THE LIVED EXPERIENCE OF PARENTS OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS ON PUBLIC AND PRIVATE INSURANCE: A PHENOMENOLOGICAL STUDY

by

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A Dissertation Submitted to the Faculty of Christine E. Lynn College of Nursing In Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

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This dissertation was prepared under the direction of the candidate’s dissertation advisor, Dr. Lenny Chiang-Hanisko, Department of Nursing, and has been approved by all members of the supervisory committee. It was submitted to the faculty of the Christine E. Lynn College of Nursing and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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ABSTRACT

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Due to recent advances in medical technology, the number of children with special healthcare needs (CSHCN) is steadily growing in the United States. CSHCN comprise more than 40% of overall healthcare costs nationwide, even though this group is only comprised of 16% of the U.S. child population. There are significant differences between private and public health plans in terms of cost, adequacy, and parent satisfaction. As an added benefit, some public and private health insurance plans offer nursing care coordination (or nursing case management) services. The purpose of this study was to understand the experiences of parents of CSHCN enrolled in public and private insurance with or without a nurse care coordinator assigned. A phenomenological approach was used. One-to-one semi-structured interviews were conducted with 16 participants. Colaizzi’s (1978) eight steps of data analysis was the selected methodological interpretation. Five themes emerged from this study: Struggle with Self-Preservation, Abandonment and Isolation, Self-Reliance and Advocate, Interdependence,
and Lifeline. These study findings highlighted the major differences with parents navigating their child’s health insurance. These differences were dependent on the type of insurance and sources of support available. The experience of parents with a nurse care coordinator differed from parents without a nurse. Parents of CSHCN enrolled in public insurance with a nurse care coordinator considered the nurse to be a primary source of support. These nurses were instrumental in solving problems with the public health plan. On the contrary, parents with CSHCN enrolled in private insurance without a nurse care coordinator carried this additional burden. There were also noticeable differences in parents’ satisfaction with the adequacy and cost of their child’s health insurance. Parents of CSHCN enrolled in private insurance voiced dissatisfaction with higher costs associated with their child’s plan. Meanwhile, parents of CSHCN enrolled in Medicaid expressed that out-of-pocket expenses were covered. Results from this study can be used to make policy changes by insurance companies. Incorporating nursing care coordination not only results in healthcare savings for the health plan but improved health outcomes for its members as well.
DEDICATION

This manuscript is dedicated to my family, particularly, my parents, Jean-Claude and Luce Andre, who taught me strength and perseverance. Thank you for showing me the value of education. I thank my grandmother, Cia, for continuing to watch over me. To my sister, Mary-Lee, who persistently advocates and fights for my niece, Jade, while still being a wonderful mother to my oldest niece, Lina. To my best friend and sister, Hernrika, for her continued support and reminders about my faith in God during the difficult times. Last, but not least, thank you to my husband, Sam, for the unconditional love. Thank you for always understanding the late nights and hours of writing. Thank you for being my life partner and loving me through the beautiful and the ugly times.
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CHAPTER 1. INTRODUCTION

The purpose of this chapter is to describe the phenomenon of interest, background, and link to caring science for parents with children diagnosed with special healthcare needs (CSHCN). This chapter will also discuss the purpose, goals, aims, and research questions for this study.

Phenomenon of Interest

Due to recent advances in medical technology, the number of CSHCN is steadily growing in the United States. According to the United States Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), and the Maternal and Child Health Bureau (MCHB), CSHCN are defined as “…those who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998, p. 137). These conditions can be expected to last at least 12 months or longer. Hence, the number of children with either acquired or congenital conditions as well as varying degrees of chronicity continues to increase (Graham, 2008). CSHCN comprise more than 40% of overall healthcare costs nationwide, even though this group is only comprised of 16% of the U.S. child population (Child and Adolescent Health Measurement Initiative [CAHMI], n.d.).

Some of the most common conditions of CSHCN include physical conditions such as muscular dystrophy, multiple sclerosis, chronic asthma, and epilepsy. Common developmental conditions are Down’s syndrome, autism, dyslexia, and processing
disorders. Examples of behavioral or emotional disorders include attention deficit disorder, bipolar disorder, and oppositional defiance disorder. Lastly, common sensory impairments include blindness, visual impairment, and deafness. Although advances in medical technology have been beneficial for CSHCN, accessing services that are appropriate through timely and affordable means remains a challenge (CAHMI, n.d.). This presents as an arduous task and challenge for parents caring for these children.

**Background and Significance**

According to MCHB, approximately 20% of children under the age of 18 were diagnosed with a special healthcare need between 2011 and 2012. This represented about 14.6 million children residing in the United States (HHS, HRSA, & MCHB, 2014). Moreover, 23% of American households had at least one child with a special healthcare need (HHS, HRSA, & MCHB, 2013).

In terms of costs, parents of children with special healthcare needs experience increased financial burden. Expenses for chronic conditions such as cystic fibrosis, muscular dystrophy, cardiac issues, and emotional problems can range anywhere from $2,669 to $69,906 in annual out-of-pocket medical costs (excluding monthly insurance premiums). This was compared to costs for families of children without special healthcare needs, which ranged from $676 to $3,181. Also, monthly premiums ranged from $2,058 to $3,593 based on a family’s health insurance plan. Unfortunately, parents must deal with costly healthcare expenses and the additional costs of durable medical equipment (DME), medications, food, and housing requirements such as electricity and heat. Caregiver burden is further complicated when parents lose their primary income if
they are unable to work regular hours, miss work, or quit their job because of their child’s needs (Lindley & Mark, 2010).

**Sociodemographic Differences**

There are profound differences between sociodemographic characteristics. In terms of gender, more males were reported to suffer from special health care needs versus females (22.5% versus 17.0%, respectively). Interestingly, school aged children had a higher incidence of special healthcare needs compared to children from birth to age 5. Additionally, one-quarter of children ages 6-11 and 12-17 years were reported as having a special healthcare need (22.7% and 25.1%, respectively) versus 11.4% of children from birth to 5 years (HHS, HRSA, & MCHB, 2014).

When race and ethnicity were examined, African American children had the highest rate of suffering from a special healthcare need as compared to their Caucasian counterparts (24.2% versus 21.6%, respectively). Hispanic children had the lowest rate, with 14.7%. In terms of primary language spoken, children who resided in English-speaking homes (21.9%) had a higher prevalence of special healthcare needs compared to homes where another language was the primary language spoken (8.7%) (HHS, HRSA, & MCHB, 2014).

Children residing in homes where at least one adult earned a high school diploma were found to have more special healthcare needs compared to those who lived in households where an adult did not complete their high school education (approximately 20.5% versus 15.9%, respectively). Children who resided with two biological parents (16.4%) had lower incidences of special healthcare needs compared to other family arrangements (approximately 26%) (HHS, HRSA, & MCHB, 2014).
Parents’ Quality of Life

Being a parent of a child with a special healthcare need has significant impacts on quality of life (QOL) as compared to being a parent with a child not diagnosed with a special healthcare need. According to the World Health Organization (WHO, n.d.), QOL is defined as “the individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.” The definition is further defined as “a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment” (WHO, n.d.).

Not only is QOL an issue for CSHCN, but the parents’ QOL is affected by the condition of their children. Parents of children with autism have poor health outcomes as compared to the normative population (Kuhlthau et al., 2014). In terms of health-related quality of life (HRQOL), single parents and parents with more than three CSHCN experience greater caregiver burden and higher depression symptoms. Parents’ physical health is also affected since the focus remains more on their child and less on themselves. As a result, they neglect their own health and eat improperly. Kuhlthau et al. (2014) also asserted that 45% of parents report experiencing moderate or severe pain and discomfort. Parents will also push through their illnesses and miss their own medical appointments. The responsibility of caring for a CSHCN further affects their mental health. Mothers experience increased levels of anxiety as well as stress. This is further complicated by feelings of isolation, frustration, and guilt because of the stigma of having a CSHCN.
Overall, parental HRQOL is negatively influenced by their child’s autism spectrum disorder (ASD; Kuhlthau et al., 2014).

Similarly, HRQOL has been examined in relation to physical, mental, and social well-being from the disabled child’s perspective (Sylvester et al., 2014). Overall, children provide positive reports pertaining to family relationships, school, and their physical health. However, children feel differently about social activities with their peers. CSHCN feel sad and excluded from activities. These feelings are similar with expectations of achieving academic qualifications and furthering their education. Perceived QOL in terms of school, friendships, and peer support are overall lower than their European counterparts (Sylvester et al., 2014).

Thus, significant differences exist in terms of age, race, ethnicity, and economic status for CSHCN. The severity of their conditions adversely affects their own quality of life as well as their parents’ HRQOL. Parents are willing to neglect their own healthcare needs to assure that their child’s medical needs are met. This neglect can result in significant adverse effects for parents in the future, which may jeopardize their ability to adequately care for their children.

**History of Children with Special Healthcare Needs**

It is important to understand both the past and present state of children with special healthcare needs. During the 19th century, children with disabilities were either hidden from the public or killed. The burden of this stigma created feelings of guilt or shame after giving birth to a child who was different. It was also common for the child’s condition to be blamed on the parents and their sins. Sadly, facilities that cared for the ill or disabled children did not exist until the mid-19th century. Like ill adults, children were
sent to municipal almshouses if they could not be cared for at home. It was not until the 1860s that hospitals for children became a necessity because general hospitals refused to admit children (King, 1993).

During the 1940s and 1950s, parents of children with disabilities began advocating for education and services. Public views began changing after wounded and disabled veterans returned home from World War II. The civil rights movement and the feminist movement further contributed to these changing views. Ultimately, several legislative actions were later signed into law including the Education of All Handicapped Children Act of 1975 (EAHCA, 1975), later renamed the Individuals with Disabilities Education Act (IDEA, 2004) and the Americans with Disabilities Act of 1990 (ADA, 1990). With these laws in place, individuals with special healthcare needs had access to reasonable accommodations for education, employment, technology, and transportation. Thus, the perception of children with disabilities has evolved over time (King, 1993). Different insurance plans for children’s healthcare would ultimately become an important issue in the United States.

