, 2002) in particular, was a good fit for this study, it was not a perfect fit. Due to the very small population being studied, it was acknowledged that the
The qualitative portion of this study would carry a lot of weight when explaining the findings. Thus, theory development became an important component in this mixed methods study.

The data in this study focused on the event of having a child who has complex medical needs. The internal and external contexts surrounding the family, as illustrated in the Contextual Model of Family Stress (Boss, 2002), were not present in these data; therefore, the first analysis focused only on the A, B, C, and X portions of the model. Further analysis of the data revealed a problem with the model’s circular nature. These families were dealing with stress resulting directly from having a child with complex medical needs. This seemed to suggest more of a linear model: first A, then B, and so on.

Continued analysis of the data using the constant comparison method suggested that access to information, connection, and communication were critical components in determining whether a family was able to access resources and support or whether they continued to live with isolation and increased stress. As a result of this new information, the model was redrawn as a set of scales. The crisis event, being the child’s condition, stood as a pillar, with stress hanging in a basket on one side and resources and support on the other. Information, connection, communication, perception, and isolation were drawn as bars that would fall into either of the two baskets. With this vision I was closer to explaining the findings; however, information, connection, and communication did not neatly fall neatly into one side or the other, and isolation was more closely intertwined with stress than this model seemed to indicate, so further revisions were necessary.

Data analysis continued for a period of several months. When each new finding was revealed, it was categorized and checked against the existing model. Several rounds
of analysis took the model in new directions. Given the model’s goal was to help explain the findings of this study; rather than try to fit data into the existing model, the model continued to stretch and morph as the data expanded. The visual image of the scale created a clearer focus and was a breakthrough in explaining the initial findings from the qualitative interview data; however, the model underwent several more modifications before arriving in its current state.

The Parental Stress Model for Families of Children With Complex Medical Needs Who Are Receiving Early Intervention (Young, 2015) contains all the elements of its previous iterations; however, representation of the concept shifted from scales to a geyser effect. A visual representation of this model is displayed in Figure 4.

![The Parental Stress Model for Families of Children with Complex Medical Needs Who Are Receiving Early Intervention](image)

Figure 4. The Parental Stress Model for Families of Children with Complex Medical Needs Who Are Receiving Early Intervention (Young, 2015)
The event, being the child’s condition, caused an eruption in the family system. Access to information, connection, and communication were filtered through the families’ perceptions, resulting in either isolation and stress, or resources and support from a number of different systems. A change in any one of these components, particularly the child’s condition, may set the entire chain of events back in motion. Boundary ambiguity was seen to impact the families’ access to resources and support and was drawn as a bridge between family and formal support systems.

Along with the evolution of the conceptual framework, the data in this study were constantly being measured against the research questions to see if the questions were being answered. The first two follow-up questions fell under the quantitative portion of the study, while the third, fourth, and fifth follow-up questions were answered by qualitative interviews which occurred in the second phase of the study.

**Research Questions**

This research was guided by the following question: What do parents of 0-3 year-old children with complex medical needs say about the relationship between early intervention and parental stress? Follow-up questions included:

1. Do stress levels change after receiving 6 months of early intervention services?
2. Is there a relationship between the number of hours of early intervention services received and parental levels of stress?
3. How do various family members experience stress?
4. How do family members respond when asked about their satisfaction with the early intervention services provided for their child and family?
5. Are other supports available to the family?

Quantitative Findings

This mixed methods study employed the explanatory sequential design (Creswell, 2015). The study was completed in two phases. In the first phase, the PSI/SF was administered twice. Participants completed the PSI/SF at intake and 6 months later. Research questions one and two were designed to be answered using quantitative data collected from the PSI/SF scores. In this section I report the findings from my quantitative data analysis.

Degree of Stress

The degree of stress reported by family members in this study is presented in Tables 2, 3, and 4. The first research question sought to determine if a change in stress levels occurred after receiving 6 months of early intervention services. To determine if a change had occurred in participants’ stress levels, each participant was pre-tested within one month of receiving early intervention services and post-tested 6 months later using the PSI/SF (Abidin, 2012). The null hypothesis for this research question was there would be no change in the stress scores after 6 months of services. A paired samples t-test was run on the Total Stress scores and on each of the three subscales (PD, P-CDI, and DC) as measured by the PSI/SF to determine if there was a difference in the mean scores at intake and after receiving 6 months of early intervention services. A Total Stress score is used to assess the overall level of parenting stress. The degree of Total Stress reported by family members at intake ranged from 54-139 ($M = 94.89$, $SD = 23.97$). Results indicated the Total Stress scores were lower after 6 months of service than they
had been at intake \((t (8) = 2.853, p = .021)\). Thus we reject the null hypothesis of no change and state that stress scores were lower after receiving 6 months of early intervention services. Cohen’s \(d = 0.951\) indicating a large effect size.

According to Abidin (2012), Parental Distress is used to assess “the level of stress a parent reports as a function of personal factors directly related to parenting” (p. 3). Normal range for this subscale is 18-37. The degree of Parental Distress reported by family members at intake ranged from 20-56 \((M = 37.78, SD = 12.17)\) indicating high stress for family members in this category. In fact, five of the nine participants scored above the 90th percentile, indicating clinically significant stress in this area. The degree of Parental Distress after 6 months of service ranged from 24-38 \((M = 31.78, SD = 4.66)\) with eight of the nine family member’s scores in the normal range and the ninth dropping from clinically significant to within the high range; however, t-test results indicated the Parental Distress scores did not change after 6 months of service and were not significantly different than at intake \((t (8) = 1.62, p = 0.144)\). Cohen’s \(d = 0.54\) indicating a medium effect size. Table 4 illustrates the results from this subscale.

Parental-Child Dysfunctional Interaction (P-CDI) assesses “the extent to which the parent perceives the child as not meeting expectations and finds that interactions with the child are not reinforcing his or her parenting role” (Abidin, 2012, p.3). The degree of Parental-Child Dysfunctional Interaction reported by family members at intake ranged from 18-42 \((M = 26.78, SD = 6.44)\) with eight participants scoring in the normal range and one scoring within the clinically significant range. The degree of Parental-Child Dysfunctional Interaction after 6 months of service ranged from 13-24 \((M = 31.78, SD = \)
Seven of the family member’s scored in the normal range, and two scored within the low range. T-test results indicated the degree of Parental-Child Dysfunctional Interaction scores were lower after 6 months of service than they had been at intake ($t(8) = 3.48, p = .008$). Cohen’s $d = 1.61$ indicating a large effect size.

Finally, the Difficult Child (DC) subscale “assesses the temperament or behavioral characteristics of the child that influence the parent-child relationship” (Abidin, 2012, p.3). The Difficult Child scores at intake ranged from 14-41 ($M = 30.33, SD = 7.80$). Participants’ intake scores covered a wide range in this area. One scored above the 90th percentile indicating clinically significant stress, one scored at the 86th percentile indicating high stress, one scored below the 18th percentile indicating low stress, and six scored within the normal range for stress in this area. The scores on the Difficult Child subscale after 6 months of service ranged from 15-37 ($M = 23.89, SD = 6.90$). Seven of the family members scored in the normal range and two scored within the low range. The family members who had scored in the clinically significant and high ranges dropped to normal; however, the family member whose intake score had been low was raised to normal on the second PSI/SF. Results from the t-test also indicated lower scores in the Difficult Child subscale after 6 months of service ($t(8) = 2.66, p = .029$). Cohen’s $d = 0.89$ indicating a large effect size.

A paired samples t-test was run on the Total Stress scores and on each of the three subscales (PD, P-CDI, and DC) as measured by the PSI/SF to determine if a difference occurred between the mean scores at intake and after receiving 6 months of early intervention services. Results indicated a change in Total Stress scores and on two of the
three subscales. T-test results from the P-CDI and DC subscale scores indicated a difference after 6 months of early intervention services. No change could be found in the PD subscale scores.

Table 2

<table>
<thead>
<tr>
<th>Parenting Stress Index (Total Stress and Subscales)</th>
<th>Normal Range*</th>
<th>Sample Range</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Stress</td>
<td>54-109</td>
<td>52-139</td>
<td>94.89</td>
<td>23.97</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>18-37</td>
<td>20-56</td>
<td>37.78</td>
<td>12.17</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Interaction</td>
<td>15-33</td>
<td>18-42</td>
<td>26.78</td>
<td>6.44</td>
</tr>
<tr>
<td>Difficult Child</td>
<td>19-37</td>
<td>14-41</td>
<td>30.33</td>
<td>7.8</td>
</tr>
</tbody>
</table>

*Derived from Abidin (2012)

Table 3

<table>
<thead>
<tr>
<th>Parenting Stress Index (Total Stress and Subscales)</th>
<th>Normal Range*</th>
<th>Sample Range</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Stress</td>
<td>54-109</td>
<td>54-95</td>
<td>75.33</td>
<td>13.32</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>18-37</td>
<td>24-38</td>
<td>31.78</td>
<td>4.66</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Interaction</td>
<td>15-33</td>
<td>13-24</td>
<td>19.56</td>
<td>4.16</td>
</tr>
<tr>
<td>Difficult Child</td>
<td>19-37</td>
<td>15-37</td>
<td>23.89</td>
<td>6.9</td>
</tr>
</tbody>
</table>

*Derived from Abidin (2012)
Table 4

Parental Distress Subscale Pre and Posttest Percentiles and Stress Ranges

<table>
<thead>
<tr>
<th>Name</th>
<th>PD Pre %</th>
<th>PD Post %</th>
<th>Stress Range Pre</th>
<th>Stress Range Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gordon</td>
<td>99</td>
<td>64</td>
<td>CS</td>
<td>N</td>
</tr>
<tr>
<td>Antonia</td>
<td>99</td>
<td>76</td>
<td>CS</td>
<td>N</td>
</tr>
<tr>
<td>Maggie</td>
<td>96</td>
<td>70</td>
<td>CS</td>
<td>N</td>
</tr>
<tr>
<td>Anne</td>
<td>96</td>
<td>70</td>
<td>CS</td>
<td>N</td>
</tr>
<tr>
<td>Jody</td>
<td>90</td>
<td>86</td>
<td>CS</td>
<td>H</td>
</tr>
<tr>
<td>Carlos</td>
<td>78</td>
<td>80</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Becky</td>
<td>66</td>
<td>78</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Gary</td>
<td>36</td>
<td>54</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Diane</td>
<td>26</td>
<td>46</td>
<td>N</td>
<td>N</td>
</tr>
</tbody>
</table>

Note. CS=Clinically Significant, H=High, N=Normal

The second research question sought to discover if there was a relationship between the number of hours of early intervention services received and parental levels of stress. To determine if a relationship between early intervention services and parental levels of stress had occurred, a Pearson product-moment correlation coefficient was run on the number of hours of early intervention services received per month and the parental stress change score, which was the difference between the Total Stress scores at intake and 6 months later. Due to the small n, this was not expected to be a significant test, and it was not (p = 0.292). The direction of the correlation was negative (r = -0.395). A negative correlation indicates that as one variable increases the other decreases; however, the findings from this test were not significant and we cannot conclude there is a
relationship between the number of hours of early intervention services received and a change in parental stress. Effect size ($r^2 = 0.156$) was small.

**Qualitative Findings**

This mixed methods study was designed so data gathered in the qualitative phase would help explain the quantitative results. Results from Phase 1 of this study, the quantitative phase, suggested a change in stress levels after 6 months of early intervention services and stress levels generally went down. What the statistics did not reveal is why that might be so. Semi-structured interviews allowed me to explore questions 3 through 5 with family members. In this section I report the findings from my qualitative data analysis.

**Family Members’ Experience of Stress**

The third research question looked at how various family members experience stress. To answer this question I shared with each family member the results of his or her PSI/SF pre and posttests. All of the family members in this study had previous experience with looking at percentiles on their children’s growth charts, so I used that prior knowledge as an example of how to read their scores in percentiles on the PSI/SFs. After explaining the different categories and where their own scores ranked, I asked two questions. Because the change in the stress scores was so dramatic, I first asked if anything in their results surprised them. Second, I asked if they could tell me what had happened or what may have changed between the two time frames to create their results. These were the first two questions asked in the semi-structured interviews for each family member. The interview data were coded and categorized. The data from these interview
questions were used in three ways: 1) categories were compared to determine relevance to each other, 2) categories were compared to existing literature on family stress for mothers, fathers, and grandparents to determine if similarities or differences existed, and 3) findings from this question were compared to the Contextual Model of Family Stress (Boss, 2002) to see what fit and what changes needed to be made to the model to accurately reflect the experiences of the family members in this study as was the case for each section of qualitative data analysis.