**Insurance for Children with Special Healthcare Needs**

According to Preskitt et al. (2013), having adequate health insurance, particularly for CSHCN, is crucial for overall good health. Adequate health insurance ultimately leads to lower unmet health needs and coverage from higher financial burden. Unfortunately, having adequate insurance is more complex than simply having coverage (Preskitt et al., 2013). Parents perceive that their child’s health insurance is inadequate (13%), does not cover costs sufficiently (28%), or does not permit the child to see providers (9%) (Szilagyi, 2012). Due to high increases in healthcare costs, high deductible plans were
eventually formed. Although families paid lower monthly premiums, they were still faced with the burden of paying higher deductibles (Szilagyi, 2012).

Although there are limitations for CSHCN covered privately, children covered by insurance are more likely to have a pediatrician, can reach a specialist, and have access to supportive services. CSHCN who are insured had lower unmet needs in terms of medical and dental care and received this type of care quickly. Ultimately, having health insurance also improved access to care for children who were both healthy and suffered from a special healthcare need (Szilagyi, 2012).

There are marked differences between public and private insurances. Thomas et al. (2016) examined parent’s insurance ratings, child expenditures, and financial burdens among children with autism. Parents of children enrolled in Medicaid reported having insurance that was adequate as compared to those parents of children enrolled in private insurance. The lowest out-of-pocket costs were found with Medicaid (Thomas et al., 2016). In terms of expenditures, higher total expenditures derived from those children covered under private insurance and Medicaid wrap-around services ($11,596) and the highest expenditures paid by their insurance ($10,638). Wrap around services are defined as services not covered by the private insurance that are necessary to meet the desired outcomes. Thus, Medicaid covers these unmet needs. In regards to Medicaid, children covered by this program fell in the middle category for expenditures ($7,238 and $7,088; \( p < .0001 \)). Lastly, autistic children who were insured privately had lower total expenditures and lower costs paid by insurance ($4,486 and $3,151) (Thomas et al., 2016).
Overall, parents with CSHCN enrolled in public insurance spent less for out-of-pocket costs while those under private insurance had higher expenditures. While there are differences as far as costs, some public and private health insurance plans offer nursing care coordination services (or nursing case management) as a benefit.

**Public Funding for Children with Special Healthcare Needs**

Public funding for CSHCN is divided into several types of programs: Medicaid, Children’s Health Insurance Program (CHIP), and Medicaid waivers. Medicaid and CHIP are two major programs that were monumental in the financing and delivery of services to children with special needs. According to Szilagyi (2012), “nearly half of children with special healthcare needs who have insurance are covered by one of these two programs; 90 percent are enrolled in Medicaid, the other 10 percent in CHIP” (p. 129).

Medicaid serves low income individuals, the disabled, and children. Although Medicaid is financed by federal and state governments, each state creates their own eligibility guidelines. CHIP, also known as Title 21, provides coverage for those children whose parents fall into a higher income bracket and do not qualify for Medicaid (Goldstein et al., 2010).

Under Title 21 of the Social Security Act (SSA, 1965), CHIP was first introduced in 1997 and later reauthorized in 2009. An estimated seven million children are covered by CHIP. Similar to Medicaid, each state is responsible for determining eligibility based on family income. For states that administer the program separately from Medicaid, services are generally limited and do not include ancillary services such as occupational, physical, or speech therapy. Additionally, CHIP includes the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program, which provides diagnostic and
treatment services for children suffering from chronic illnesses. EPSDT plays an important role because of its availability of non-covered services (Goldstein et al., 2010).

Lastly, Medicaid waivers provide long-term care services in the community to individuals with disabilities who would otherwise reside in institutional settings. Medicaid waivers originated with Katie Beckett, a ventilator-dependent child diagnosed with complex needs who resided in an institution for most of her life. Goldstein et al. (2010) explained that Katie’s expenses would be covered as long as she remained at an institutional facility. However, if she transitioned home from the facility, her benefits would be ineligible because of her parents’ income. A provision under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA, 1982) was later enacted that allowed children with complex healthcare needs to transition home with no change to their federal aid (Goldstein et al., 2010).

Overall, Medicaid, CHIP, and Medicaid waivers are programs that make access to care and services a possibility for CSHCN. With advances in technology, the delivery of quality healthcare and appropriate funding continue to be challenges and major issues. Hence, it is important to highlight the experiences of parents managing and navigating the healthcare system.

In 2017, the Senate took legislative action to repeal the Patient Protection and Affordable Care Act (ACA, 2010). Repealing the ACA would have subsequently resulted in significant changes to healthcare for CSHCN whether they had public or private coverage. Currently, Medicaid coverage for children ages 6 to 18 extends to families who fall below 138% of the federal poverty line (FPL). Repealing the ACA would have resulted in the FPL eligibility returning to 100%, which would have impacted
approximately 1.5 million children in 21 states (Schubel, 2017). This ultimately would have changed how Medicaid was financed as well as end Medicaid expansion. This expansion made it possible for young adults with special healthcare needs to have coverage once they reached adulthood. Without this expansion, many young adults would not meet the criteria for Social Security Income disability (Schubel, 2017).

Similarly, Medicaid plays an important role in CSHCN covered privately. According to the Center on Budget and Policy Priorities (Schubel, 2017), Medicaid covers approximately 44% of CSHCN. This coverage extends to children under private insurance who depend on Medicaid for wrap-around coverage for services not covered by their private plan. This additional assistance allows healthcare to be affordable for many families who would otherwise have limited means of paying for services not covered privately (Schubel, 2017).

CHIP covers approximately nine million children among middle-class families across the United States (Schubel, 2017). The benefits for families and communities from CHIP are many. First, CHIP is crucial in providing financial security and prevents families from suffering catastrophic losses. CHIP not only benefits children who are healthy but those with complex, special healthcare needs as well. This program assures that comprehensive needs are met. In 2017, Congress was unable to reauthorize CHIP by the September 30th deadline (Schubel, 2017). However, funding was later approved retroactively from 10/1/2017 to 9/20/2023 (Brooks, 2018).

**Private Funding for Children with Special Healthcare Needs**

Adequacy and continuity in health insurance coverage are positively associated with reductions in delayed care as well as access to primary and specialty care.
According to Ghandour et al. (2015), the proportion of CSHCN insured by private insurance declined from 64.7% to 50.7% between 2001 and 2009-2010. The proportion of children enrolled in private insurance plans with adequate coverage also declined from 62.6% to 59.6% (Ghandour et al., 2015).

Data from the National Survey of Children with Special Healthcare Needs NS-CSHCN was used to analyze coverage and adequacy of health insurances from 2009-2010 and to evaluate changes since 2001 (Ghandour et al., 2015). Consistency and adequacy were measured by the following: coverage status; gaps in coverage; coverage of needed service; reasonableness of uncovered costs; and ability to see needed providers, as reported by parents. In terms of adequacy measures, CSHCN with private insurance did not show improvements with two of the three areas: “usually/always met their needs” and “ability to see needed providers.” CSHCN with private insurance also experienced a decline in “affordability with coverage” and the “proportion with costs not covered by insurance that were usually or always reasonable” decreased from 69.2% to 63.8% (Ghandour et al., 2015, p. 456).

Kreider et al. (2016) conducted a cross sectional analysis and compared healthcare access, quality, and cost outcomes by insurance types (Medicaid, CHIP, private insurance, and uninsured). Data were derived from the U.S. National Survey of Children’s Health for a sample of 80,655 children in families with low to moderate incomes. Children enrolled in private insurance were more likely to come from two-parent households where the parent’s education level was greater than high school and parents were more likely to be White (Kreider et al., 2016).
Access to care as well as costs were challenges for families of children enrolled in private insurance. Parents of privately insured children expressed difficulty with accessing specialty care as compared to children enrolled by CHIP and Medicaid. Sixty-three percent of parents reported that their child’s needs were met by their private insurance as compared to 73% of parents with children enrolled in CHIP and 76% of parents with CSHCN enrolled in Medicaid. Twenty-eight percent of parents with CSHCN enrolled in Medicaid reported feelings of frustration with obtaining healthcare services as compared to 36% of parents with CSHCN enrolled in private insurance. In terms of cost, CSHCN on private insurance were more likely to experience out-of-pocket expenses as compared to children insured by Medicaid and CHIP (Kreider et al., 2016).

**Nursing Care Coordination**

Nursing care coordination is a benefit that many health plans offer. This care coordination team may consist of a multidisciplinary team that includes registered nurses, physicians, therapists, and social workers. However, the perspective and focus of each discipline may vary. For example, social workers provide nonmedical interventions for clients. They assess nonmedical issues and assure that clients are linked to appropriate community resources (Rowe & Rizzo, 2013). According to the Robert Wood Johnson Foundation (2011), social and economic barriers inhibit a client’s ability to comply with their prescribed medical treatment. This may lead to new or exacerbated medical conditions and can also affect healthcare utilization, treatment plan adherence, and healthcare outcomes (Rizzo et al., 2016).

There is value, however, in the role that registered nurses play when coordinating care. Nurses have an expanded depth and breadth of knowledge that integrates a medical
background with nursing knowledge. Registered nurses possess an advanced clinical skill level that aids in the care coordination process. Nurses can also obtain specialized certifications in case management. This certification enhances the expertise and knowledge of coordinating care for individuals with complex medical conditions. Theoretical frameworks and research knowledge grounded in evidence also add to the value of registered nurses. In addition, nursing care coordination includes visits to clients’ homes and to hospitals. Most importantly, registered nurses work with both physicians and families on how to best meet the care plan goals (Looman et al., 2013).

Many health insurance plans offer nursing care coordination services to help special needs families navigate a very complex healthcare system. This is especially true for children covered through publicly funded health programs such as Medicaid. Unfortunately, this is not the case for many CSHCN covered under commercial insurance.

According to the American Nurses Association (ANA, 2012), care coordination is “foundational to the health care reform goals of improving the quality of care for individuals and populations via the efficient and effective use of resources.” The Agency for Healthcare Research and Quality (AHRQ, 2018) stated that nursing care coordination includes helping families with referrals; assessment that is comprehensive; planning of care; client and family participation; and monitoring, follow-up, and referral to community partners. AHRQ further stated that care coordination assures that the needs of the client are met over a period of time. Care coordination also organizes care activities orchestrated primarily by health care providers. It is not limited to the healthcare team but also involves input from clients and their families (AHRQ, 2018). Ultimately,
coordination of care encourages client-centered care while a multidisciplinary team is actively involved.

In addition to meeting the needs of patients and working closely with providers, care coordination has significant contributions from a health outcomes perspective. According to the ANA (2012), care coordination contributes to reductions in emergency department visits, significant savings per patient, and improved quality of care as well as overall improved patient satisfaction. ANA also affirmed that care coordination contributes to “significant increases in survival with fewer readmissions, increased patient confidence in self-managing care and improved clinical outcomes and reduced costs.”

Many states have implemented programs focused on care coordination activities to better manage the needs of CSHCN. In 2013, the state of Ohio transitioned children enrolled under their Medicaid plan from a fee-for-service structure to managed care plans. According to Song et al. (2016), Partners for Kids is a pediatric accountable care organization (ACO) that manages the financial responsibility of approximately 8,000 children. It is the nation’s largest pediatric ACO and includes a care coordination component for children identified as high risk. The program the ACO implemented consists of selecting patients, staffing, working with managed care organizations, and streamlining records (Song et al., 2016).

In terms of staffing, training was provided for registered nurses and social workers. An unlicensed staff coordinator was also added to support the nurses and social workers. This three-member team managed the care of approximately 75 to 150 CSHCN. Their primary functions included home visits, communication by phone, and
collaboration with providers. Next, working with managed care organizations guaranteed “formal care management plans” where care coordinators “have greater access to providers and their offices, where meetings with patients can occur” (Song et al., 2016). Lastly, streamlining records involved documenting all care coordination activities in an electronic medical record. Essentially, the program the ACO implemented resulted in gains from a cost-saving and health outcome perspective. Among a cohort of 163 children, the following results were found: inpatient admissions declined by 53%, total inpatient days decreased by 42%, and there was a 22% decline in emergency department visits (Song et al., 2016).

Similarly, the state of Florida implemented a program that emulates Partners for Kids in Ohio. Children’s Medical Services (Wellcare, n.d.) is a public health insurance program for CSHCN enrolled in Medicaid. Services provided through this network are also paid on a fee-for-service basis. An integrated care system (ICS) was created with three major elements: (a) enrollees could only see providers contracted with the ICS, (b) a third-party administrator (rather than the network itself) was responsible for reviewing all claims before submitting them to Medicaid, and (c) providers were held to additional authorization procedures (Bradgon, 2011).

Between 2006 and 2008, administrative data from 3,947 CSHCN were analyzed for two treatment counties (Broward and Duval) and two control counties (Palm Beach and Orange) (Bradgon, 2011). The new managed care structure was implemented in the two treatment counties. With the ICS, there was a decrease in overall costs, decreased costs specifically in inpatient care, outpatient care, and pharmacy. These changes were statistically significant for one of the reform counties. Emergency room costs increased
slightly; however, the increase was not significant (Bradgon, 2011). Hence, the implementation of the integrated care system decreased the frequency of hospitalizations. CMSN nurse care coordinators worked closely with the child’s primary care provider, specialists, and ancillary providers. In order to address any unmet needs, clinical and psychosocial assessments were completed. Since CMS offices offered on-site specialty clinics, nurse care coordinators were present to advocate for families and assured that parents understood the information being given during a visit. The CMSN nurse care coordinators followed up on any unmet needs and coordinated services that were missing after the visit. Nurse care coordinators also participated in interdisciplinary collaborations with other providers, schools, and community partners. Their duties also included attending individual education plan (IEP) meetings, collaborating with home care agencies and equipment suppliers as well as communicating plan of care changes with these agencies and schools (Florida Department of Health, n.d.).

In February 2019, Florida Department of Health’s CMSN contracted with Wellcare of Florida, Inc. to manage the plan’s operational functions. Care coordination, provider relations, claims payment, and customer service continues to be the primary focus (Wellcare, n.d.). Ultimately, this model supports a family-centered approach while maintaining collaborations with a multidisciplinary team (Cady et al., 2014). It is an inclusive approach consistent with caring science principles.

**Link to Caring Science**

Swanson’s (1991) theory of caring is a middle-range theory originating from Swanson’s work with mothers who suffered from miscarriages as well as with families with infants in the intensive care unit. This theory was chosen because it provides a basic
premise of caring and support to parents. It also describes the role that registered nurses have in the lives of parents navigating public and private health insurance. Swanson’s theory includes five basic processes: knowing and understanding, being with and in the moment, doing for, enabling, and maintaining belief.

First, knowing requires the registered nurse to understand parents’ plights and difficulties when navigating their child’s health insurance plan. This means being empathetic and understanding of parents’ frustrations. Knowing also requires the registered nurse to listen to parents’ stories regarding challenges or barriers they face on a daily basis. The nurse must avoid any assumptions while doing this. It is imperative that nurses step out of their own worldview, although this may be difficult for nurses with previous insurance knowledge and experience. Lastly, knowing entails showing genuine compassion and respect for parents’ experiences. Hence, when knowing occurs, both the nurse and parent become fully engaged. Thus, knowing is the primary focus of this research study using a phenomenological approach to explore and understand the experiences of parents.

Next, being with and in the moment go one step further than knowing. It includes being emotionally open to the experience of the parent navigating their child’s health insurance plan. It also allows parents to share their feelings and allows them to not feel like a burden to others. Next, doing for entails “doing for the other what he or she would do for the self if it were at all possible” (Swanson, 1991, p. 163). Doing for means that the nurse anticipates parents’ needs of challenges they may face while they attempt to understand the health insurance process. Overall, it should be the nurse’s main objective to reduce any type of stress that might occur during this process. This is important to
remember since asking for help can be perceived as a sign of weakness and embarrassment.

Next, enabling occurs when the registered nurse provides guidance, information, and explanations when the language of the insurance is unclear. The nurse must be available to provide clarification when needed and assist with tasks that are too difficult for parents to manage on their own. The nurse also provides emotional support and validates the parents’ feelings (Swanson, 1991). Lastly, maintaining belief is continuing to have faith that parents can get through an event and “face a future with meaning” (Swanson, 1991, p. 162). Nurses should believe in the ability and capability of the parent to navigate their child’s health insurance plan; however, they understand that there are challenges. Registered nurses have a responsibility to “assist clients to attain, maintain or regain meaning in their experience” (Swanson, 1991, p. 162).

**Purpose of Study**

The purpose of this study was to understand the experiences of parents of CSHCN enrolled in public and private insurance. To better understand the everyday challenges of these families, a phenomenological approach was conducted. Creswell (2012) described phenomenological studies as “the common meaning for several individuals of their lived experiences of a concept or a phenomenon” (p. 76).

**Goal**

The long-term goal of this study was to understand the experiences of families who had public and private coverage for their CSHCN as well as how parents experienced support to affect their child’s healthcare.
Aims

The three aims of this study were:

1. To understand the experience of being a parent who had a CSHCN enrolled in a public health plan with or without a nurse care coordinator assigned.
2. To understand the experience of being a parent who had a CSHCN enrolled in a private health plan with or without a nurse care coordinator assigned.
3. To understand the experience of support for parents of CSHCN.

Research Questions

The three research questions that guided this research were:

1. What is the lived experience of being a parent who has a CSHCN on a public health plan with or without a nurse care coordinator assigned?
2. What is the lived experience of being a parent who has a CSHCN on a private health plan with or without a nurse care coordinator assigned?
3. How does a parent who has a CSHCN experience support?

Researcher’s Perspective

As a registered nurse, I have worked with families and CSHCN as a pediatric nurse care coordinator for over 10 years. I was employed with two major health insurance plans that offered care coordination services to families of CSHCN enrolled in Florida Medicaid and Florida Kidcare. Both plans were public insurance types. I would often receive referrals for families who were privately insured and who were seeking additional help.

Parents with children enrolled in public and private health plans encountered challenges pertaining to understanding the insurance language and navigating the
process. Fortunately, most parents of children enrolled in Medicaid and Florida Kidcare were given the option of working with a nurse care coordinator if the child was determined to be clinically eligible. However, most parents of children enrolled in private insurance were referred to the customer service line of their insurance carrier for further assistance.

These parents of children enrolled in private insurance would often express feelings of frustration and feeling overwhelmed because they could not afford the deductible, premiums, or copayments. The process for determining if certain equipment or medications were covered was also challenging for families. Mothers and fathers contemplated quitting their jobs in order to meet financially eligibility for public insurance. With this decision, however, came the risk of being unable to afford other monthly expenses such as their mortgage. Families of CSHCN on public insurance may have experienced issues with navigation; however, nurse care coordinators worked behind the scenes to guide them through the process.

**Conceptual Definitions**

For the purpose of this study, conceptual terms are defined as follows.

*Care coordination.* The deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of healthcare services (ANA, 2012).

*Case management.* A collaborative process of assessment, planning, facilitation, and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality, cost-effective outcomes (Case Management Society of America, n.d.).
Children with special healthcare needs. Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998).

Nurse care coordinator. A nurse who engages directly with a patient and manages their care. Tasks include the development and communication of the care plan as well as assuring that care needs are arranged and delivered (Clinical Oncology Society of Australia, 2015).

Nurse case manager. A registered nurse who has special training in how to plan, manage, and evaluate all aspects of patient care, especially for patients who get treatment over a long time. Also called case management nurse (National Cancer Institute, n.d.).