When family members were presented with the results from the PSI/SFs, their responses varied. Some family members were not at all surprised by the results, while others displayed emotions such as surprise, confusion, relief, and concern. One of the fathers called the results “spot on,” whereas two of the mothers expected the stress levels on their second PSI/SF to still be high and were surprised they had come down into the normal range. While scheduling the interview to discuss the results one mother asked, “Have I gone up or down?” The PSI/SF results were a topic of great interest to most of these family members and thus provided an excellent starting point for the interviews because they offered the family members an opportunity to identify and discuss their stress.

The changes family members reported as affecting their stress levels over the 6 month time period between the two stress surveys fell into three categories: change in the child’s condition, access to information, and increased support. Although the first category (change in the child’s condition) did not align with the topics found in the literature, nor with the Contextual Model of Family Stress (Boss, 2002), which was
chosen as a framework to guide this study, the families’ stories provided rich data from which to answer this question. A discussion of each of the three categories follows.

**Change in the Child’s Condition.** Toly et al. (2012) discussed the importance of the child’s status in determining a parent’s ability to perform their duties as a caregiver. An improvement in the child’s condition was identified most often as a factor in a parents’ decreased stress level. In the time between the first and second surveys, two children had undergone successful surgeries. Gary stated that as he adapted to his daughter’s special needs, including “going through surgery and things,” he felt a lot of his stress “dissipate.” Antonia described the change in familial stress after her son’s surgery:

He already had his second one, so I think we’re done with surgery right now. He doesn’t need any more. It all depends on one of his valves, that it keeps narrowing, but it’s not a big, big deal like it used to be. Now it’s, we’re just going to watch it, and his heart looks fine and he looks fine and we just have to deal with his syndrome, I guess. (AT, 2, 17)

Although not all families in this study had children who required surgery, all of the children had complex medical needs and had experienced dangerous hurdles in infancy. Gordon described relief in his stress levels over time because his son continued to make progress, “Things have been eliminated from the table that were huge. . . . initially we didn’t know that night if he was going to need a ventilator” (GN, 8, 28). Jody described the relief and reduction in stress she felt when her daughter got a little more independent and quit wanting to be held constantly:
One of my biggest things was like God, I can’t even do the dishes or brush my hair because she always wants to be up and her doctor always told me, ‘Well don’t let her cry excessively because it’s really bad for her heart.’ So here I was all the time just holding her, you know, trying to comfort her constantly.

(JY, 4, 48)

The child’s condition was also responsible for one family member experiencing increased stress between administration of the first and second PSI/SFs. Although her overall scores remained low when compared to those of the other participants, there was an increase in the Total Stress score and in the score on the Difficult Child subcategory over the 6 month period. When asked about changes that may have contributed to this increase, Diane explained there had been no changes and her increased scores likely reflected the on-going demands of providing care for her twin grandsons. “Even though all kids make demands on their parents or whatever . . . you just have to be mentally and physically there because there’s always going to be something going on. . . . It’s 24/7”

(DE, 15, 131).

**Access to Information.** Steele (2002) reported that parents sought knowledge about their child’s illness. Having access to information provided stress relief for many of the family members in this study. Several participants identified not knowing what was going to happen to their child as a source of stress. Anne stated, “We didn’t know anything, and it was just, life was ‘I don’t know,’ and it made everything hard”

(AE, 3, 19). The need for information was a large contributing factor to Gordon’s stress levels. He said, “If they don’t give you an answer I’m still going to Google it 12,000
times, or I’m going to stay up all night thinking about it. I mean, it’s not something that goes away” (GN,26,163). Gordon stated that having answers about his child’s condition helped “dramatically” to reduce his stress level. Antonia stated not knowing what was going to happen next caused her fear and stress, but as she came to know more, things settled back to normal.

**Access to Support.** Finally, access to support was identified as a factor in reducing parental stress. Social support as a buffer against stress has been documented in the literature and has been negatively correlated with family care strain for parents of children with chronic health conditions (Tac & McCubbin, 2002). When asked what had changed over the past 6 months Maggie stated she could think of only one thing; she had started receiving more help from her brother, and she credited this for her reduced stress scores. Becky identified support from a professional as helpful. This family had spent some time on the waiting list for early intervention services. When she developed concerns about her child’s feeding and received a call back from the dietician at early intervention, her stress was greatly relieved.

When asked to identify what may have contributed to their change in stress scores in the 6 month period between administration of the two PSI/SFs, family members’ answers fell into three categories: the child’s condition, access to information, and access to support. A change in the child’s condition resulted in both increased and decreased stress levels for family members over a 6 month period, whereas access to information and support were stress reducers.
Isolation

The relationship between isolation and stress cannot be overstated. The literature has suggested caring for a child with disabilities can be socially isolating for parents and grandparents (Kirk, 1998; Ross & Aday, 2006). Ratcliffe et al. (2002) reviewed and analyzed literature pertaining to the stress experienced by families of children with complex medical needs and divided the stressors into four main themes. Independence/isolation was one of those four categories. Isolation and stress were so closely related in the stories told by family members in this study they are represented as two concentric circles in the Parental Stress Model for Families of Children with Complex Medical Needs Who Are Receiving Early Intervention Services (Young, 2015). Isolation took many forms and each family member identified it differently. Some were more direct than others. Jody clearly stated she felt physically isolated because the condition of her child did not allow her to leave the home or have many visitors. Jody stated:

So now that she’s getting a little bigger it’s gotten a little bit easier and people can come and visit and we have more of a social life now. . . . Whereas before it was just kind of like, isolation, just me and the kids and my husband when he would come home from work. So it was kind of, and doctors. That was all I saw.

(JY,4,50-52)

Murphy (1997) stated that parents who do not regularly leave their home within the first 6 months after initiating home care tend to become increasingly isolated. Although he never used the term isolation directly, the topic arose several times during my interview
with Gary. He seemed to be very aware that he and his wife were at risk for social isolation and was taking precautions. It appeared to be of great importance “just having outlets that are not at home with the baby” (GY,8,70).

Carnevale et al. (2005) stated that parents may feel no one can take care of their child the way they can and worry about leaving their child in someone else’s care. This seemed to be the case for Anne who discussed both physical and emotional isolation. She said:

It’s scary and you feel alone. I know I feel alone and it’s just because nobody else, I’ve never met anybody else like Marcus . . . All my friends who are moms, they all go to work every day. I can’t go to work every day. He’s never been left alone with anybody but my mom. I’m scared. Even respite care, and they’re professionals. I’m terrified to drop him off. And other people are like, my kid’s in daycare, and I’m like, good for you, but I can’t do that. It’s different and it’s hard. (AE,23,221-227)

Antonia was isolated from her husband and two older children when she had to leave with her son for his surgery. Part of her family lives in the city where the surgery was being performed and they were able to help her. She said, “When I was over there by myself they pretty much helped me by going with me to the hospital, and also they took me to their home so that I wouldn’t be by myself during the whole process” (AA,5,43).

When Gordon’s son was in the hospital he described feelings of intense emotional isolation, “It’s just a dark tunnel and people telling you, you should wait” (GN,5,20). He added:
. . . so here you are feeling like a prisoner to your child’s health, but they tell you you have to maintain . . . really the difference between prison and home is the medication that is received and the intervals that it is received. (GN,5,20)

Diane not only cares for her twin grandsons, but also her older grandchildren. She described the physical challenges involved with transporting the children to appointments outside the home:

I tried to make sure that last week and this week, because the kids were going to be out of school, I wouldn’t have to take this double stroller, and a 5 year-old, and an 8 year-old into the doctor’s office. Even though I have support here, I just wanted to make sure I would be home with them. (DE,14,126)

For family members in this study, isolation was closely entwined with stress. Several factors contributed to isolation including the child’s condition, which family members also identified as one of the primary elements affecting their stress levels. For some of the participants in this study, having social support helped to alleviate the isolation and stress.

**Similarities and Differences in Family Members’ Reaction to Stress**

Historically, women have reported higher levels of psychological distress than men (Boss, 2002); however, the literature specifically related to family stress for parents of children with complex medical needs does not always reflect this. There is conflicting information in the literature, with some studies showing a difference in the stress experienced by mothers and fathers of children with complex medical needs and some that did not. Knafl and Zoeller (2000) stated that parents were more alike than different in
their responses to their child’s condition. In this study, although family members’ responses showed subtle differences, it would appear mothers and fathers were similar in their descriptions of family stress. An interesting finding was the stress described by the only grandparent who participated in this study was lower than that of either mothers or fathers.

Knafl and Deatrick (2002) reported fathers did not want the illness to become the entire focus of family life. This study found having a social life was important to both mothers and fathers. Jody stated things became easier when family and friends were able to start coming over to the house again. Gary stated:

. . . probably a bigger stressor at first for my wife than a help, but I really pushed for us to find somebody that we could call for a maybe a date night for ourselves. . . . It’s tough for probably most moms to let go of their kiddos, but I think it’s harder when you have all these complications. (GY,17-18,152)

Two of the fathers mentioned fighting with their spouses, although one described it as part of the normal adjustment to parenting and stated he had heard things like “not sleeping” and “lots of fighting with your spouse” were pretty typical as part of the transition from being childless to having a child. The other father described fighting as a byproduct of trying not to say the wrong thing in a stressful situation. His perception was his wife saw his silence as disengagement, whereas he felt he was trying to protect her. This is similar to findings in Steele’s (2002) study in which fathers tended to show support and comfort by avoiding talk. None of the mothers discussed having conflict with their husbands.
Knafl and Deatrick (2002) found mothers reported stress related to the work of managing the child’s illness and experienced higher anxiety than fathers. In my study, all three of the fathers credited the mothers with being the primary caregivers for the child who has complex medical needs, but only one of the five mothers stated she was not getting any help from her spouse. This parent felt her husband expected her to “do it all” because as the mother it was her responsibility.

As previously mentioned, having access to information relieved stress for many of the family members in this study. Access to information as a buffer to stress is well documented; however, the literature regarding family stress for parents of children with complex medical needs highlights differences in mothers’ and fathers’ need for information. Latour et al. (2011) stated fathers wanted honest information from health care professionals even when they did not know the answers, whereas mothers more often related honesty to certainty. In this study all family members reported a desire for information. Gordon echoed the desire for honest information in this statement, “I never wanted an answer from someone who didn’t know, but maybe you could find out at some point, or maybe you know someone who does” (GY,25,157). He also addressed the issue of professionals’ uncertainty in this statement:

. . . when it comes from someone else it seems more like you’re doing the right thing than if you just guess. At this point I almost want to take a six-sided dice and write down six ideas and say, okay, if I roll a number 4, every time he does that we’re going to tickle him. You know? Like it’s our best guess. (GN,22,129)
Maggie rated support from her child’s physician as “non-existent” because a lot of her questions had gone unanswered, while Diane praised early intervention for giving her the information she needed “to go to the next level with the kids” (DE,13,122). Finally, Anne expressed her reliance on information because of fear her child may “fail” without it.

Harrison et al. (2000) studied parental stress in grandparents versus parents raising grandchildren with behavioral problems and found grandparents reported lower levels of stress than both single and married parents. This is consistent with the findings in this study. In addition to receiving the lowest scores on her initial PSI/SF in every category, Diane, the only grandparent who participated in the study, was responsible for twin boys who both have complex medical needs. When asked about her stress scores, she very matter-of-factly commented, “I can’t let that stress me out. I can’t let it hold me back” (DE,1,6).

**Perception**

Perception is an important variable in Family Stress Theory. It determines how an event is viewed individually as well as by the family as a whole (Boss, 2002). In The Parental Stress Model for Families of Children with Complex Medical Needs Who Are Receiving Early Intervention (Young, 2015), perception became one of the most important concepts for understanding family stress. Two stories illustrate the impact perception can have on parental stress and contribute further explanation to the quantitative data, which was a primary goal of the qualitative interviews in this mixed methods study. These stories follow:
Scores on the Child Domain are typically higher than scores on the Parent Domain for parents of children with disabilities, including children with chronic medical conditions (Abiden, 2012). Anne scored in the clinically significant range in the Parental Distress subscale but had relatively low scores in the Difficult Child subscale on her initial PSI/SF. Abiden (2012) explains that when these discrepancies occur “it is likely that the parent is experiencing personal adjustment problems that are at least partially independent of the parent-child relationship” (p. 60). I asked Anne about this discrepancy in scores, and her response was that she blamed herself for her son’s condition. She said, “. . . it’s not his fault. I mean, he didn’t asphyxiate on purpose. . . . I kind of felt like it was my fault, and I think that’s really what it was” (AE,3,25). Having an awareness of Anne’s perception of herself as being somehow to blame for her son’s condition is critical to understanding her increased stress level.

Conversely, Gary had stress scores within the normal range in all areas on the first PSI/SF, and his scores in Total Stress and in the Difficult Child subscale dropped to low after 6 months. In spite of the fact that his daughter Rachel had surgery to repair her cleft lip when she was 12 weeks old and was expected to have another surgery to repair her palate at 10 months of age, his perception was that his experience was not much different from the parent of a typical child. He stated, “A lot of parents don’t . . . have their kid on a vent overnight and all that stuff, but a lot of things we go through are really similar to everything that other parents go through” (GY,10,92). Rehm and Bradley (2005) studied the concept of normalization for families with children who have both medically fragile status and developmental delays and found parents sometimes reframed their experiences
with their children as positives in their lives. This perception of a normal parenting experience seemed to offer Gary some protection against high stress levels.

Boss (2002) advised that although perceptions are important, we need to consider other data. In this mixed methods study, the perceptions of family members were vital to understanding their stress levels and factors that may be contributing to their stress. The discussion began and was facilitated by the collection of quantitative stress scores; however, narratives provided illumination for understanding these family members’ unique situations.

**Summary of Family Members’ Experiences with Stress**

The third research question looked at how various family members experience stress. To answer this question the PSI/SF pre and posttests were shared with each family member, and interview questions were asked regarding changes in the 6 month interval between the pre and posttests that would affect their stress scores. Family members identified three categories that may have affected their stress scores: a change in the child’s condition, access to information, and increased support. The experience of family stress for mothers, fathers, and grandparents was explored. Finally, examination of two of the parents’ narratives highlighted the concept of perception as a tool for building a better understanding of parental stress.

**Satisfaction with Early Intervention**

The fourth research question dealt with how family members respond when asked about their satisfaction with early intervention services provided to their child and family. To answer this question, I used data collected from the qualitative interview questions. I
reviewed the services on their IFSP line by line with each family member and asked the following question: If you could write your own plan, would the services you gave yourself be the way they are now, would it have been more, would it have been less, or how might it have looked different? This same question was applied to each early intervention service the family was receiving. After completing the list of services, I asked each family member the following questions: If you had the opportunity to train a new developmental specialist, what would you tell them? What are some things that you, as a [grand]parent, would say have been helpful or not helpful? What would you want them to know? One father declined to answer questions about his satisfaction with early intervention because he is usually at work during the day when the therapists come and did not feel he had an opinion. He said, “I can’t tell you how good they are or . . . if I wanted to see them more. . . . I see a lot of people here, but I come and I go, and I can’t really tell” (CS, 11, 122). The answers given for each of these questions by the remaining eight family members follow.

McDowell et al. (1995) reported early intervention participants who perceived an increase in support and resources experienced a reduction in parental stress. This appeared to be consistent with the findings in this study. The differences between the amount of services families were receiving in minutes and what family members reported they would prefer is displayed numerically in Table 5, along with a visual representation in Figure 5. Overall, family members were fairly satisfied with the amount of services received; however, Gordon made an excellent point when he responded to the question of
services with this statement, “I don’t know if it’s so much the interval that they come, it’s more the aspect of what they bring” (GN,21,125).

Table 5

<table>
<thead>
<tr>
<th>Service</th>
<th>N</th>
<th>Minutes Received/mo</th>
<th>Range</th>
<th>M</th>
<th>Minutes Desired/Mo</th>
<th>Range</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>DS</td>
<td>8</td>
<td>650</td>
<td>30-120</td>
<td>81</td>
<td>700</td>
<td>20-120</td>
<td>81</td>
</tr>
<tr>
<td>PT</td>
<td>4</td>
<td>600</td>
<td>120-240</td>
<td>150</td>
<td>720</td>
<td>120-240</td>
<td>180</td>
</tr>
<tr>
<td>SLP</td>
<td>7</td>
<td>360</td>
<td>30-60</td>
<td>51</td>
<td>420</td>
<td>0-120</td>
<td>60</td>
</tr>
<tr>
<td>NT</td>
<td>6</td>
<td>220</td>
<td>20-60</td>
<td>37</td>
<td>2240</td>
<td>20-1800</td>
<td>373</td>
</tr>
<tr>
<td>OT</td>
<td>1</td>
<td>240</td>
<td>NA</td>
<td>NA</td>
<td>240</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>VS</td>
<td>1</td>
<td>60</td>
<td>NA</td>
<td>NA</td>
<td>60</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

Note. DS=Developmental Specialist, PT=Physical Therapist, SLP=Speech-Language Pathologist, NT=Nutritionist, OT=Occupational Therapist, VS=Vision Specialist

**Nutrition.** The one service family members consistently desired was more nutrition. When asked “in a perfect world” how often she would want support, Maggie answered, “[The] feeding specialist would live with me” (ME,12, 187). She added, “I’d want them every day, but that’s kind of unrealistic, cause, I mean, they’ve got other appointments” (ME,12, 191). Diane echoed Maggie’s sentiments stating, “Of course I can’t have them daily. That would be unrealistic. That would be great, but that would be like babysitting, so they do what they need to do and teach us what we need to follow through with” (DE,11, 112). Gary explained his dependence on nutrition services:

I’m sure that as Rachel has more things to check up developmentally, I mean speech wise and all that stuff, then other parts of her team will become just as
important to us. But I think because that was the biggest crisis, and that is the biggest thing for cleft lip and palate anyways. . . . so, holy cow, that lady saved our baby. (GY,23,188)

Summary. The desire for increased nutritional support stands to reason when we examine the population involved in this study. These family members were collectively caring for seven children. Of those children, one had a cleft lip and palate, three were entirely g-tube dependent, one had a condition that caused severe vomiting, and two had heart conditions that contributed to difficulty with feeding and poor weight gain. These children ranged in age from 1-10 months at the time of initial data collection. Feeding is an important developmental skill for infants, and it was an area these children struggled with due to their various medical conditions.

Physical Therapy. The second service family members expressed a strong desire for was physical therapy. Of the four family members receiving services from a physical
therapist, no one was receiving less than twice per month, and no one expressed any interest in decreasing the amount of time they were receiving. Anne explained her reason for wanting increased physical therapy for her child:

He just does so much more progress when she’s around, and we’re doing the same things but I think he just gets tired of me. And maybe if she came more he’d get tired or her, but I know when she does come, like last time he actually started to crawl a little bit, and he won’t do that. He just rolls around the house.

(AE,16,163)

Antonia also discussed the progress her son had made with the help of his physical therapist:

He’s already trying to walk, which is a huge thing for us, cause we’re like, before his surgery, the second one, we thought he wasn’t even going to be crawling yet. . . . and he seems to be pretty, like learning pretty fast and she always challenges him to do more and more and more everyday instead of just sticking to one thing. (AA,9,101)

**Summary.** As with nutrition, the desire for increased physical therapy stands to reason when we consider the developmental stage these children were in at the time this study was conducted. Crawling and walking are important developmental milestones for children transitioning out of infancy, which most of these children were when these interviews were conducted. Helping their children meet these milestones was a concern for these families.
Speech Therapy. Of the seven family members receiving services from a speech-language pathologist, four were satisfied with the amount of services received and desired no change, two wanted to increase the amount of service, and one stated she felt her son no longer required the service and would like to suspend it. Speech-language pathologists work on communication and language goals with families, but they may also assist with feeding, particularly when there is a concern with chewing and/or swallowing. Such was the case for many of the children whose families participated in this study; however, over time some of the children had resolved their feeding issues, and family members were ready to work on other developmental areas. Berge and Holm (2007) described role conflict as a pervasive problem for parents of children with complex medical needs. As parents gain knowledge and become the experts on their child’s care, role conflicts may arise between parents and service providers. Creating a match between the family’s needs and the speech-language pathologists’ goals was a concern. During our interview, Anne revealed she was experiencing difficulty communicating with her son’s speech-language pathologist. Anne did not feel her son required continued speech services because his feeding issue was resolved, but stated her therapist “would not let go.” She had not voiced this problem to anyone and was afraid to take the service off her IFSP in case he needed it later. She described her frustration:

When he came home he had trouble swallowing because he was intubated for so long. He was intubated for like two and a half weeks and he didn’t know how to suck and swallow, and for like the first 7 months she was like, he’s still having difficulty eating, and we’re like, he’s really not and I’m around him every
day. . . she is a professional and that’s wonderful, but she’s around him an hour a month and I am around him every other second and it was hard . . . it’s like an argument to have her come over, and I’m not saying that what she sees is in her head, but I don’t notice it and nobody else notices it. . . . It’s to the point now where I just don’t say anything. (AE, 14, 145-149)

Jody expressed a desire to have her speech-language pathologist work with Ashley more; however, it appeared the strategies the therapist used were not a good match for the family. Jody stated:

. . . she doesn’t have a very broad vocabulary yet, and [speech-language pathologist] says that’s fine, but I would like to see her start talking more, and she’s working on sign language with her, so I have no idea. I mean, I know how to say thank you and that’s about it. I don’t know sign language so when [speech-language pathologist] comes and works with her it would be nice if she could work with her a little bit more I guess. (JY, 15, 188)

Conversely, Gary expressed satisfaction with the level of speech therapy his daughter was receiving. There also appeared to be a good match between the role of the family and the speech-language pathologist. He explained:

Part of the team is actually helping us to kind of monitor Rachel’s speech and language growth and then giving us the tools to use to help that development, and the reason why that becomes important is because her surgery schedule becomes dependent on how her speech develops. So, depending on the sounds she can and can’t make and those kinds of things, will determine if she needs another surgery
when she’s three to lengthen her soft palate; which, not like that rides on the
shoulders of this speech and language pathologist, but I really like her coming
over and just assessing where Rachel is at and letting us know a little more
specifically what things we should be seeing from our daughter and what we’re
expecting to see from her. (GY, 24, 206-208)

Diane expressed satisfaction with her speech-language pathologist’s work even though
her children were encountering difficulty:

. . . the boys are not doing well with feeding so she just comes once a month now
to do oral stimulation with them and see if they’re ready to try foods, and they’re
not quite ready to nipple feed. They choke on the pacifier, and it’s strange because
even though she works with them and they choke, sometimes they just smell a
food and will gag, but when they put items in their mouth they’re fine. . . . They
do it, but when they’re trying to be taught to do it, they’re not ready yet. So just
once a month, and that’s fine. (DE, 10, 97)

**Summary.** Speech-language pathologists were working with these families on
language and feeding goals. As in all areas of this study, a change in the child’s condition
dictated the amount of services needed. While most families were satisfied with the
services from their speech-language pathologist, in one case, a poor match between the
family’s needs and the therapist’s goals resulted in role conflict. Another parent identified
the use of sign language as a strategy, but it may have been a poor match for that family’s
needs. This is a problem because although the child may receive multiple services
through early intervention, the family is ultimately responsible for carrying out the strategies when the therapist is not present.

**Developmental Specialist.** The developmental specialist provides Part C services called specialized instruction and acts as the service coordinator. Every family receiving early intervention services has a developmental specialist on their IFSP. Of the eight family members receiving services from a developmental specialist, six were satisfied with the amount of services received and desired no change, one wanted to increase the amount of service, and one felt she could use slightly less service. The number of times families received developmental specialist visits ranged from once per quarter to twice per month. As with all the other therapists, the child’s condition determined the need for this particular service. Jody expressed an interest in increasing specialized instruction from once per month to twice per month. She explained:

> She’s not the typical child that you can . . . teach the way I taught my other kids how to grasp things and so it was a big help when I was kind of guided on you know, well, we want to see her doing more of this and this and this, and this is how you would help her do that. So I’m not saying she’s falling behind or anything, but just that extra support was kind of nice to have cause I knew that, you know, if I had questions she would be there next week. (JY,13,172)

Conversely, Becky had reduced the service from her developmental specialist to only once per quarter because her daughter was progressing well. She explained, “I think when we were seeing her more than that it made us question Rachel’s development more
often, you know, just worrying about is she doing what she’s supposed to be doing, which she’s right on track” (BY,11,163).

**Summary.** Developmental specialists act in the dual role of service coordinator and service provider. While most of the families in this study expressed satisfaction with the amount of service they were receiving from their developmental specialist, in one case, looking ahead to future milestones caused a parent to worry about her child’s development and services from her developmental specialist were reduced. Conversely, worry about a child’s development resulted in another parent desiring increased services from her developmental specialist.

**Occupational Therapy and Vision Therapy.** Only one family in this study was receiving these two services. The occupational therapist was seeing the children weekly, and the vision therapist was visiting once per month. When asked about these two services, Diane commented they were both “fine” but did not offer any details about either.