Private insurance. Health insurance plans marketed by the private health insurance industry, as opposed to government-run insurance programs. Coverage includes policies obtained through employer-sponsored insurance as well as coverage outside of the workplace on the individual health insurance market, both on and off-exchange (Healthinsurance.org, n.d.)

Public health insurance. A program run by U.S. federal, state, or local governments in which people have some or all their healthcare costs paid for by the government. The two main types of public health insurance are Medicare and Medicaid. Medicare is a federal health insurance program for people aged 65 years or older and for people with certain disabilities. Medicaid is a public health insurance program for some individuals and families with a low income or with disabilities (National Cancer Institute, 2018).
Chapter Summary

The number of children diagnosed with a special healthcare need continues to increase in the United States. Although there are many federal and state programs designed to fund services, there are stark differences between public and private insurances in regard to healthcare expenditures, adequacy, and the overall satisfaction reported by clients. Nursing care coordination serves as a stepping stone for organizing care coordination activities. These activities help alleviate the stress that parents face in dealing with issues and challenges alone.

The remainder of the study is organized into four chapters. Chapter 2 discusses Swanson’s (1991) theory of caring as a theoretical framework and examines the history of CSHCN as well as public and private funding. The review of the literature is described from a qualitative and quantitative perspective and also examines parents’ experiences of support. The literature around public and private health insurance for CSHCN as well as experiences of nurses coordinating care for CSHCN is examined. The gap in knowledge is also discussed. Chapter 3 discusses the research design and methodology of the study. Next, an analysis of the data is presented in Chapter 4. Finally, Chapter 5 contains the summary, conclusions, and recommendations.
CHAPTER 2. LITERATURE REVIEW

This chapter discusses Swanson’s (1991) theory of caring as a theoretical component. A history of caring for children with special healthcare needs as well as public and private funding are also examined. A review of the literature is described from a qualitative and quantitative perspective. The qualitative results uncover the daily challenges parents experience. Three common findings include experiences with healthcare, isolation, and learning as you go. Furthermore, navigating public and private health insurance are analyzed. The quantitative findings highlight the role that nursing care coordination plays in the lives of parents with CSHCN. Next, parents’ experiences of support of caring for their child with special healthcare needs are examined. Lastly, the discussion of the gap in knowledge base and the link to caring science are presented.

Critical Synthesis of Theoretical and Empirical Foundation

The experience of parents with CSHCN can be linked to caring science principles. Swanson’s (1991) theory of caring is a middle-range theory originating from Swanson’s work with mothers who suffered from miscarriages as well as her work with families with infants in the intensive care unit (Figure A1, Appendix A). This theory was chosen because it provides a basic premise of caring and providing support to parents. It explicitly describes the caring actions that should be implemented. Swanson’s theory of caring is intentional and takes a humanistic approach. This theory is ultimately concerned with the well-being of the person being cared for. The review of the literature unveiled
two research studies that used Swanson’s theory of caring for parents of children with special healthcare needs (Kavanaugh et al., 2015; Roscigno, 2016).

Swanson’s (1991) theory of caring is comprised of five basic processes: knowing and understanding the experience of the patient and their family, being with and in the moment with the patient, doing for patients as they would do for themselves if it is at all possible, enabling the patient to care for themselves and their family, and maintaining belief and sustaining faith that the patient can face a transition and move forward with their lives.

Roscigno (2016) conducted an original study of 42 parents and caregivers of children diagnosed with moderate to severe traumatic brain injuries (TBI). Parents and caregivers described experiencing caring and uncaring behaviors from nurses during their child’s care in the acute stages of illness. Roscigno then conducted a secondary analysis of this qualitative study and analyzed how Swanson’s (1991) theory of caring was used to categorize and explain these accounts. The goal of the study was to understand the experiences of parents with a child suffering from a traumatic injury five years post injury (Roscigno, 2016).

Kavanaugh et al. (2015) also examined parents’ perception of caring while facing the risk of delivering an extremely premature infant. The purpose of their study was to explain how parents at risk of delivering an infant before 26 weeks gestation interpreted caring actions with healthcare providers. A secondary analysis was performed using directed content analysis for 54 parents who participated in prenatal interviews (Kavanaugh et al., 2015).
Roscigno (2016) and Kavanaugh et al. (2015) described caring nursing encounters using the five dimensions of Swanson’s (1991) theory. Parents said that nurses demonstrated *knowing* by understanding the rollercoaster of emotions they experienced, from grief to resiliency. This resiliency was often the key to families getting through each day. Parents also said that *knowing* meant avoiding assumptions, listening intently, and asking questions. Conversely, parents saw irrelevant or unsolicited advice as an uncaring action (Kavanaugh et al., 2015; Roscigno, 2016).

It was important that parents felt they were free to ask questions when they were unsure when navigating health insurance. Parents receiving information they believed will help them help their child was crucial to knowing. Also, families should be able to seek advice and guidance when available. Lastly, *knowing* involves parents understanding their rights as they relate to their child’s health insurance and parents feeling empowered.

Next, *maintaining belief* was defined as helping the family work through difficult events and collaborating to resolve any unmet needs and challenges. Parents of children with severe TBI voiced that they did not seek pity from the providers caring for their children. Parents desired to have empathetic understanding of their complex situation (Roscigno, 2016). Parents appreciated when providers treated them like they were part of the healthcare team and allowed them to make decisions. Information sharing was particularly important (Kavanaugh et al., 2015). *Maintaining belief* occurred when parents were confident that they could navigate their child’s health insurance plan and go above and beyond to meet their child’s needs.
*Being with* involved being available to parents as well as being mindfully present. It also included empathizing, caring for the individual being cared for, and sharing feelings in a way that was authentic. Parents expressed that this was shown when nurses actively listened and showed respect (Roscigno, 2016). When healthcare providers spent ample time with parents and made them feel as though they mattered this was also accomplished (Kavanaugh et al., 2015). *Being with* occurred when parents knew there was someone available to guide them through the challenges and barriers of navigating their child’s health insurance and focused their attention on them.

*Doing for* occurred when nurses performed as competent health professionals and protected and preserved the dignity of the family. *Doing for* also meant assisting families with tasks they would normally do for themselves, but through circumstances found themselves incapable of handling (Roscigno, 2016). *Doing for* meant making parents comfortable, addressing their physical needs, and reducing their stress (Kavanaugh et al., 2015). *Doing for* was the ability of parents to meet their child’s needs by meeting the requirements of their health insurance plans. Examples of this included obtaining necessary referrals or medical records. Insurance companies could help with this by assigning a nurse care coordinator. This study informed doing for practicing nurses.

Lastly, *enabling* in a caring context meant supporting, explaining, and informing parents through complex situations (Roscigno, 2016). Parents saw *enabling* displayed through proper planning, the anticipation of needs, and a team effort between nurses and physicians to explain options to parents in a way they could understand. Parents are especially appreciative when physicians and nurses made time to explain and re-explain important aspects of care (Kavanaugh et al., 2015). In terms of parents of CSHCN and
insurance, parents were not only active participants but the primary decision makers regarding their child’s medical options.

Ultimately, caring actions form a collaborative relationship in which parents feel respected. Parents of CSHCN experienced various stages of grief and used different methods of coping. Swanson’s (1991) theory of caring helped parents through this difficult process. These actions showed that parents were cared for, proving that caring is the essence of nursing practice.

**Lived Experiences of Parents**

Parents of CSHCN carry a greater amount of stress and emotional burden than other parents. Managing complex health needs comes with responsibilities and challenges that not only affect the child but also the entire family. Three common findings found in the literature included *experiences with healthcare, isolation, and learning as you go*. These findings were singled out because of the frequency with which they appeared in the literature. *Experiences with healthcare* was chosen because it was most closely related to navigating the insurance system. The qualitative findings in the literature showed that part of this management and responsibility included navigating a healthcare system filled with various roadblocks. Parents also experienced *learning as you go* in terms of managing their child’s care while acquiring new knowledge (oftentimes by chance). Unfortunately, they also experienced *isolation* by doing this management alone (Hayles et al., 2015; Pelenstov et al., 2016; Redquest et al., 2015; Robert et al., 2014; Walker et al., 2016). Based on the current literature, these findings were also chosen because they further informed the lived experience of parents with children diagnosed with special healthcare needs.
Experiences with Healthcare

Experiences with healthcare was most closely related to navigating the insurance system. According to Hayles et al. (2015), parents of CSHCN faced many challenges in their experiences with healthcare. For example, searching for services to meet their child’s needs remained a challenge. This search included identifying various eligibility requirements, accessibility, availability, policies, procedures, and funding. Parents felt a constant need for information and guidance about services regardless of their child’s age or developmental stage. Parents used phrases such as: “doing it on your own,” “lacking support,” or “chasing the care needed” (Hayles et al., 2015, p. 1145). One parent stated that it was difficult to gather information and that additional guidance would have helped (Hayles et al., 2015). Also, gaps in services played a major part in navigational difficulty. One participant noted that it was difficult to find services as well as what to look for: “We’ve always had to try and find out where do we receive these services from? Where should we be looking?” (Hayles et al., 2015, p. 1144).

Navigation of the insurance system continued through childhood and the anticipation of future needs was common during the transition to adulthood. Parents’ experiences differed depending on the type of need, the complexity of the healthcare system, and their participation during the transition process. According to Hayles et al. (2015), parents were more likely to navigate the system for general health needs during the child’s infancy.

On the other hand, parents navigated between different care systems later in childhood. Parents went back and forth between the healthcare system and the educational system during this period. Walker et al. (2016) asserted that parents also had
trouble once their young adult reached the legal age of 18. Many providers suspend services and refer children to an adult physician. Parents voiced that this caused a great amount of stress and anxiety. According to Walker et al., children were unable to receive the required services needed due to age or another type of regulation.

Parents and youth also struggled when it came time to transition the young adult to adult healthcare. Okumura et al. (2015) conducted semi-structured interviews with 41 young adults, ranging from ages 16 to 25, with special healthcare needs (YASHCN). The focus of these interviews was to understand how YASHCN transitioned from pediatric to adult healthcare services. Okumura et al. examined how community and healthcare resources assisted during the transition process. A multi-step analysis process was used via a grounded theory approach (Okumura et al., 2015).

Ultimately, YASHCN relied on a healthcare advocate to support them through this complex period of transition to an adult healthcare system. These advocates (particularly healthcare professionals) served as role models and educators for young people and taught youth how to become their own advocates (Okumura et al., 2015). Additionally, advocates ensured that youth could speak up for themselves so that transition to adult services were done in a timely manner (Okumura et al., 2015). Most importantly, these advocates served as links between health, vocational, and educational resources crucial to the success of a YASHCN’s journey into adulthood (Okumura et al., 2015).

Under Florida Medicaid’s Children’s Medical Services Network (Florida Department of Health, n.d.), most physicians and specialists continue to see CSHCN through age 21. Transition planning begins at age 12 and continues each year until the
young adult graduates from the program on their 21st birthday. This easily resolves parents’ fears of feeling alone or navigating the adult healthcare system without any guidance. There is clear value in having an experienced healthcare professional present during this vulnerable time when additional support is needed.

Robert et al. (2014) addressed other concerns for parents navigating the healthcare system. Delays in services can extend anywhere from a few weeks to a few months. During this time, parents felt they are left to fend for themselves and were “left in limbo” (Robert et al., 2014, p. 168). Unfortunately, services were not rendered, and parents worried that their child was a “victim” while waiting for services to become available (Robert et al., 2014, p. 168). This waiting further added to parents’ anxiety and stress as they waited for necessary medical services.

Somanadhan and Larkin (2016) conducted a study using a hermeneutic phenomenological approach and interviewed eight parents with children diagnosed with Mucopolysaccharidoses (MPS) regarding parents’ experience of living and caring for a child with MPS. The purpose of their study was to assess the perspective of parents of children living with MPS (Somanadhan & Larkin, 2016). Parents felt that the organization of their child’s healthcare was often disjointed. Specifically, families felt vulnerable because of a lack of collaboration and communication among healthcare providers. Parents expressed frustration and disbelief toward the healthcare system and felt that providers did not have a general understanding of the daily challenges parents with special needs children experience. Parents also described this fragmented perception of the healthcare system as a revolving door and that the healthcare infrastructure was not caring enough (Somanadhan & Larkin, 2016). Families also described feelings of
disbelief, frustration, and anger towards the system. One parent expressed wanting to walk away and not return and felt that decisions made by the healthcare system took too long (Somanadhan & Larkin, 2016).

Most importantly, this perception of a fragmented healthcare system resulted in families’ feelings of frustration at having to navigate the healthcare system without support. Families expressed difficulty with obtaining diagnostic records from one hospital to another (Somanadhan & Larkin, 2016). Parents also had concerns over various shortcomings within healthcare that caused confusion and apprehension for the future (Somanadhan & Larkin, 2016). It was understandable how these experiences could be very isolating if the process was done without support.

**Isolation**

Managing the care of a child with special healthcare needs is a challenging and, oftentimes, lonely journey for parents. This is further complicated when this management is done without any additional help or support. Redquest et al. (2015) examined the lived experience of parents of children diagnosed with various conditions such as Down syndrome, fetal alcohol spectrum disorder, cerebral palsy, atrial septal defect, congenital muscular dystrophy, Angelman syndrome or chromosome 18 complex rearrangement duplication, and deletion 18p- disorders. Parents felt socially restricted because of limitations with participating in activities (Redquest et al., 2015).

Similarly, Pelenstov et al. (2016) interviewed parents of children diagnosed with rare diseases. Although these parents maintained close relationships with family and friends before the birth of their child, they found it difficult to stay socially connected. This was described as “feeling boxed in outside the box” (Pelenstov et al., 2016, p. e210).
This feeling was further complicated when parents attempted to connect to friends and family who did not have CSHCN. Parents felt that a lack of understanding contributed to friends and family not relating to their experiences and why they were unable to attend social gatherings. Thus, parents felt excluded from society because of less frequent contact with their peers. *Isolation* also occurred when parents refrained from having their child around others to avoid infections (Pelenstov et al., 2016).

*Isolation* was also evident throughout several other phenomenological studies. Walker et al. (2016) interviewed parents living in rural and urban areas of Georgia with young adults diagnosed with autism, hearing impairments, speech or language impairments, TMI, or visual impairments. Not only did the youth feel trapped in their homes because of their parents’ work schedules and lack of transportation, but parents also felt confined because of the demands of their child’s schooling. For families living in rural areas, the situation was that much worse. This *isolation* contributed to many negative outcomes for both youth and their families that included a lack of social-emotional support (Walker et al., 2016).

*Learning as You Go*

Receiving information that was timely and accurate helped alleviate the stressors of managing a CSHCN’s care. However, a lack of information can be very confusing for parents trying to navigate the healthcare system. Parents described this experience as a *learning as you go* process. Parents voiced learning about their child’s condition as situations occurred. Parents stated not being told what to expect and having to “wing it each year, by the year” (Hayles et al., 2015, p. 1143). Many parents learned about their child’s condition either at the time of diagnosis or when a new health need occurred.
Parents also learned to come to terms with their child’s situation and needs. One parent described being apprehensive about her child’s new wheelchair; then, a few months later, growing to like it. As parents learned to adjust to their child’s changing needs, they also learned to think ahead and anticipate any issues that may arise in the future (Hayles et al., 2015).

Furthermore, the *learning as you go* process meant learning about the child’s needs either through experience or guidance. For example, parents learned about their child’s care each time an event happened. One participant described this as “flying blind” (Hayles et al., 2015, p. 1143), which ultimately created uncertainty. Parents found it helpful when information was received from healthcare providers; however, this did not happen frequently or at the extent parents thought it should. In fact, parents reported that the information they received from healthcare providers was frequently received by chance. One parent did not learn about growth plates until it was mentioned by the physical therapist. Although some parents learned about their child’s condition over time, other parents described it as “living with the unknown” (Hayles et al., 2015, p. 1144). One parent stated that they would never get the answers that they were seeking (Hayles et al., 2015). It is understandable how this feeling of uncertainty and the unknown leads to frustration. Parents also reported that information received from healthcare professionals was not comprehensive nor ongoing. In fact, parents named either the internet or guidance from other parents as alternative methods of receiving pertinent information. This difficulty navigating the system was further complicated by large amounts of paperwork, limited eligibility criteria, and limited access to services (Hayles et al., 2015).
Quality versus quantity of information was also a shared concern. Parents agreed that healthcare professionals should be conscious about the amount of information being delivered (Pelenstov et al., 2016). According to Pelenstov et al. (2016), professionals should be cognizant of the balance between quality and quantity of information all while keeping in mind where parents are in the diagnostic journey. Additionally, parents voiced that an overload of information resulted in feeling overwhelmed, stressed, and anxious (Pelenstov et al., 2016). According to Pelentsov et al., parents felt they should have the knowledge and skills about their child’s condition so that healthcare providers were more willing to discuss important aspects of their care and include them in the decision-making process.

Khoury et al. (2013) analyzed the experiences of Lebanese families with children diagnosed with cancer by using a phenomenological-Heideggerian approach. Twelve parents were interviewed using purposive sampling. All parents expressed a fear of the unknown, along with uncertainty. This fear was mainly attributed to the fear of the future, fear of the disease recurring, and fear of the possible loss of their child. According to parents, these feelings created anxiety and confusion. One parent described feeling scared of the future and what was to come (Khoury et al., 2013).

Somanadhan and Larkin (2006) also found that parents of children living with MPS shared these same feelings of uncertainty and ambiguity. Parents often experienced feelings of frustration, confusion, and devastation. Life was described as a rollercoaster with the constant battle of raising a child with MPS. However, despite these tumultuous emotions, parents had a desire to be proactive in their child’s healthcare care. Parents often forced themselves to remain optimistic about their child and their family’s future.
(Somanadhan & Larkin, 2016). According to Somanadhan and Larkin, no man’s land was a term that families used to describe their journeys, which were often unending and lonely. Hence, parents experienced an internal battle between having a positive outlook and worrying because they want the best for their child.

Overall, the findings of parents’ experiences with the healthcare system, isolation, and learning as you go demonstrate the many hardships faced when caring for a child with special healthcare needs. Parents described constantly seeking information and needing guidance to meet the needs of their child. Information is often difficult to find and gaps in services make the experience that much harder for parents. Without proper information, parents are unable to build the confidence they need to adequately fulfill their child’s needs, nor do they feel empowered.

Parents’ experiences are further complicated when transitions between different care and educational systems occurs. Transitioning to adult healthcare presents challenges for both parents and young adults as well. A fragmented system also adds to this stress, making navigation harder. The findings learning as you go and isolation are similar to walking into the unknown for parents. Although parents are hopeful of the best outcome, the journey is a lonely one. Unfortunately, encounters with healthcare professionals do not provide clarification when needed.

Parents of CSHCN experience daily challenges with managing their child’s care as well as determining how to steer certain aspects of the healthcare system. These challenges are especially difficult when parents navigate healthcare on their own. The next steps in this study examined the experiences of parents with CSHCN on public insurance who have the support of a nurse care coordinator. This study also examined
experiences of parents with a CSHCN enrolled in private insurance while navigating the healthcare system on their own.