**Summary.** Families in this study were receiving services from a wide range of therapists including nutrition, physical therapy, speech therapy, specialized instruction, occupational therapy, and vision therapy. Families were satisfied with the amount of services offered with the exception of nutrition, which most families wanted to increase. As with all areas in this study, the child’s condition was an important consideration in determining the amount of service required by the family.
Quality of Services

This was a two-part research question. The first part had to do with families’ satisfaction with the amount of services received. The second part delved into family members’ satisfaction with the quality of services, specifically from their developmental specialist. To answer the second part of this question, family members were asked to imagine themselves training a new developmental specialist and what they would want them to know. Responses fell into three categories: access to information, communication, and connection. Each of these categories follows.

Access to Information. A desire for answers was a topic that cut across all domains of this study. It affected parental stress levels and influenced families’ satisfaction with early intervention services. Gordon reiterated the need for information, “Maybe they don’t have all the answers, but they’re not startled by any of your questions or anything” (GN, 25,153). He suggested the developmental specialist could possibly set up an email box where he could send his questions ahead of time so they could bring answers on the next visit. Anne reflected on her fear of not knowing what the future could hold for her son:

It’s scary not knowing what’s going to happen tomorrow. I think that if a new DS understood that, like this isn’t just something that I have to do because it’s good for my kid. This is something that I have to do because he may fail without it.

(AE,22,223)

Finally, Diane talked about receiving support when acquiring information from other agencies, “She’s come to meetings. She’s come to doctor’s appointments when I’ve taken
my grandkids, you know, to the doctor, to get the same information I’m getting” (DE, 7, 64).

**Summary.** Assisting families in gathering information is an important part of the developmental specialist’s role. Families rely on the developmental specialist to answer questions and help them process new information. Gaining knowledge, particularly about their child’s condition, helps alleviate stress and increase family satisfaction with early intervention services.

**Communication.** Latour et al. (2011) described communication as “an influencing factor for distress among parents” (p. 323). Several family members in this study conveyed the urgency for communication. Anne stressed the need for on-going communication with her developmental specialist after intake so that she was aware of the changing needs of the child and family:

> I feel like just having a meeting, or a get-together, or a conversation, I mean, obviously your kid’s going to be there because he’s everywhere I go, but just knowing what’s, like sitting down and finding out what’s going on from the parent and not from a list of questions that were asked. (AE, 21, 214)

Becky appreciated having access to her developmental specialist, “I have [the developmental specialist’s] cell phone number. She was very open about communicating with her if I have any questions . . .” (BY, 13, 184). Jody discussed how helpful it was to have her developmental specialist speak to her in family-friendly terms:

> A specialist I know will sort of just tell you like, this diagnosis, and they can’t speak to us in layman’s terms and we don’t have any clue what some of them are
talking about . . . they’re kind of coming down, not down onto my level but she was trying to understand more of my concerns and my needs too before just saying this is what we are going to do. (JY,17,208)

Maggie discussed communication from a different point of view. In addition to having her therapists communicate with her, she wanted them to listen to her and value her expertise on her child. McIntosh and Runciman (2008) identified information sharing as one area where the balance of power as the expert frequently shifts back and forth between parents and health care professionals, thereby creating the potential for both increased partnership and elevated stress. Maggie gave an example of a situation with one of her son’s therapists that illustrates this, “I tried telling her that he was going to throw up. She didn’t really believe me until it happened” (ME,14,218).

Both Anne and Gary identified the importance of parents clearly stating their needs; however, they approached it from very different viewpoints. Whereas Gary described this type of communication as increasing the agency’s ability to help, Anne seemed to suggest it more as a preventative measure against receiving something unwanted. Anne commented, “You need to be really clear with what you want. I think they kind of just give you whatever they think you need if you don’t say anything. I think that’s half of where I am now” (AE,20,200). Gary stated:

Ask for how to get what you need if it can’t come from them because the office has tons of other information about local resources . . . and I’m sure there would be people all over the place that would be able to help us out. (GY,26,216)
**Summary.** Several parents in this study spoke strongly about the importance of communication. These parents had many suggestions for developmental specialists to foster communication with family members including having on-going conversations with families, providing access to contact information, speaking in family friendly terms, and listening when parents shared knowledge of their child. Parents were encouraged to be good communicators as well and clearly state what they needed from the program.

**Connection.** The word connection did not appear as a topic in the literature I examined; however, it was used by three of the nine family members in this study. Gary described having a connection to his daughter. Jody discussed a connection to another parent at her child’s school, and Anne felt the absence of connection when her developmental specialist was replaced. A desire for connection with their therapists became a theme that emerged several times during interviews with family members in this study. Carlos was nervous about having strangers in his home. He said, “The first thing that came up to my mind when we started the program is what kind of people are going to come to my house. . .” (CS,9,103). Jody said, “It helps that she’s really personable, and at the very beginning she tried to get to know me a little bit before we stepped right into what is going on with Ashley” (JY,17,206). Jody further pointed out how helpful it was that her developmental specialist included her older daughter in Ashley’s therapy to foster sibling interaction. Antonia described connection as “getting close to the family” and creating a “bond” with them. She said:

She’ll ask me about the baby but it kind of gets a little bit more, you know, kind of close, kind of personal instead of just, oh, okay, I’ll be there for an appointment
in the next two weeks or so and that’s it. You don’t know anything about them.

(AA, 15, 177)

When this closeness or connection was absent, it affected how parents felt about the services they were receiving. To describe the void she felt, Anne stated, “I’m sure I’m getting everything that’s required by the state for him, but it doesn’t feel complete. It doesn’t feel like, there’s no connection, and it’s wonderful that she’s there to help Marcus, but she doesn’t know Marcus” (AE, 22, 218). Gordon described not only a lack of connection, but also the perception some people did not want to work with his child. He stated, “It’s got to be difficult to come to someone that has issues with their child and then to help them with it. I think some people felt so impacted by it that they were quick to leave” (GN, 24, 149).

**Summary.** The family members in this study expressed a desire for a connection to the people who are working with their child, which makes sense when we consider the population being served. As Carlos pointed out, these family members feel vulnerable. They are caring for very young children with complex medical needs and are receiving early intervention services in their homes. Understanding the need for connection is vital to providing appropriate and effective services to these families.

**Summary of Satisfaction with Early Intervention**

The fourth research question dealt with how family members responded when asked about their satisfaction with the early intervention services provided to their child and family. This question was answered in two parts using data collected from the qualitative interview questions. In the first part of the question, family members indicated
they were fairly satisfied with the amount of services received, with the exception of nutrition, which several participants expressed a desire to increase. The child’s condition played an important part in determining families’ satisfaction with the amount of services received. Creating a match between the needs of the family and the therapists’ goals was a concern, particularly in the area of speech therapy. Role conflict between a family member and a therapist resulted in less desire for that service. The second part of the question explored family members’ satisfaction with the quality of services, particularly from their developmental specialist. Answers to this part of the question fell into three categories: access to information, communication, and connection.

**Resources and Support**

The fifth research question examined supports available to the family in addition to early intervention services. To answer this question I used semi-structured interview questions guided by the FSS. Each family member was asked to describe the support they may have received from 19 different sources. The interview data were placed into three categories: family and kin, informal supports, and formal supports, which were loosely based on Cooley’s (1994) categories of support for caregiving families. Figure 6 breaks down the sources of support in each category. From these categories, a table was constructed in which all of the variables appearing in the data were listed along with the corresponding participants. Support from family and kin generally fell into four categories: financial, emotional, respite or childcare, and other. Figure 7 depicts which participants received support in each category. Informal support generally fell into the following four categories: information sharing, emotional, respite, and other. Figure 8
demonstrates which participants received support in each of these categories. Finally, formal support fell into four categories: access to information, emotional support, availability and/or flexibility, and other. Figure 9 illustrates which participants received support in each of these categories.

![Diagram of Resources and Support]

**Figure 6. Resources and Support**

Sources of support were divided into three categories; family and kin, informal, and formal. Of these three categories, study participants reported receiving the most support from family and kin. Financial, emotional, respite, and other were identified as forms of support offered by these participants’ parents, siblings, extended family members, children, in-laws, spouses, and friends. Informal systems offered the least support to the participants. Forms of support in this section included parent groups,
neighbors, co-workers, social groups, clubs, and church. Formal support ranked somewhere in the middle, between family and informal support. Forms of support in this category included the child’s doctor, therapists, early intervention, a school or daycare, and others. Family members contributed their suggestions for what should be included in the category of other supports. These included a lawyer, a pharmacist, WIC, public assistance, a babysitter, and a home nurse. A discussion of each section follows.

**Family and kin.** Cooley (1994) considered natural supports the family’s first and most important line of defense. Participants’ parents offered support in every category; however, they were credited most often with offering financial support. This is a very important finding given that both parents and grandparents caring for children with complex medical needs have identified financial strain as a source of stress (Capen & Dedlow, 1998; Kingston, 2007; Odom & Chandler, 1990; Ross & Aday, 2006). Family members in this study also relied on their parents for respite or childcare. This is also important, as a lack of respite care has been identified as a source of stress for parents and grandparents raising children with medical disabilities (Janicki et al., 2000; Odom & Chandler, 1990; Teague et al., 1993; Valkenier et al., 2002). Anne’s mother, who lives two hours away, was the only person with whom she could leave her son. Once a month, her mother would come into town and spend the whole day so that Anne could attend a course in which she was enrolled. When her son was having heart surgery Antonia had to spend some time in a city in the southern part of the state, about 8 hours drive from where she lived, and her mother was able to care for her other two children, which was a huge relief. Although parents were acknowledged for offering emotional support, it was not
always described as being helpful, particularly when compared to more tangible support such as financial and respite. Jody’s father tried to offer financial support and called her, but it wasn’t what she needed. She explained, “The kind of support I really need right now is someone to come over and just give me a break, and they’re not here to do that . . . so emotional support, yeah. Other support, no” (JY,6,78). Maggie was living with her parents at the time of the study but did not find them supportive at all:

My dad sits in his room all day when he’s not at work and other than that he, well, that’s it. And my mom, she, you know, occasionally she’ll do dishes, but other than that she still doesn’t know how to do his feedings or his medicine or anything like that. So they really don’t help. (ME,4,37)

While family members in this study acknowledged all forms of support from their parents, they seemed to rely most on financial support and respite care. Emotional support was mentioned, but did not appear to have the same impact for these family members as other forms of support. Many of the families in this study had parents who lived a distance away from them and were not able to offer on-going support. This created a large gap in the support system for some of the participants.

Siblings offered support for only a few of the study participants, but the help they did offer was highly valued. When asked about support from family members, the first person that came to mind for Carlos was his sister. The night Carlos found out his son needed heart surgery his sister bought him a plane ticket, which was very helpful because the hospital where the surgery was taking place is in a southern part of the state about 8 hours drive from where the family lives and he was not financially prepared to make that
trip. Gary’s sister was able to offer childcare on an emergency basis when Rachel was sick and could not attend her daycare, and Diane mentioned her sister would come from the Bay Area for a week at a time if Diane needed to be out of town. Finally, Gordon and Maggie identified emotional support from their brothers as being helpful.

Next to parents, extended family most often offered financial and respite support. Extended family members included grandparents, cousins, aunts, and a sister-in-law. When Antonia was in a city in the southern part of the state for her son’s surgery, extended family members took her into their home and supported her through the process. Maggie identified her partner’s aunt as providing respite care. She stated:

I love that woman. She’s awesome. . . . She’s babysat him a couple times and I’m really cautious about who I let watch them for longer than me to run to the store or something. . . . We actually went and had a nice date for Mother’s Day. He took me to dinner and she watched him that night so I, she was very helpful.

(ME,5,60)

Anne and Gordon were living in her grandmother’s house. Although they still paid rent, Anne felt secure knowing her grandmother understood their situation and they would always have a roof over their heads. Similar to responses in the category of parents, emotional support was mentioned but not with specific examples, as was the case with financial and respite support. When asked about emotional support from his extended family Carlos said, “We know they’re there, and we know they’re asking for him and so on” (CS,6,61).
<table>
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<tr>
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<th>Respite/childcare</th>
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Figure 7. Support from Family and Kin

Responses regarding support from in-laws were very similar to those for parents. This is because the three participants who identified their in-laws as being supportive are spouses whose husbands or wives reported financial and respite support from their parents. Two of the participants, Jody and Gary, who identified emotional support from their parents also discussed receiving emotional support from their in-laws. When
Antonia was with her son in the hospital, her mother-in-law took her mother shopping and brought food over. Gary’s mother-in-law decorated to “make the home more of a home” (GY,5,42).

In addition to the child with complex medical needs, all but one of the families in this study had older children in the home. These children ranged in age from 3-12 years, with the exception of Diane’s adult daughter, who is the children’s aunt. Siblings were considered supportive when they played with the child with complex medical needs, or in any way tried to help the child. Maggie commented about her 4-year-old son, “When he’s throwing up I ask him to get his binky and he does” (ME,6,70). Jody praised her son for his help with his sister, “My son is 12 and he’s, he probably couldn’t be better. He takes her and plays with her while I cook dinner, and he’s just really good with her, with Ashley. He’s just the best” (JY,8,104). Gordon talked about his 7-year-old son modeling skills for Marcus such as crawling and clapping. Anne laughed when talking about her step-son. She said, “He loves Marcus to death, but he’s not quite old enough to, you know, do anything. . . . but he tries to help when he can” (AE,7,70). Carlos spoke very warmly about the relationship between his two girls, ages 3 and 5, and their baby brother: 

. . . they look out for their baby brother and are very loving. . . . My brothers, they have kids the same age and one takes the bottle from the other and it just, constantly fighting and doing this other stuff, and they’re, they don’t do that. They play with him, give him the bottle, they look after him. (CS,7,70)

All but one of the participants in this study were married. At the time of the interview Maggie’s partner had been home from military training only 24 days. When asked about
support from a spouse or partner almost everyone cited emotional support. Heims et al. (1997) reported that parents looked to their partners as best friends and the strongest of all support systems. This was echoed in the responses by parents in this study. Gary called his wife “the biggest supporter of all.” Antonia stated with a large sigh, “Ah, he has helped me a lot. He has been next to me through the whole process” (AA,51). Jody received quite a bit of support from her husband and stated, “I couldn’t ask for a better partner in crime than him” (JY,7,92). Carlos identified his wife as his main support, stating, “besides the money and all that stuff, and this case you just need that person, you know” (CS,6,61). Both Gordon and Carlos identified their wives’ organizational skills as being helpful. Antonia, Becky, Diane, Gary, and Jody found it helpful when their spouses were able to care for the children so they could do things they either wanted to do or needed to do for themselves. Finally, Jody and Diane appreciated their husbands’ assistance with preparing meals.

Friends were identified as another strong source of emotional support, and offered respite for four of the study participants. Gary identified friends as being necessary to ensure he and his wife could leave the house and have date night every so often. Carlos stated, “they try to make us feel better when we get bad feelings or get news we don’t want to hear from doctors” (CS,6,67). Maggie was able to rely on one friend to watch her boys while she went to a dentist appointment, which she identified as very helpful.

**Summary.** Support from family and kin fell into the categories of financial, emotional, respite, and other supports. Parents, in-laws, and extended family members most often provided financial and respite support. Siblings offered a combination of
emotional support and respite care, with one sibling providing emergency financial assistance. Participants appreciated their older children playing with the child who has complex medical needs and trying to help in any way they could. Friends and spouses were the strongest sources of emotional support.

**Informal support.** Of the three categories of support, informal systems offered the least support to these families. This is an important finding because Cooley (1994) stressed the importance of informal supports along with family support, “Families who are surrounded by empty rings of natural and informal support and have only formal supports are destined to remain dependent on those formal supports and are at high risk for social isolation and demoralization” (p. 118). Forms of support in this section included parent groups, neighbors, co-workers, social groups, clubs, and church. Similar to the categories of support for family and kin, I divided the types of support into four categories: information sharing, emotional support, respite, and other.

Four of the parents in this study mentioned receiving information or support from other parents. Antonia and Jody had each joined on-line support groups specific to their children’s diagnoses where they could read about other parents’ experiences and ask questions. O’Brien (2001) identified the relationship with other parents who had children with similar needs as helpful sources of information. This appeared to be the case for Antonia. She was able to read about children who already had the surgeries her child was undergoing and said that knowing what was ahead was helpful to her. Anne joined a parent advocacy training group, which teaches parents to be self-advocates. Anne described the experience as amazing and said even though it was not meant to be a
support group, it turned out to be one. She felt the people there had been through similar experiences, and she had become really close with them. Gary did not belong to any formal groups but had contact with other parents through his child’s daycare and other venues. Gary found that being able to bounce things off this community of other parents helped normalize his experience with Rachel and put her development into perspective.

Neighbors, churches, social groups, or clubs were mentioned by only one parent each. Gary stated that when Rachel was having her surgeries and the family was out of town, his neighbor kept an eye on his home. Gary did not even know this at the time; it was relayed to him when the neighbor mentioned he had noticed they had been away. Most of the participants did not know their neighbors. Antonia was the only participant who identified support from her church. She said they helped her spiritually. Most of the participants stated they did not go to church. Anne was the only participant who belonged to a club. She had recently joined a group of mothers who find various events in town and, via the Meetup website, invite other mothers to join them. When asked about clubs and groups, most of the participants stated they did not have time. When asked about social groups, Gary responded he belonged to a percussion ensemble that got him out of the house and allowed him to talk to a man with a child only 6 months older than Rachel. This man was also discussed in Gary’s community of parents.

The final source of informal support was co-workers. Carlos was the only participant to receive financial assistance from his co-workers. They threw an ice-cream social as a fundraiser to assist with his expenses when his son had to go to a hospital in the southern part of the state for surgery. In addition, Carlos’s boss had given him paid
leave time and been flexible when he needed to go to his son’s doctor appointments. Becky and Gordon also stated they had been given time off to accommodate their children’s medical needs. Antonia and Jody, both of whom were at home fulltime caring for their children, discussed emotional support from their husband’s place of work. Jody’s husband has been employed at his job for 13 years and Jody is Facebook friends with a number of his co-workers who use this venue to check in with her and get updates on Ashley.

**Summary.** Study participants received much less support from informal systems than from family and kin. With the exception of Carlos’s co-workers, who threw a fundraiser for him, and two more participants who were granted time off from work, the support was much less tangible than the support provided by family members. Few parents were involved with support groups or community organizations, mainly due to a shortage of time. Most of the support received from informal systems fell under the category of emotional support and much of it was on-line versus face-to-face contact.

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<td>Church</td>
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**Figure 8. Informal Support**
**Formal support.** The category of formal support was the largest of the three categories; however, it did not offer the most support. Professionals offered more support than informal systems, but less than family and kin. Cooley (1994) identified formal support as the layer of support most removed from the family circle and warned it should be only one part of a continuum of services for the family because of the potential to disrupt or usurp the family’s natural supports. Forms of formal support included the child’s doctor, therapists, early intervention, a school or daycare, and others. When asked what fell into the other category, family members identified a lawyer, a pharmacist, WIC, public assistance, a babysitter, and a home nurse. As with the other two categories, the types of formal support were divided into four types: access to information, emotional support, availability/flexibility, and other. A discussion of each follows.

The child’s doctor was an important source of support for participants in this study, and for good reason when we consider the population. Doctors provided vital information to these family members. Gordon stated the pediatrician was “invaluable” when teaching him about his son’s medications:

... he was taking Keprin and Phenobarbital and was having some issues with it and so they had to slowly take him down. You know, you have these drugs that have other drugs that he had to take when he was sick at one point, and he’s very knowledgeable in this aspect. (GN,18,94)
Antonia talked about feeling safe with her cardiologist because he always knew what to do. She had also received vouchers from the Children’s Heart Center to pay for a hotel during her stay. Gary said his daughter’s ear, nose, and throat specialist (ENT) was the best he had ever seen at assessing an infant. “All she did was laugh at the guy while he’s looking in her mouth, and there’s nobody else on her care team that she lets look in her mouth . . .” (GY, 14, 116). Diane described her grandsons’ pediatrician as “the best.”

She stated:

. . . informational, caring, concerned. She would call me in the evening to check on how they were doing. If we had a doctor’s appointment, or if we had lab work done, she would call me to let me know what the results were, no matter, you
know, I mean within a reasonable time frame . . . to assure me everything was okay, or if it wasn’t, what I needed to do. (DE,6,56)

The families in this study all had children with serious medical conditions and as a group they spent an enormous amount of time at doctor’s appointments. Kirk and Glendinning (2004) stated parents are reassured when they feel that health care professionals are accessible, know their child and family, and value their expertise. This appeared to be the case for the family members in this study. Having access to their child’s doctors when situations arose was a priority for Becky. She stated, “They’re always available, they’re always very professional, and we can always get in to see them the same day if we need to” (BY,8,117). Anne described her attentive pediatrician, “I can call for anything, and I get a call back like ten minutes later. So, they’re just wonderful. . . . When I call my doctor, I’m lucky to get a call in a week” (AE,10,109). Jody had a similar experience with her daughter’s pediatrician. The doctor had to run some tests on Ashley and called Jody on a Saturday with the results.

Although most of the family members in this study had exceptionally positive experiences with their children’s doctors, Carlos related a very negative experience when his wife took his son to the pediatrician:

She went to the appointment and they said oh, we forgot to call you, the appointment’s been canceled and we forgot to call you. And she takes the bus. . . . and when we really needed to talk to him or make an appointment they put you on hold for like 15 or 20 minutes, then they answer. It’s just horrible. The only
reason we keep with them is because his pediatrician is really nice and takes care of him. (CS,9,97)

The next area discussed in the category of formal supports was early intervention services. As with the children’s doctors, support from early intervention was very important to these families. In addition to access to information and emotional support, these family members identified the importance of availability and flexibility. Both Gary and Diane stated it was helpful to have the program brought to the home. For Gary it was convenient to have home-based services, but for Diane it was a necessity:

I don’t have to drag the boys out once a week. That would be very hard on me. It would be detrimental, lugging the oxygen tanks, and it’s just, it’s a job, as when I take them to the doctor’s appointments, and it’s always, you need two or three. I need two or three. I can’t do it by myself. I always have to have someone with me when I’m with the boys because they throw up all the time and that’s okay, we deal with that, but you always have to have someone in the back seat to make sure they have oxygen on because they pull it off, and someone has to be in the back to ensure that if they’re de-sating that you can pump up that oxygen and get them back where they need to be. You know, so it could be where I would have to go to NEIS once a week, and I don’t. They come to the home, which makes it great, fantastic for me, and the boys. (DE,12,116)

Although the numerous early intervention appointments can offer a lot of support to families, they can put a strain on families’ time when the child is seeing many other doctors. Duplication of assessments while trying to access services was identified by
Townsley et al. (2004) as a source of frustration. Such was the case for Gary who stated between the audiologist at early intervention services, the pediatrician at early intervention, his own pediatrician, and the ENT, he felt he was doubling up on some things. His wife, Becky, described her frustration:

We were going in to see the audiologist and she was performing the hearing test and then it turns out she might have fluid in her ears so we have to reschedule for 4-6 weeks, but you also need to go and see your pediatrician. So then that didn’t work out, so we would go in for our next hearing test, oh, still fluid so now you should probably go see an ENT. You know, so because of this one test we ended up having to see 4-6 appointments within a 2 month window because of this one test. So that was hard, but I don’t know that it could be helped. (BY,13,184)

Three parents reported support from a school or daycare. Antonia and Diane discussed assistance for the older children in their home, while Gary talked about support from his daughter’s daycare. Antonia recalled that when she had to go to the hospital with her son, her daughters began crying all the time. She was able to explain the situation to the school and they intervened. “They tried to make sure they were always active and things like that so they wouldn’t think so much about what was going on” (AA,10,112). Gary was pleased with his daughter’s daycare because they bumped her up to the 1 year-old room early, which helped with her development. He said, “We noticed changes right away, especially with her talking cause the kids in that room are 1-2 year-olds” (GY,16,136).
In the other category, family members identified support from a lawyer, a pharmacist, WIC, public assistance, a babysitter, and their home nurse. The lawyer and WIC provided access to information. WIC also loaned Anne a portable breast pump and paid for the special formula Maggie’s son requires. Maggie described her relief, “He just got switched over to this prescription type food that is, for 24 eight ounce bottles, is $180. . . I’d be paying $900 a month for his food” (ME,11,159-161). One participant discussed receiving services from a private therapist, and one identified support from the diaper bank and food stamps. Diane was the only participant in the study to have a home nurse from whom she received not only assistance taking care of the boys, but also emotional support. She said, “I had to go through a couple of them, but, you know, I wound up with a great one” (DE,8,79). Gary was the only participant who discussed hiring a babysitter.