**Navigating Public and Private Health Insurance**

There is ample literature about the overall experience of being a parent caring for a child with special healthcare needs (Hayles et al., 2015; Pelenstov et al., 2016; Robert et al., 2014; Walker et al., 2016). However, limited literature exists that specifically examines parents’ experiences navigating either public or private health insurance for a CSHCN. The literature that currently exists focuses on specific services such as disability, medical, and behavioral health services. Based on the previous three findings, the need for additional research is warranted. It is evident that parents of children with special healthcare needs yearn for more guidance and information when it comes to their child’s health insurance, be it public or private. The shortcomings of health insurance and the complexity of insurance language as well as the complicated processes and policies created a platform to further examine parents’ experience. In addition to navigating insurance alone, parents must deal with the social isolation that comes with managing the care of their child. The feeling of not being understood was that much more amplified when it was done alone. Lastly, *learning as you go* further magnified the feeling of *isolation*. Not having information readily available or learning about components of their child’s care by chance contributed to feelings of isolation. Based on these findings, a gap certainly exists, and additional research must explore how parents’ experience the journey of public and private health insurance. The type of support received by parents of CSHCN can have a major impact on their overall daily experiences. This aspect, along with the experiences of nurses coordinating care for CSHCN, are discussed.
Parents’ Experiences of Support of Caring for Children with Special Healthcare Needs

Support is a crucial factor in a parent’s ability to cope with the challenges of caring for a CSHCN. Pelentsov et al. (2016) examined the lived experiences and supportive needs of parents whose children suffered from rare conditions. Several findings were discovered that included feeling “boxed in outside the box” and “practicalities of care and relationships” (Pelentstov et al., 2016, p. e210).

Parents did not feel supported by their child’s healthcare providers. Parents expressed that children with definitive diagnoses, particularly cancer, received more support such as financial support and counseling as well as coordinated care (Pelenstov et al., 2016). This meant parents of children with rare conditions received less support from healthcare professionals than those whose children had cancer and they were not given the attention needed to support their child.

Work limitations and impact on employment was another finding. Parents were forced to reduce the number of hours worked after the birth of their child. Oftentimes, mothers were the ones who either reduced their hours or quit altogether. The balance of keeping medical appointments made it difficult for parents to maintain financial responsibilities if they were forced to work less hours. On the other hand, if parents continued working, they struggled to find flexible employment and to adjust schedules to accommodate the needs of their sick child (Pelenstov et al., 2016).

Parents’ busy work schedules and employment challenges were also accompanied with meeting the daily needs of their child’s care. Pelenstov et al. (2016) described this as “practicalities of care” (p. e212) in which the primary source of support came from
immediate family members. The meaning of support included not only emotional support but extended to practical and technical support as well. For instance, parents said that family members who safely and independently cared for their child were the most valued. Unfortunately, parents also voiced that there was no one else besides these family members they trusted to properly care for their child (Pelenstov et al., 2016).

Lastly, taking care of a chronically ill child is overwhelming and time consuming. As a result, there is a need for respite and leisure time from caregiver duties. Parents often felt physically and emotionally exhausted. This greatly affected their ability to socialize with their peers. One parent stated, “people talk to me and sometimes emotionally I just don’t have the energy. And it’s not that I don’t care. Sometimes I just simply don’t have the energy to invest any more of my brain” (Pelenstov et al., 2016, p. e213).

Having a CSHCN also took a toll on the relationship between parents (Pelenstov et al., 2016). Parents agreed that having a CSHCN impacted their relationships with their partners. In some instances, this experience strengthened their relationship while others thought the impact was harmful and was compounded with negative stress. For example, couples spent less time with each other and considered quality time with each other to be a low priority. Sadly, some parents expressed feelings of being a single parent or the sole provider even though they were married (Pelenstov et al., 2016).

Also, the caregiver role was gendered. Mothers were the primary caregivers and carried many responsibilities such as day-to-day care, medical appointments, advocating for their child, and discussing health concerns with healthcare professionals. Mothers also felt their lives have been impacted more than their husbands. One mother thought her
husband’s life was not impacted as much as hers and that he did no more than the average father would have to (Pelenstov et al., 2016).

Parents may experience various roadblocks such as attempting to comprehend the disease and its effects and coping with uncertainty (Bruce et al., 2014). As a result, parents often searched for reassurance from healthcare providers. The time after the parent learned about their child’s diagnosis was a critical period if ongoing support for the child was a necessity. Healthcare professionals have the important task of providing encouragement and explaining all aspects of the child’s care in simple terms. Social support includes emotional support and encompasses the type of relationship an individual has with others (Bruce et al., 2014).

There were also different types of support experienced by parents of children who are chronically ill. Bruce et al. (2014) examined the aspect of support as relayed by mothers of children with congenital heart defects. A qualitative research design with a phenomenological hermeneutic interpretation method was used. Findings from interviews included receiving good support, poor support, and the absence of support. First, receiving good support meant that mothers regained their mental well-being and strength. Having private time for themselves to reenergize was important. Meeting other parents who shared their experiences increased their ability to cope. Being able to vent about their problems to other parents lowered their own feelings of loneliness. Mothers also felt that other parents who shared their experience shared similar situations and gave adequate advice versus those parents who did not have a child with special needs (Bruce et al., 2014). Connecting with other parents who shared the same experience created a sense of community where parents did not feel alienated.
Healthcare professionals also played a key role in support as far as coordinating a child’s care. This happened when healthcare professionals were skilled, honest, and had access to relevant knowledge and helpful resources. Conversely, parents did not feel supported when their presence or participation were constantly needed to coordinate their child’s care (Bruce et al., 2014). Parents formed relationships with support workers whose main roles were to improve the daily life of the child and to provide moral support. Parents felt a void if this support worker left or was replaced by another professional. They were also filled with anxiety over concern about their child’s well-being and whether they would have a positive relationship with a new support worker. Families considered this type of change in their child’s life a gap in support services as well as a step backwards.

Parents considered the relationship they had with their support workers as a partnership and desired mutual respect from the healthcare professional. The need to be heard and regarded as someone who knows their child best was an important factor for parents. Most importantly, parents of CSHCN wanted to have a voice in their child’s care and be asked their opinion (Hayles et al., 2015). Although parents wanted to grow confident in managing the needs of their child, they also relied on the expertise and services of healthcare professionals. They felt most empowered when their trust and confidence in healthcare professionals was high. This was exemplified through constant and consistent guidance from healthcare professionals and parents knowing where to get help and having a voice in their child’s care. Alternatively, parents felt unsupported when their concerns were unaddressed and when they had difficulty obtaining information (Hayles et al., 2015).
Parents who lacked support from healthcare professionals faced a myriad of challenges. For example, there was a tremendous amount of time dedicated to caring and managing their child’s care alone. This was further complicated when parents felt they must guide healthcare professionals on how to handle their child’s condition, which led to a lack of confidence and respect for the healthcare profession (Bruce et al., 2014).

Mothers perceived that some healthcare professionals had limited knowledge about their child’s condition, which led to finding information through other resources (Bruce et al., 2014).

It was evident that parents of CSHCN experienced challenges with support while managing their child’s care. There were many similarities between parents feeling isolated and lonely. Social isolation led to emotional strain such as fear, anxiety, and worry. Feelings of isolation came from a lack of knowledge on the part of healthcare professionals as well as a lack of adequate support networks. Parents’ perceived healthcare professionals as not having the proper expertise, leading to more responsibilities for parents and causing them additional stress. Not only did parents have a desire to belong, they also wanted reassurance from healthcare professionals that their child’s needs would be addressed. This current study examined the experiences of parents of a child diagnosed with special healthcare needs and their perceptions of support.

**Experiences of Nurses Coordinating Care for Children with Special Healthcare Needs**

Registered nurses are key members in coordinating care for CSHCN. Their knowledge, experience, and advanced clinical skill level facilitates the care coordination process. There is limited research focusing on the importance of care coordination led by
registered nurses and its effects on health outcomes for CSHCN. The studies that were found were completed between 2006 and 2011. The Patient Protection and Affordable Care Act (ACA 2010) was passed in the Senate on December 24, 2009 and passed in the house on March 21, 2010. Care coordination was a major provision under this legislation, which concentrated on controlling costs and improving quality of care (ANA, 2012). Specifically, Section 2717 states that healthcare professionals and stakeholders “shall develop…health care provider reimbursement structures that improve health outcomes through activities such as effective case management, care coordination, [and] chronic disease management” (Congress.gov, n.d.). Therefore, the period before and after the implementation of ACA was chosen to examine nursing care coordination and its role in the lives of CSHCN.

Gordon et al. (2007) conducted a retrospective record review of 227 medically complex children assigned to a special needs program pediatric nurse care coordinator. The measured outcomes were the number and length of hospital admissions and emergency visits. Pediatric nurse care coordinators were available to parents from Monday to Friday from 8 am until 6 pm. Using pre- and post-enrollment data, Gordon et al. found a statistically significant decrease for hospitalizations and total number of hospital days with the presence of a pediatric nurse care coordinator. Sutton et al. (2008) conducted a prospective cohort study of 220 children with chronic and complex needs examined. Outcome measures were ER visits and admissions. The number of emergency department presentations and hospitalizations remained unchanged and were not statistically significant (Sutton et al., 2008).
Similarly, Peter et al. (2011) conducted a pre- and post-cohort evaluation design of 101 children with complex care needs. A nurse-led telephonic program providing care coordination services was used to measure ED presentations, hospital admissions, and the number of hospital days. Phone calls were triaged, and illnesses were addressed over the phone. Pediatric nurse care coordinators also accompanied parents to their child’s appointments and helped coordinate care during discharge planning if the child was admitted. Peter et al. found a decrease in ED presentations, hospital admissions, and hospital days. An impact on case savings was reported using an economic analysis.

Levy et al. (2006) examined a school-based nurse case management program for 243 students with poorly controlled and severe asthma. A randomized, controlled trial was done in which 115 students received nursing case management (CM) while 128 students received usual care (UC). In this study, CM students had significantly lower emergency room visits and fewer hospital days as compared to UC students (Levy et al., 2006).

Cady et al. (2015) conducted a retrospective chart review of 43 children with moderate to high intensity health needs. Unplanned hospitalizations were examined and a telephonic case management program was provided. Cady et al. found statistically significant reductions in the number of unplanned hospitalizations. During the first year of enrollment, there were 74 hospitalizations followed by almost half (35) the second year.