**Summary.** Study participants received less support from professionals than from family and kin, but more than they did from informal systems. Formal supports included the child’s doctors and early intervention program, as well as community programs such as WIC. Most of the support received from professionals fell under the category of access to information. Some tangible support was received from professional sources. Antonia was given hotel vouchers while she was away for her son’s surgery, and Maggie was receiving prescription formula for her son. Parents appreciated having access to their child’s doctors and therapists, but stated numerous or overlapping appointments could be time consuming, frustrating, and increased their levels of stress.
Summary of Resources and Support

The fifth research question looked at the range of supports available to the family in addition to early intervention services. To answer this question I used semi-structured interview questions guided by the FSS. Each family member was asked to describe the support they may have received from 19 different sources. The interview data were placed into three categories: family and kin, informal, and formal. Support from family and kin generally fell into four categories: financial, emotional, respite or childcare, and other. Parents, in-laws, and extended family members provided much-needed financial and respite support, while spouses and friends provided emotional support. Participants reported receiving the most support from family and kin and the least from informal supports. Informal support was sparse; however, participants did acknowledge time off from work as a valuable form of support and identified a connection to other parents as helpful. Formal supports included the child’s doctors and early intervention program as well as community programs such as WIC.

Boundary Ambiguity

The role of boundary ambiguity in this study cannot be overstated. Boundary ambiguity is unique to the Contextual Model of Family Stress (Boss, 2002), which was chosen as the conceptual framework to guide this study, and is defined by Boss (2002) as “not knowing who is in and who is out of one’s family” (p. 95). This concept drew particular attention for its potential to create stress for families, thereby making it highly relevant to this study. Berge and Holm (2007) defined two dimensions of boundary ambiguity. These were role ambiguity and membership ambiguity which were applied to
the family with a chronically ill child and specifically defined. Role ambiguity referred to internal family boundaries that defined who was responsible for what, while membership ambiguity referred to external boundaries that defined the difference between the family and the outside world. Many researchers (Berge & Holm, 2007; Mu, et al., 2009; Ratliffe et al., 2002) identified an intrusion into the family by health care providers as a source of boundary ambiguity and a possible cause of family stress. The findings from this study found evidence of both role ambiguity and membership ambiguity. The Parental Stress Model for Families of Children with Complex Medical Needs Who are Receiving Early Intervention Services (Young, 2015) recognized the impact boundary ambiguity has on families’ access to resources and support, and was therefore drawn as a bridge between family and formal support systems. While role ambiguity created stress for some family members, the blurred lines of membership ambiguity seemed to offer some families comfort as their early intervention team became woven into the fabric of their family. This occurrence appeared to be unique to early intervention services, perhaps because it is a home-based program. Boundary ambiguity, particularly membership ambiguity, was not described with other categories of professional services such as the child’s doctor, even though family members identified many of the same supportive traits, such as access to information and flexibility in both.

Anne’s experience with her son’s speech-language pathologist appeared to be an example of role ambiguity, resulting in her wish to decline the service. McIntosh and Runciman (2008) studied partnerships between families and professionals and found trusting relationships were built on critical listening and respect. Anne felt she had
knowledge about her son’s condition to that was not being recognized by his therapist. She was frustrated the therapist did not seem to be listening to her and stated “it was difficult arguing with somebody because I do know” (AE,14,145). Maggie appeared to have a similar problem when she tried to tell the therapist her son was going to vomit. “She didn’t really believe me until it happened” (ME,14,218).

Conversely, several family members sought connection to their child’s therapists creating the potential for the second type of boundary ambiguity, membership ambiguity. Jody was unsure about beginning early intervention services but became more comfortable with the idea when she was approached on a less formal level. She explained:

At first I was kind of like, I don’t know if I even want this for Ashley, but then when I met [my developmental specialist] and she was just like, no, this is what we’re going to do, and then she was just like a friend instead of a whatever, like a doctor or . . . (JY,18,208)

Carlos was cautious about beginning services because it meant having strangers in his home but he empathized with the therapists stating, “. . . or it can be the other way. You don’t know where you’re going.” (CS,9,105). Antonia stated in addition to helping her with the baby, she felt she received support from her early intervention team for herself. She described “closeness” and having a “bond” with them. She said, “I think that’s kind of what I like also with what I have with them. . . . Maybe I’ll say that it’s kind of a good thing just to have that little support from them, too” (AA,15,179).
Boundary ambiguity has the potential to both create and alleviate stress for families with children with complex medical needs. The presence of early intervention providers in the home may create role conflict, but may also create connection which reduces the stress caused by isolation. Family members in this study shared experiences that illustrated both sides of boundary ambiguity.

**Summary**

In this study, I examined the stress experienced by eight parents and one grandparent (who was acting in the parental role) of children with complex medical needs who were newly enrolled in Part C early intervention services. I used a mixed methods design which incorporated pre and post stress survey results from the PSI/SF (Abiden, 2012) along with parent interviews to help explain the results. I investigated several means of support including those from family and kin, informal support systems, and formal support systems. The goal of this study was to examine the relationship between stress experienced by family members of infants and toddlers with complex medical needs and their participation in home-based Part C early intervention services.

This research was guided by the following question: What do parents of 0-3 year-old children with complex medical needs say about the relationship between early intervention and parental stress? Five follow-up questions were explored in this study. The first follow-up question sought to determine if there was a change in stress levels after receiving 6 months of early intervention services. This question was answered using statistical analysis of the scores from the pre and post parental stress surveys. A paired samples t-test was run on the Total Stress scores and on each of the three subscales (PD,
P-CDI, and DC) as measured by the PSI/SF to determine if a difference in the mean scores at intake and after receiving 6 months of early intervention services had occurred. Results indicated a change in Total Stress scores and on two of the three subscales. T-test results from the P-CDI and DC subscale scores indicated a difference after 6 months of early intervention services. No change could be found in the PD subscale scores.

The second research question sought to discover if a relationship existed between the number of hours of early intervention services received and parental levels of stress. This question was written to be answered quantitatively; however, the small number of participants made statistical significance difficult. A Pearson product-moment correlation coefficient was run to show the direction of the relationship, which was negative; however, the findings from this test were not significant and we cannot conclude there is a relationship between the number of hours of early intervention services received and a change in parental stress.

The third, fourth, and fifth questions were answered using data collected from semi-structured interviews with the family members. The third research question looked at how various family members experience stress. Family members identified three categories that may have affected their stress scores: a change in the child’s condition, access to information, and increased support. The experience of family stress for mothers, fathers, and grandparents was explored. Finally, examination of two of the parents’ narratives highlighted the concept of perception as a tool for building a better understanding of parental stress.
The fourth research question dealt with how family members respond when asked about their satisfaction with the early intervention services provided to their child and family. In the first part of the question, family members identified their satisfaction with the amount of services received. Most family members were fairly satisfied, with the exception of nutrition, which several participants expressed a desire to increase. The child’s condition played an important part in determining families’ satisfaction with the frequency of services. Role conflict was identified as a factor in one parent’s desire for less speech service. The second part of the question explored family members’ satisfaction with the quality of services, particularly from their developmental specialist. Answers to this part of the question fell into three categories: access to information, communication, and connection.

The fifth research question looked at the range of supports available to the family in addition to early intervention services. Answers to questions about support from 19 different sources were placed into three categories: family and kin, informal supports, and formal supports. Participants reported receiving the most support from family and kin, and the least from informal supports. Parents, in-laws, and extended family members provided much-needed financial and respite support, while spouses and friends provided emotional support. Informal support was sparse; however, participants did acknowledge time off work as a valuable form of support, and some identified a connection to other parents as helpful. Formal supports included the child’s doctors and early intervention program, as well as community programs such as WIC.
The roles of isolation, perception, and boundary ambiguity were explored and discussed in this chapter. Isolation and stress were closely related in the stories told by family members in this study. Isolation took many forms and each family member identified it differently, some more directly than others. Perception shaped the way two family members experienced their situation and had the potential to either elevate or relieve stress levels depending on how the participant viewed his or her experience. Boundary ambiguity has the potential to both create and alleviate stress for families of children with complex medical needs. Role ambiguity and membership ambiguity were identified as the two types of boundary ambiguity that may affect families’ stress. Family members in this study shared experiences that illustrated both types of boundary ambiguity. In the next chapter I summarize and discuss my findings, address limitations of this study, and present implications for future research.
CHAPTER 5 – DISCUSSION OF FINDINGS, LIMITATIONS AND IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

Introduction

The number of children with special health care needs is rising in this country (Child Trends, 2012). Consequently, the need for early intervention services is also rising (Child and Adolescent Health Management Initiative, 2012). Caring for a child with complex health care needs is stressful for families (Enrione et al., 2005). Parents and grandparents seek support from professionals to assist in this caregiving role, but to date the information available to guide early intervention service providers on how to care for these children has not kept pace with the need (Steele, 2002). The body of research documenting parental stress for families of children with complex medical needs is expanding; however, investigations into parental stress for children with complex medical needs who are receiving home care have centered mainly on the role of home nurses. The relationship between early intervention and parental stress has not been widely examined. The role of Part C early intervention, as a developmental service, in the care of children with complex medical needs is virtually uncharted territory, leaving early interventionists without direction as they try to help families navigate the difficult time period from birth to age 3. A review of the literature revealed only two studies that discussed parental stress, the experience of having a child with complex medical needs, and participation in early intervention services together (Bailey et al., 2004; McDowell et al., 1995). Clearly there is a growing need to fill this gap in the literature. It is important to explore the relationship between parental stress and involvement in early intervention
services to meet the needs of families being served by early intervention and to avoid adding an increased and unnecessary burden to their already stressful lives.

The purpose of this study was to examine the relationship between stress experienced by family members of infants and toddlers with complex medical needs and their participation in home-based Part C early intervention services. In addition to measuring parental stress levels, I examined family support systems and satisfaction with the early intervention services provided to the family to determine what, if any, relationship existed between early intervention services and parental stress. Findings from this study have the potential to guide practice and assist developmental specialists in understanding families of children with complex medical needs so as to more effectively support them. In this chapter I summarize and discuss my findings. Following this discussion, I address limitations of the study and present implications for future research and recommendations for practice.

**Summary and Discussion of Findings**

In this study, I examined stress experienced by eight parents and one grandmother who were caring for children with complex medical needs. I further examined their satisfaction with early intervention services and supports available to the family. Findings in each of these areas are discussed below.

**Degree of Stress**

Boss (2002) developed a system of categorizing family stressors. She believed the type of stress experienced by a family was highly correlated to how well the family handled the situation and whether the family would escalate into crisis. The families in
this study all had children with complex medical needs present at, or shortly after, birth. This resulted in high stress levels for these family members. Five of the nine participants scored above the 90th percentile, indicating clinically significant stress in the area of parental distress on their initial PSI/SF. Six months later, eight of the family members had scores within the normal range, and one had fallen from clinically significant into the high range. This was the only posttest score above the normal range in any of the stress categories. Two family members had scores in the low range. Eight of the nine family members had decreased stress scores in every area; however, scores increased in total stress and the difficult child category for the one grandmother in this study. Family members identified a change in the child’s condition, access to information, and increased support as factors contributing to their lower stress scores. Although a negative correlation resulted when family stress scores were statistically compared with the number of hours of early intervention services received, the test was not significant and we cannot state there is any relationship between family stress scores and the hours of early intervention services.

**Family Members’ Experience of Stress**

An improvement in the child’s condition was identified as the largest factor in reducing these parents’ stress levels. Carlito and Rachel had undergone successful surgeries in the six-month period between the first and second surveys, which caused these families great relief. Gordon had been experiencing clinically significant levels of stress in all areas but began to feel his stress reducing when he saw his child making progress. Diane, the only grandmother who participated in this study, was caring for twin
boys, both with complex medical needs. She did not experience a change in her children’s condition and experienced increased stress caused by continuous care demands. Understanding the level of stress these family members are under when they begin early intervention services is of primary importance if early intervention service providers are to begin offering services that will meet the needs of the child and family. The clinically significant level of stress experienced by five of the nine participants at the time of enrollment in this study is of concern. Given the importance of improvement in the child’s condition to reducing parental stress, every effort needs to be made to ensure positive outcomes for the child. Placing unnecessary demands on families’ time by duplicating assessments or implementing strategies that families do not view as improving the child’s condition is unfair to ask of anyone but is particularly harmful to these family members who are already dealing with such a stressful situation.

Consistent with findings in the literature (Latour et al., 2011; Steele, 2002), family members required access to information to reduce their stress levels. Access to information may be of particular importance when a child is newly enrolled in early intervention and family members have multiple questions. Gordon wanted to know what to expect from his son. Antonia wanted to know what was coming next; however, Becky found that looking too far down the road made her question Rachel’s development when she was truly doing very well, which increased her stress level. This finding suggests that just providing information to families is not enough. It has to be current, accurate, and relevant to the specific family situation.
Increased support was identified by family members as contributing to their change in stress levels. This finding is consistent with the research of both McDowell et al. (1995), who found that early intervention participants who perceived an increase in support and resources experienced a reduction in parental stress, and with Young and McCubbin (2002), who found communication with health care personnel, receiving support from extended family, and relying on support from a marital partner to be positive coping mechanisms. In this study, support manifested in many different forms and was unique to each individual. Although participants reported receiving support from family, informal support systems, and professionals, the bulk of support was from family and friends. An interesting finding in this study is the family members’ desire for specific types of support from different sources. Four family members valued emotional support from their parents, but most stated support in the form of financial assistance or respite childcare from their parents was necessary. Seven family members relied on emotional or respite support from friends. Of the eight participants who were married, most considered their spouse their strongest support.

Although the literature stresses the benefit of parents and grandparents of children with disabilities connecting through informal support systems such as parent support groups (Cooley, 1994; Kresack et al., 2014; Mu et al., 2009; O’Brien, 2001), very few family members in this study had availed themselves of such support. Jody and Antonia gained access to other parents through on-line support groups, and Anne had begun a parent-advocacy training class and had joined a mom’s group. Gary did not specifically seek out other parents of children with special needs but rather found support from
parents of children Rachel’s age at her daycare or through activities with his percussion ensemble. With the exception of Gary, who directly stated he had not sought informal support from parents whose children shared his child’s diagnosis and did not think he would find it helpful, most of the family members cited a lack of time rather than lack of interest. Consistent with the findings of O’Brien (2001), the child’s health status and finding someone to care for the child made it difficult for family members in this study to leave their homes, therefore they could not attend support group meetings. Co-workers also fell under the category of informal support. With the exception of Carlos’s co-workers, who threw him a fundraiser, the two additional parents who identified support from co-workers discussed receiving time off work, which seems to suggest a more formal type of support. Participants did not widely access support from church or neighbors, a further type of informal support.

Most of the support received from professionals fell under the category of access to information, although some tangible support was received from professional sources. Antonia was given hotel vouchers while she was away for her son’s surgery, and Maggie was receiving a prohibitively expensive prescription formula for her son through WIC. In spite of five family members displaying stress scores in the clinically significant range on their first PSI/SF, Anne was the only parent who sought professional counseling for herself. Parents appreciated having access to their child’s doctors and therapists, but Becky and Gary identified numerous or overlapping appointments to be time consuming and a cause for increased levels of frustration and stress, which is consistent with previous research (Townsley et al., 2004). As service coordinators, it is essential to
connect families to appropriate resources. Ensuring referrals are made to appropriate sources of support requires communication with the family to determine their needs; however, early intervention providers should inform parents of all forms of potential support.

Isolation has been identified by numerous researchers as a source of family stress for parents and grandparents of children who have complex medical needs (Carnevale et al., 2005; Enrione et al., 2005; Janicki et al., 2000; Ratcliffe et al., 2002). Isolation and stress were closely related in the stories told by family members in this study. Isolation took many forms, and each family member identified it differently, some more directly than others. Several factors contributed to isolation; however, the child’s condition primarily dictated family members’ ability to leave home. This finding is relevant for early intervention as a home-based service. Jody described complete isolation from anyone other than her immediate family and Ashley’s doctors. She portrayed her relationship with her developmental specialist as almost that of a friend. Understanding the close relationship between the isolation and stress experienced by these families and the need for social support is important as early intervention services are provided in the home.

Perception determines how an event is viewed not only by each individual family member, but also by the family as a whole (Boss, 2002). An important finding in this study was the impact of various family members’ perceptions on communication between spouses, satisfaction with early intervention services, and individual’s stress levels. Anne’s perception of herself as being to blame for her son’s medical condition was
contributing to her high levels of stress, whereas Gary’s perception of his parenting experience as fairly normal offered him protection from stress, resulting in scores within the low and normal ranges. Having an awareness of family members’ perceptions is critical to understanding their increased levels of stress and being able to offer support.

In this study I examined the stress experienced by five mothers, three fathers, and one grandmother. Prior research on the differences in stress experienced by mothers and fathers resulted in conflicting information. Some studies found differences between the two, and others did not (Pinelli, 2000). Many of the previous studies did not include fathers (Latour et al., 2011), and only one compared the stress experienced by parents and grandparents (Harrison et al., 2000). In this study, although there were subtle differences in family members’ responses, it would appear mothers and fathers were similar in their descriptions of family stress. An interesting finding is that the stress described by Diane, the only grandparent who participated in this study, was lower than either mothers or fathers. This is consistent with the research of Harrison et al. (2000), who found grandparents raising children with behavioral problems reported lower levels of stress than either single parents or married parents. This finding should be interpreted with caution; however, because this grandparent was the only participant whose Total Stress scores rose over the course of the study. It may be that grandparents are more susceptible to increased stress over time.

**Satisfaction with Early Intervention**

Overall, family members were fairly satisfied with the amount of early intervention services received with the exception of nutrition, which several participants
expressed a desire to increase. The child’s condition played an important part in determining families’ satisfaction with the amount of services received and explained the desire for increased nutrition services. Both Maggie and Diane, whose children are exclusively fed by g-tubes, expressed a desire for daily nutrition services. When Gary and Becky’s daughter experienced feeding difficulty due to her cleft lip and palate, they expressed a need for increased nutrition services; however, once her cleft lip was repaired their speech-language pathologist took a more primary role on her care team. Blann (2005) emphasized the focus of Part C early intervention on the family and supporting caregivers to meet the needs of their child. Ensuring adequate support for families is vital to family members in helping their child achieve outcomes. Although early intervention services is a developmental program, in cases where a child has complex medical needs and is receiving services such as nutrition, blurring between developmental and medical services can occur. Role conflict was identified as a factor in one parent’s dissatisfaction with her speech-language pathologist and a desire to discontinue the service. Another parent expressed the need for more speech services as the speech-language pathologist’s use of sign language did not appear to be an effective strategy for use by the parent when the therapist was not present. This mother’s perception appeared to be that her child would benefit from more speech therapy. The role of professionals in Part C early intervention is to assess, support, and monitor the child within the context of the family, providing services that fit into their everyday routines in a natural environment. Service providers must deliver services that address the family’s concerns and support parents in working on specific goals to help the child reach those outcomes.
In addition to examining family members’ satisfaction with the quantity of services received, I explored family members’ satisfaction with the quality of services. Participants identified access to information, communication, and connection as factors contributing to both their satisfaction with early intervention services and a reduction in stress levels. Gordon’s primary concern during our interview was getting his questions answered. This was what he wanted from Marcus’s doctor as well as his early intervention therapists. He suggested setting up an email box so he could send his questions ahead of time and the developmental specialist could bring the answers when she came on the next home visit. The need for information was a finding in several areas of this study. It affected family stress levels and satisfaction with early intervention services. Assisting families in gathering information is an important part of the developmental specialist’s role as service coordinator. Families rely on the developmental specialist to answer questions and help them process new information. Gaining knowledge, particularly about their child’s condition, helps to alleviate stress and increase family satisfaction with the early intervention services they are receiving.

Prior research has addressed the importance of communication as a factor contributing to increased stress for parents of children with complex medical needs (Latour et al., 2011). Similarly, the topic of communication arose in some fashion during interviews with every participant in this study. Several aspects of communication were identified. McIntosh and Runciman (2008) identified information sharing as one area where the balance of power as the expert frequently shifts back and forth between parents and health care professionals, thereby creating the potential for both increased partnership
and elevated stress. McIntosh and Runciman (2008) further found trusting relationships with parents are built on critical listening, respect, and empathizing with parents. Maggie’s experience with a therapist indicated her expertise on her child was not valued and the therapist was not listening to her. This resulted in Aiden vomiting during a therapy session, which created elevated stress for Maggie. Anne’s experience of having to argue with her speech-language pathologist is another example of an imbalance of power and a lack of communication between the family and therapist. Jody discussed the importance of speaking in family-friendly terms. She felt communication with one of Ashley’s doctors was thwarted because the specialist was using professional jargon rather than speaking to her in layman’s terms. Both Anne and Gary identified the need for parents to clearly state their wants and needs to their therapists; however, each indicated different reasons for doing so. Anne indicated a failure to do so may result in receiving unwanted services, while Gary suggested it would help the early intervention agency locate additional support for the family. These family members’ experiences illustrate the importance of effective communication. Gordon’s suggestion to use an email box to answer questions is a good example of the importance of discussing how family members would like to communicate and what form of communication would work best for them.

Connection was the final area participants identified as increasing their satisfaction with early intervention services. This was an interesting finding because the word connection was not found in my review of the literature, yet it was used in my interviews by three family members and described by two more. Antonia and Jody shared experiences of closeness and bonding with their early interventionists. For Antonia this
resulted in a feeling of being supported, and for Jody it became a family connection, as her developmental specialist included her older daughter in the home visits. When connection was absent, it affected parents’ satisfaction with the quality of services received. Anne felt her services were incomplete and Gordon actually had the perception some people did not want to work with his child. These families were caring for very young children with complex medical needs and receiving early intervention services in their homes. The families’ desire for connection may be closely related to the effects of isolation they experienced due to their children’s complex medical needs. Understanding the need for connection is vital to providing appropriate and effective services to these families.

**Boundary Ambiguity**

While several of the parents in this study expressed a desire for connection with their early intervention providers, this creates the potential for boundary ambiguity, which may become a source of stress. Role ambiguity, defined by Berg and Holm (2004) as internal family boundaries that defined who was responsible for what, was experienced by Anne with her speech-language pathologist and Maggie with another therapist. This caused increases in stress levels. Membership ambiguity, which referred to external boundaries that defined the difference between the family and the outside world (Berg & Holm, 2004), seemed to offer Jody and Antonia comfort and perhaps a reduction in isolation, as the lines blurred between their families and the early intervention teams. This occurrence appears to be unique to early intervention services, possibly because it is a home-based program. Although family members identified the value of many
supportive traits such as access to information and flexibility from both the early intervention program and their health care providers, connections with other professional services, such as the child’s doctor, were not mentioned. This finding is important because boundary ambiguity is a double-edged sword. While it is important to develop a compassionate relationship with families to provide an adequate level of support, professional boundaries need to be maintained, and role ambiguity should be avoided.

**Limitations of the Study**

This study examined the relationship between the stress experienced by eight parents and one grandparent of children with complex medical needs and their participation in early intervention services using a mixed methods approach. One limitation in this study was the small sample size. Statistical significance was found on all but one of the paired samples t-tests. The PD subscale, which did not demonstrate a statistically significant difference between the pre and posttests, had a medium effect size. With a larger sample, the t-test may have had enough power to reach statistical significance.

Recruitment for this study proved to be difficult due to the subject matter and the population being studied. Although attempts were made to involve families from all agencies providing early intervention services in the area, families from only one agency were enrolled in the study. The experiences of these nine family members were unique and cannot be assumed to generalize to families receiving services from other agencies or residing in other areas. The participants in this study all lived within 30 minutes of a large city within a western state. These findings may not reflect the experiences of families in
larger urban communities or rural/remote locations. Further, the experiences these families had with therapists may not generalize to service providers in agencies outside of early intervention or in other areas of the country.

Use of the FSS to guide semi-structured interviews produced rich data; however, because the participants did not complete the scales statistical data could not be run on them. Having the participants complete the scales and then follow up with interviews may have produced more rigorous data and would have fit nicely into the mixed methods approach.

Family members in this study represented a fairly diverse group. Of the nine participants, six were Caucasians, two were of Latin descent, and one was African American. This group included five mothers, three fathers, and one grandmother. Eight participants were married, and one was a single mother. Four of the mothers stayed home with their children, and one worked full time. All of the fathers were employed full time, and the grandmother was retired. Even with such diversity in this small group, some populations were absent. These participants were all able to speak and read English. Stress levels may have been different for parents of children with complex medical needs whose language was not English. Culture may also play a role as stress levels may be different for parents with large families living together or in close proximity.

The families in this study all had family incomes of less than $50,000. Given the relationship between stress and socio-economic status, stress levels for parents of children with complex medical needs with higher incomes, or those challenged by unemployment status may have been different from the participants in this study.
The majority, (8 of 9) participants, identified an improvement in the child’s condition as the primary reason for their decreased stress levels. For one family, whose children’s condition did not improve, stress levels rose over time. If all of the participants had children with similar prognoses, the results from this study may have been different. Six participants did not complete the study. Two of these participants voluntarily exited because they were moving out of state. The other four were lost to contact; however, it is possible their inability to complete the study may be linked to their level of stress and not being able to manage one more responsibility.

**Implications for Future Research**

The findings from this study point to several directions for future research. Given the paucity of literature on the relationship between early intervention, parental stress, and children with complex medical conditions, more research is needed in this area. Larger samples are necessary so quantitative methods can more effectively assist with the generalization of findings. Inasmuch as Part C early intervention services are found throughout the entire country, this study should be repeated in different areas, including urban and more remote locations, to determine the specific needs of families in those areas.