Nursing care coordination has been shown to have various benefits for families of CSHCN. The constant contact, monitoring, and follow up with families provided a means of support for families when it was most needed. This constant vigilance supported the
need for coordinated care. Collectively, these quantitative findings highlighted how care coordination leads to better health outcomes by reducing hospitalizations and emergency department visits and by contributing to overall better health.

**Discussion of Gap in Knowledge Base and Link to Caring Science**

Several gaps in knowledge were identified in the literature. One gap was the age of CSHCN whose parents participated in the studies. The age of children ranged from 12 months to 17 years. Only one study included parents of children under the age of 17 (Hayles et al., 2015). The remaining studies did not include parents of children younger than 12 months old or young adults aged 18 years old (Pelenstov et al., 2016; Redquest et al., 2015; Robert et al., 2014; Walker et al., 2016). Next, the diagnoses of children consisted of either physical or intellectual disabilities (Hayles et al., 2015; Pelenstov et al., 2016; Redquest et al., 2015; Robert et al., 2014). Only one study included children with behavioral or emotional disorders such autism or emotional disturbance (Walker et al., 2016).

Another gap was geographical. The setting of one study (Walker et al., 2016) took place in the United States (Georgia). The remaining studies were conducted in Canada (Quebec and Ontario) as well as Australia (Hayles et al., 2015; Redquest et al., 2015; Robert et al., 2014). This is significant considering that other countries have different healthcare infrastructures and resources including health insurance. Unfortunately, the type of health insurance in which CSHCN were enrolled was not indicated when discussing parents’ experiences with healthcare navigation (Hayles et al., 2015).

Next, the sample in the literature included more mothers than fathers. This was significant since the perspectives of fathers may differ. The fact that more mothers were
used may indicate that experiences were more tailored to women. Also, all but one study (Robert et al., 2014) used less than 15 parents in their study. Having a smaller sample size could mean a lack of variety in experiences. There were also gaps regarding parents’ socioeconomic status. More married couples participated in these studies than single parents. This was especially true for parents experiencing support in raising a CSHCN. There may be differences in how single parents cope considering the absence of a spouse. Lastly, no study explicitly stated in which type of health insurance CSHCN were enrolled or whether they were uninsured (Hayles et al., 2015; Pelenstov et al., 2016; Redquest et al., 2015; Robert et al., 2014; Walker et al., 2016). Including this data would have been significant in regard to healthcare needs and parents’ overall satisfaction with the care they received.

There were several gaps in the literature that focused on the experiences of nurse care coordinators. First, the type of nurse (advanced practice nurses) was clarified for only one study. It was difficult to assess whether registered nurses or licensed practical nurses were used, if any, since only the term, nurses, was used. Lastly, there was limited literature looking at the involvement of nurse care coordinators in the lives of parents with CSHCN. Despite a very thorough review, only six articles were found.

Based on these gaps, the current study addressed several issues including the type of health insurance and demographics such as parents’ age and socioeconomic status (particularly marital status). By conducting a phenomenological study, experiences of parents whose children are on both public and private insurance were analyzed. The recruitment of parents who are married and single helped examine differences of support
among marital status. Lastly, this phenomenological study analyzed differences in experience as related to parents who vary in age.

In this current political climate, there is potential for policy changes, particularly with the Affordable Care Act and the Children’s Health Insurance Program (Brooks, 2018). These changes could have potential negative impacts on CSHCN. Families of these children would be adversely impacted by being underinsured and having limited access to healthcare services. Improving health outcomes for vulnerable children with complex needs is imperative and having adequate insurance is one way of accomplishing this.

**Chapter Summary**

Parents who have a child with special needs may feel extremely overwhelmed and carry a great amount of stress. This emotional burden often leads to feelings of worry and fear as well as social isolation. This feeling of isolation makes it difficult to socialize with friends or participate in social activities. This demanding role of caregiver can be emotionally draining, and it is important that parents have a strong support system as a foundation. It is imperative that healthcare professionals involved with the child’s care be knowledgeable and viewed as a resource of information for parents. Registered nurses can play an integral role in alleviating the difficulties parents face.

Based on the literature, the lived experience of parents who have a child with special healthcare needs is one that is dynamic and difficult. Having limited support from healthcare professionals further adds to feelings of isolation. Caring for a child with special healthcare needs is not only overwhelming for the parent but creates undue stress for parents who do not have assistance from a nurse care coordinator. Navigation of the
healthcare system includes identifying accessibility and availability as well as having a knowledge of policies and procedures. It is important that the nurse care coordinator caring for these parents is aware of these challenges.

There is limited literature describing the experiences of parents on public and private insurance. Additional research is needed that reports parents’ need for care coordination as well as their experiences receiving nurse care coordination. This study filled these gaps by allowing parents to tell their stories through a phenomenological approach.
CHAPTER 3. RESEARCH METHODOLOGY

This study used a qualitative descriptive design to describe the lived experience of being a parent who has a child with special healthcare needs enrolled in public or private insurance. Husserl’s (1965) descriptive phenomenology was used as a philosophical foundation for this research method. Parents of children diagnosed with special healthcare needs were interviewed about their experiences with public and private insurance as well as their experiences with support.

This chapter describes the research methodology, sampling, and recruitment process. This chapter also describes the setting, data generation and analysis, study rigor, and ethical considerations including the protection of human subjects. Strengths and limitations of the research plan and a timeline are also discussed.

Research Design Including Philosophical Foundations of the Method

Phenomenology is often referred to as a research method as well as a philosophical discipline (Wojnar & Swanson, 2007). The origins of phenomenology stem from the protest of philosophers responding to the limitations of the positivist paradigm. This positivist worldview asserts that reality is logical, ordered, and rational (Creswell, 2012). The positivist paradigm also asserts that “objectivity measured knowledge was independent of human interaction” (Reiners, 2012). On the other hand, the naturalistic paradigm states that reality is not fixed and is instead based on individual and subjective realities. The philosophy of phenomenology closely aligns with the principles of a naturalistic paradigm (Creswell, 2012). Edmund Husserl, a German philosopher and
mathematician, is considered the founder of phenomenology; he first introduced this approach in the early 20th century (Creswell, 2012). Phenomenology is used widely in the social and health sciences and in disciplines such as nursing, sociology, education, and psychology.

As a research method, the primary purpose of phenomenology is to describe what individuals have in common and how they experience a phenomenon, which is defined as an object of human experience. According to Creswell (2012), the researcher is attempting to capture individual experiences from a description of the phenomenon. Data are collected from each person experiencing the phenomenon. The researcher then creates a description of the essence for all participants. This research method not only describes what these individuals experience but also how they experience the phenomenon (Creswell, 2012). Thus, phenomenology is an exploration of lived experiences as they appear to the person experiencing the phenomenon.

According to Shosha (2012), when conducting a phenomenological study, the following questions should be considered:

- What is this experience like? (Laverty, 2003); what is this or that kind of experience like? (Van Manen, 1990); what is the essence of this phenomenon as experienced by these people? (Polit & Beck, 2008); or, what is the meaning of the phenomenon to those who experience it? (p. 32)

A phenomenological study creates a natural environment and allows the participants to report on their experience and its multiple meanings (Creswell, 2012).

Descriptive (eidetic) and hermeneutic (interpretive) approaches to inquiry are two schools of phenomenology commonly used in nursing. Husserl is considered the founder
of the descriptive phenomenology approach. The main objective of this approach is to provide descriptions as they relate to consciousness (Tuohy et al., 2013). Hence, rather than describing the individual experiences, descriptive phenomenology describes the phenomenon’s general characteristics to establish the meaning or essence. Husserl (1965) believed that human actions were influenced by what they perceived to be real; therefore, subjective information was paramount. Husserl also believed that phenomenology was related to consciousness and intentionality. According to Tuohy et al. (2013), “consciousness is the medium between people and the world. There is intentionality to consciousness, and this is always directed and related to something” (p. 18). Husserl described intentionality as the awareness or consciousness of an object or event (Tuohy et al., 2013).

Wojnar and Swanson (2007) asserted that the interaction between the researcher and participant must consist of an exchange that includes an interaction, observation, and attentive listening. During this exchange, it is important that the researcher practice transcendental subjectivity, which occurs when the researcher lets go of the idea of their reality and explains the phenomenon in its purest form. This is accomplished through bracketing, which happens when the researcher abandons any preconceived ideas (Wojnar & Swanson, 2007). Bracketing involves separating out of one’s consciousness what is already known about a phenomenon from what is discovered during the research process (Polit & Beck, 2008; Speziale & Carpenter, 2007). Bracketing occurs when the researcher strips any assumptions, bias, or prior knowledge and describes the phenomenon strictly as the participants describe it (Polit & Beck, 2008; Speziale & Carpenter, 2007).
Martin Heidegger, Husserl’s student, established the interpretive approach to phenomenology (Tuohy et al., 2013). Heidegger supported ontology, the science of being rather than the theory of knowledge, or epistemology. Thus, being in the world was the primary focus versus knowing the world. Interpreting the human experience rather than describing the experience in Heidegger’s perspective meant asking the question, What is being? Interpretive phenomenology supports that reality is influenced by the world in which individuals live. Therefore, experiences are influenced by social, cultural, and political factors. Heidegger also rejected Husserl’s idea of bracketing and believed that the researcher should be a part of the research. Hence, the researcher’s prior knowledge assists with interpretation (Tuohy et al., 2013) and it is impossible to erase the mind of any background understanding that led the researcher to study the topic (Flood, 2010).

Hence, a phenomenological approach was chosen as the most effective method to describe the lived experience of a parent who has a child with special healthcare needs. This method helped in understanding how parents describe the meaning of their experience of caring for a child enrolled in public or private health insurance. Specifically, Husserl’s descriptive phenomenology was used with bracketing and transcendental subjectivity practiced.