The finding that only one parent was receiving professional counseling in spite of clinically significant stress levels in over half of this study’s sample on the initial PSI/SF, highlights the need for further research to investigate support systems available to families of children with complex medical needs. Was counseling not an option for other members of this group? Was it offered? Further, given the challenges these family
members faced in leaving their homes due to their children’s medical status, it is important to investigate how counseling services can be provided within a home environment.

More research is required to explore this study’s unique finding of family members’ descriptions of connection with their early intervention providers. What is connection? Why do family members describe it with early intervention but not other forms of formal support? How is it related to isolation and parental stress?

Further research is required to examine the role boundary ambiguity plays in stress for families receiving early intervention services. Given the potential for boundary ambiguity to either create or alleviate stress, there is much to explore in this area. Future research in the area of boundary ambiguity could have strong implications for guiding practice.

This study examined the stress levels of family members caring for children with complex medical needs who were receiving early intervention services. It would be interesting to explore parental stress for other groups of children who are newly enrolled in early intervention. Babies are now being referred to early intervention services if they fail their newborn hearing test. How would the results from this study be similar or different for a population of family members whose children were diagnosed as deaf or hard of hearing at or shortly after birth and were receiving early intervention services?

**Recommendations for Practice**

In this study I asked participants what they would want a new developmental specialist to know if they had the opportunity to train one. Although the answers were
different for each individual, they fell into three categories. For these family members, having access to information, communication, and connection were important.

Service coordinators need to assist families in gathering information that is current, accurate, and relevant to the specific situation with which they are dealing. These family members have questions that need to be answered; however, providing information that does not address family concerns may increase family stress. Deciphering what information family members need requires communication, which was the second item family members identified.

The need for communication was addressed in some form by every participant in this study. Many had suggestions for developmental specialists to foster communication with family members including having on-going conversations with families, providing access to contact information, speaking in family-friendly terms, and listening when parents and grandparents shared knowledge of their child. Effective communication fosters trust, helps build rapport, and is the only way to determine the needs of families. Service providers cannot presume to know what a family needs or what strategies will be effective for their child without asking them. Service providers need to be both willing and able to start the conversation and listen to families’ experiences in order to provide proper services. Failure to do so destroys trust and increases parental stress levels.

Service providers need to be aware of family members’ desire for connection with their early interventionists. While it is important to establish a relationship with the family, service providers must approach cautiously so as not to cross into role conflict. Parents are the experts on their own child and must be respected as such. The family
members in this study submitted to professionals’ judgment in several cases, and this was wrong, as it resulted in dissatisfaction with the services being offered. Understanding the need for connection is vital to provide appropriate and effective services to these families. It is important to consider how information on developing a connection with families can be part of professional development and ongoing in-service programs for those choosing to provide early intervention services.

The alarming stress levels reported by this study’s participants when they began early intervention services point to the need for training on signs of stress in family members caring for children with complex medical needs. Service providers should know the resources available in their community in order to make appropriate referrals; however, they first must recognize the need.

**Summary**

The period from birth to 3 is a critical time for children and families. For families of children with complex medical needs, it is even more so. As the number of children with special health care needs continues to rise, so does the need for support. Families enter early intervention services when they are at their most vulnerable and desperately need help. Offering appropriate and adequate support is vital to reducing family members’ stress and allows them to focus their energy on caring for their child.

Early intervention providers are in a unique position to offer assistance to these families. In addition to providing valuable information, which a family relies on to improve their child’s condition, they may offer emotional support to reduce the crippling isolation that contributes to increased stress. Family members in this study identified
communication and connection as important to establishing a relationship with their service providers. Even when family members were dissatisfied with their services, they were reluctant to give them up. Service providers need to be vigilant in ensuring the services being offered are meeting the current needs of the child and family.

Findings from this study indicate the need for further research in several areas including: the relationship between family stress and early intervention services, boundary ambiguity, and connection. Findings further reveal the necessity for training service providers in identifying family stress so they are able to make appropriate referrals. Service providers cannot rely on family members to voice concerns; however, the candor these participants displayed when asked to share their stories suggests their willingness to discuss the topic of stress. Early intervention service providers have the opportunity to reduce family stress by being accessible, knowing the child and family, and establishing effective communication. With adequate support, Gordon and others like him need not be left alone in that “dark tunnel,” feeling like prisoners to their child’s health.
REFERENCES


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APPENDIX A – LETTERS OF PERMISSION TO USE COPYRIGHTED MATERIALS

RE: Permission to use figure from book in dissertation

[Binur, Michelle [Michelle.Binur@sagepub.com] on behalf of permissions (US)
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Sent Friday, January 02, 2015 11:01 PM
To: Pamela D’Young

Dear Pamela Young,

Thank you for your request. You are granted permission to use the material as detailed below in your upcoming dissertation. Please note that this permission does not cover any third-party materials that may be found within the work. We do ask that you properly credit the original source, *A Concise Introduction to Mixed Methods Research*. Please contact us for any further usage of the material, including republication.

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Dear Sage Publications,

I am doctoral candidate at the University of Nevada, Reno. I am preparing to defend my dissertation research on parental stress for families with intensive and intensive intervention teachers. I used the Explanatory Sequential Design, described in *A Concise Introduction to Mixed Methods Research* ( Creswell, 2013) for my research study.

During a recent meeting with my committee members I showed them the visual representation of this design from page 39 of the above mentioned book and it was very helpful. The purpose of my contact with you today is to ask permission to use figure 4.2 Explanatory Sequential Design in my dissertation without modifications or alterations. Thank you for your time and consideration in reading this request. I look forward to hearing from you soon.

Sincerely,

Pamela Young

https://www.unr.edu/aa/1/sr/12/14/2014/14112/4295/... 1/2/2015
FW: Permission to use Contextual Model of Family Stress for doctoral research

Pamela D Young
Sent: Friday, February 20, 2015 11:13 PM
To: pyoung@umce.edu

From: pcache@umce.edu [pcache@umce.edu]
Date: Thursday, November 30, 2012 10:11 AM
To: Pamela D Young
Subject: Re: Permission to use Contextual Model of Family Stress for doctoral research

Dear Pamela,

You have my permission to use the figures but please give full reference to me and the book and the publisher (Stapel). When your research is done, please send abstract and full reference so I can add you to the list of research on boundary ambiguity that we want to include in a review.

Pauline Boss

On Sep 5 2012, Pamela D Young wrote:

Dr. Boss,

I am a doctoral candidate at the University of Nevada, Reno. I am preparing to conduct a dissertation research on parental stress for families with infants and toddlers who are medically fragile and receiving home-based Early Intervention services. Your Contextual Model of family stress will provide the conceptual framework upon which to build this study. The unique concept of boundary ambiguity and its contribution to potential role strain between service providers and parents is what led me to your model. Based on what I have read in your book, I think it will be an important method for my research topic and the mixed methods design that I will be using.

During my dissertation proposal meeting, several committee members suggested that it would be helpful to have a visual representation of the model. The partner in my contact with you today to ask permission to use Figure 3.1 from your book Family Stress Management: A Contextual Approach, Second Edition (c) 2011 in my dissertation without adaptation or alterations. Thank you for your time and consideration in reading this request.

Sincerely,

Pan Young

Pauline Boss, Professor Emeritus
University of Minnesota
pboss@umn.edu 612 644 3024
www.paulineboss.com

https://owa.umn.edu/owa/?se=item&title=IPM.Note&n=1884&n=1074XXie6ct...  2/20/2015
APPENDIX B – AGENCY CONSENT AGREEMENTS

Family Stress and Early intervention for Families With Infants and Toddler Who are Medically Fragile

Letter of consent to participate in research

Attention University of Nevada, Reno Institutional Review Board:

Please note that Pamela Young, Doctoral Candidate in the College of Education at the University of Nevada, Reno, has permission from [Name of Institutional Review Board] to conduct research with families who are receiving early intervention services from our agency for their study, "Family Stress and Early Intervention for Families with Infants and Toddlers Who Are Medically Fragile".

We understand that families will be contacted and recruited for this study by providers of their Part C services, and may agree to have their records reviewed by Ms. Young as part of the study. Once families have expressed an interest in participating, their information will be given to Ms. Young and she will then be in contact to enroll them in the study. The plan is to have all interested parents enrolled in the study within three months after approval from the University of Nevada, Reno Institutional Review Board is granted.

Ms. Young will be asking each parent who participates in the study to complete a family demographics form at intake, and the Parental Stress Index short form at intake and again six months later. She will compare the change in stress scores after six months of services to the number of hours of early intervention service the family receives monthly. Individual parents who displayed a higher or lower than average change in stress scores over the six month period may be asked to participate in a face to face interview with Ms. Young after the completion of their second Parental Stress Index to help explain those results.

Ms. Young will compensate families for their time with a list of resources to assist parents in combating stress, and a copy of the study results when they are completed. She will also present the study results to the participating agency if desired by the agency.

Sincerely,

[Signature]

Name

[Signature]

Date: 11/10/13
Family Stress and Early Intervention for Families With Infants and Toddlers Who are Medically Fragile

Letter of consent to participate in research

Attention University of Nevada, Reno Institutional Review Board:

Please note that Pamela Young, Doctoral Candidate in the College of Education at the University of Nevada, Reno, has permission from Julie Ortiz, Advanced Practice Nurse, to conduct research with families who are receiving early intervention services from our agency for her study, “Family Stress and Early Intervention for Families with Infants and Toddlers Who Are Medically Fragile”.

We understand that families will be contacted and recruited for this study by provider of their Part C services, and may agree to have their records reviewed by Ms. Young as part of the study. Once families have expressed an interest in participating, their information will be given to Ms. Young and she will then be in contact to enroll them in the study. The plan is to have all interested parents enrolled in the study within three months after approval from the University of Nevada, Reno Institutional Review Board is granted.

Ms. Young will be asking each parent who participates in the study to complete a family demographics form at intake, and the Parental Stress Index short form at intake and again six months later. She will compare the change in stress scores after six months of services to the number of hours of early intervention service the family receives monthly. Individual parents who displayed a higher or lower than average change in stress scores over the six month period may be asked to participate in a face to face interview with Ms. Young after the completion of their second Parental Stress Index to help explain those results.

Ms. Young will compensate families for their time with a list of resources to assist parents in combating stress, and a copy of the study results when they are completed. She will also present the study results to the participating agency if desired by the agency.

Sincerely,

[Signature]

Name

1/7/13

Date
Family Stress and Early Intervention for Families With Infants and Toddler Who are Medically Fragile

Letter of consent to participate in research

Attention University of Nevada, Reno Institutional Review Board;

Please note that Pamela Young, Doctoral Candidate in Educational Specialties at the University of Nevada, Reno, has permission from the Early Intervention Services of the Nevada Department of Education to conduct research with families who are receiving early intervention services from our agency for her study, "Family Stress and Early Intervention for Families with Infants and Toddlers Who Are Medically Fragile".

We understand that families will be contacted and recruited for this study by providers of their Part C services, and may agree to have their records reviewed by Ms. Young as part of the study. Once families have expressed an interest in participating, their information will be given to Ms. Young and she will then be in contact to enroll them in the study. The plan is to have all interested parents enrolled in the study within three months after approval from the University of Nevada, Reno Institutional Review Board is granted.

Ms. Young will be asking each parent who participates in the study to complete a family demographics form at intake, and the Parental Stress Index short form at intake and again six months later. She will compare the change in stress scores after six months of services to the number of hours of early intervention services the family receives monthly. Individual parents who displayed a higher or lower than average change in stress scores over the six month period may be asked to participate in a face to face interview with Ms. Young after the completion of their second Parental Stress Index to help explain those results.

Ms. Young will compensate families for their time with a list of resources to assist parents in combating stress, and a copy of the study results when they are completed. She will also present the study results to the participating agency if desired by the agency.

Sincerely,

[Signature]
Name

[Signature]
Date
BIOGRAPHICAL SKETCH

Born and raised in Manitoba, Canada, Pam Young grew up with a family of farmers who valued strong work ethics. The first college graduate in her immediate family, Ms. Young received an associate degree in Early Childhood Education in May, 1989 and began a career in child care. She returned to school to complete a Bachelor of Science in Early Childhood Education in December, 2005, and a Master’s of Education in Early Childhood Special Education in December, 2007 after relocating to the USA in October, 2000. Upon graduating from the Master’s program she began work as a developmental specialist with the state’s Part C early intervention services.

Although there are no career changes planned after completing the doctoral program, Ms. Young intends to continue conducting research on family stress with families who are receiving early intervention services. A current area of interest is families of children diagnosed with hearing loss as a result of concerns detected on the newborn hearing screening.

Ms. Young lives in Reno and frequently visits her family in Canada. She enjoys hiking, cooking, reading, and yoga.