There are various approaches to data analysis for the different schools of phenomenology. Colaizzi (1978), van Kaam (1959), and Giorgi (1970) are three data analysis methods based on Husserl’s descriptive phenomenology (Reiners, 2012). Colaizzi’s (1978) method of data analysis validates the findings by verifying with the study participants, while van Kaam’s (1959) method of data analysis requires
confirmation through expert judges. Giorgi’s (1970) analysis rejects validation from participants and believes that asking participants is inappropriate (Reiners, 2012).

**Sampling, Recruitment, and Setting**

The participants of this study were parents of children and young adults with special healthcare needs. For this phenomenological study, purposive and snowball sampling were used. According to Creswell (2012), a purposive sample occurs when the researcher selects “individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study” (p. 156). Snowball sampling was used to allow parents to refer other parents who could contribute to the study (Polit & Beck, 2008). An attempt was made to balance the number of number of parents with children enrolled in public and private insurance. This attempt was also made for parents enrolled in insurance with and without a nurse care coordinator assigned.

**Inclusion Criteria**

This study included a sample size of 16 parents. The inclusion criteria were:

- Parents who were 18 years of age or older.
- Parents of infants, children, and young adults from 12 months to 21 years of age.
- Parents residing in Miami-Dade, Broward, or Palm Beach County, Florida.
- Children and young adults diagnosed with a special health care need as defined by the MCHB.
- Children who were continuously enrolled in a public or private health plan.
• Children continuously enrolled in a public health plan with or without an RN coordinator managing their care.

• Children continuously enrolled in a private health plan with or without an RN coordinator managing their care.

Exclusion Criteria

Exclusion criteria were parents who did not speak English.

Recruitment and Setting

Using community-based organizations that serve special needs children was one method of accessing this population. These organizations were well known because of the researcher’s prior experience as a registered nurse working for Children’s Medical Services. There are several community organizations across Miami-Dade, Broward, and Palm Beach counties that work directly in providing services to families of CSHCN. The following organizations are key resources across the tri-county area and were initially used to access the target population: The Debbie School, Linda Ray Intervention Center, United Cerebral Palsy Foundation, the Epilepsy Foundation, Early Steps, Sickle Cell Support groups, and Pediatric Associates. The researcher met with members of leadership to discuss the research study and obtain permission to recruit parents. The researcher originally planned on using letters of cooperation if permission was granted (Appendix B). A decision was later made to omit letters of cooperation and only leave flyers at each organization.

Pediatric Associates is a popular pediatric primary care practice with over 100 offices across the tri-county area. Pediatric Associates also provides comprehensive medical services to children from birth to age 21. The researcher initially planned to
obtain permission from the practice’s medical director whom the researcher knows through her former regional nursing director at Children’s Medical Services. After contacting the executive office, the researcher discovered that, unfortunately, this practice does not allow flyers to be left in their office.

Support groups, particularly those for sickle cell patients, were also targeted. The researcher worked with the lead registered nurse for these support groups in identifying potential participants. The medical director of Pediatric Associates and lead nurse of the support groups were also personal contacts whom the researcher knew from working at Children’s Medical Services. They were both qualified referral sources.

Although these organizations were helpful in identifying potential parents, the primary source of recruitment came from snowball sampling. Participants in this study were instrumental in referring other parents who met the eligibility requirements. The researcher also asked family members, friends, and colleagues if they knew potential parents who might have been eligible for the study.

First, the researcher met with members of leadership from each community-based organization. The researcher described the study, asked for participants, and obtained permission. The researcher explained the qualifications for participating. Gatekeepers from each organization were identified and used to select potential families. If permission was granted, the researcher left flyers (Appendix C) at each organization. These flyers described the study and asked potential participants to contact the researcher. The researcher also asked gatekeepers to screen out participants who did not speak English.

Once interested potential participants were identified, the researcher contacted them directly by phone. The researcher scheduled interviews at the participant’s choice of
location and designated time. The researcher called participants prior to the scheduled appointment as a reminder. Upon meeting the participants, the researcher explained the purpose of the study and the procedure. Informed consent (Appendix D) and the demographic form (Appendix E) were obtained if the participant agreed to participate. Participants were asked to complete the Sources of Support form as well (Appendix F). The decision to participate in this interview was voluntary. The researcher was available to answer any questions the participants had. One-to-one semi-structured interviews were conducted. Each interview took approximately 60-90 minutes. The researcher also notified the participants if a follow up interview was necessary.

The following questions were asked in the interviews:

• What source of support do you use as a parent who has a child with special healthcare needs?
• How does this type of support help in caring for your child?
• What challenges did you face early on or what challenges are you currently facing with your child’s insurance company?
• In what ways were you able to cope and deal with these challenges?
• How well do you feel you were able to navigate your child’s health insurance plan to meet the needs of your child? Give examples of what went well and what did not go well.

Additionally, for participating in the study, each participant received a $15 Publix gift card upon completion. Participants were notified if a follow up interview was necessary, after which another $15 Publix gift card was given (for a single follow-up visit).
Data Generation

Two digital audiotapes were used during the interviews. The researcher initially planned to hire a transcriptionist to transcribe each interview. However, to save on expenses, the researcher transcribed each interview and compared the transcripts with the audio to assure credibility was established.

REDCap is a database that securely manages online surveys (Harris et al., 2009). REDCap was used to store the demographic data and sources of support. Max QDA was the qualitative data analysis software used. Max QDA’s main function is to code, memo, and create categories during the research process. In addition to supporting phenomenological studies, this software is also useful for grounded theory, thematic analysis, and discourse analysis as well as content analysis (Silver & Lewins, 2014).

Data Analysis

Colaizzi’s (1978) eight steps of data analysis method was the selected methodological interpretation chosen for this study. These eight steps include:

1. Providing a vivid description of the phenomenon.
2. Collecting descriptions of the phenomenon from the participant and reading all these descriptions.
3. Reviewing the original transcripts.
4. Extracting important statements.
5. Creating codes, categories, and themes.
6. Integrating the findings of the study into an exhaustive description of the phenomenon.
7. Describing the structure of the phenomenon.
8. Validating the findings with research participants to compare the researcher's descriptive results with their experiences.

The lived experiences of being a parent with a child diagnosed with complex healthcare needs was described using this eight-step method. Additionally, all transcripts were read multiple times to assure that each participant’s full story was captured in its entirety (Colaizzi, 1978). From these transcripts, the researcher extracted important statements from phrases or sentences related to the phenomenon. Next, the researcher formulated meanings for statements that were significant (Colaizzi, 1978). Colaizzi (1978) also affirmed that the researcher creates meanings that are not directly related to the data. Lastly, validation was sought to identify meanings and themes being described in the phenomenon (Colaizzi, 1978).

**Study Rigor**

Methodological rigor is an important component in qualitative research. Trustworthiness is established through credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity) (Miles, 2019). In the current study, credibility was established by comparing the interview transcripts with the audio. All interviews were conducted by the researcher to enhance credibility. The researcher used member checking, which was done by restating the information then asking the participant about the information’s accuracy. If participants agreed with the data and interpretations, then credibility was established. However, if the participants disagreed, the researcher reclarified and made corrections to the interpretation (Creswell 2007; Lincoln & Guba, 1985).
Next, according to Polit and Beck (2008), transferability is the extent to which study findings can be applied in other settings. Transferability in the current study was accomplished by providing a thick description whereby the researcher conducted data collection until the data were saturated. Saturation is achieved when there is enough data to ensure that the research questions can be answered adequately (Creswell, 2007).

Confirmability occurs when the results are derived from the point of view of the participants and not from the researcher’s bias (Polit & Beck, 2008). Hence, confirmability is used to help shape the findings from the participants’ view versus the researcher’s view. Audit trails and reflexivity were two techniques used in the current study to establish confirmability. First, audit trails occurred when the researcher documented details of activities during data collection, data analysis, and interpretation. The researcher documented thoughts about coding, explained why codes were merged together, and explained the meaning of the themes created. Reflexivity happened when the researcher reflected on activities during the research process. Researchers must examine their own background and reflect on how this may influence the research (Polit & Beck, 2008).

Lastly, dependability occurs when study results are consistent with the data collected. Hence, similar findings, interpretations, and conclusions would occur if the study is conducted again. For the current study, the researcher asked her dissertation chair to serve as an external auditor since she is an expert, qualitative nurse researcher. The dissertation chair screened 20% of the transcribed data and validated the themes. The researcher reviewed and compared the dissertation chair’s findings. Any new themes found by the dissertation chair were considered. Both confirmability and dependability
were further established by comparing the results with the transcripts as well as with the existing literature (Polit & Beck, 2008).

**Ethical Considerations Including Protection of Human Subjects**

Researchers must consider ethical consideration in order to protect participants. Approval for the current study was obtained from the Institutional Review Board at Florida Atlantic University (Appendix G). Participants were informed about the purpose as well as the procedures for the study. The researcher and dissertation chair were the only individuals involved in conducting this study. The researcher is a registered nurse with an extensive background in community health nursing and more than 10 years of experience working with CSHCN. The dissertation chair is a registered nurse with research experience in aging and cultural diversity as well as qualitative approaches to data analysis.

Furthermore, a parent who discussed their child’s condition could experience feelings of frustration, sadness, or depression, which are all psychological risks. If this were to occur in the current study, it would have been necessary to assess the situation at the end the interview. Also, a referral would be made to Henderson Community Health’s Youth and Family Services program in Broward County for additional assistance. Also, as a registered nurse, the researcher is considered a mandatory reporter by the state of Florida. Therefore, the researcher was obligated to report any disclosure of sexual, physical, or emotional abuse.

Two digital recorders were used during the interviews. All information provided by the participants were transcribed verbatim. Only the researcher and dissertation chair had access to the data. Any information collected about participants was kept confidential.
and secured. Only the researcher and dissertation chair working with the study saw the data, unless required by law.

Audio recordings were transcribed and entered into Max QDA qualitative data management system on the Biomedical Health Research Informatics Core (BHRIC) according to the data management plan (DMP). At this stage of the research process, data were only accessible to the researcher and the dissertation chair. No data were transmitted via email. Data were shared only with other members of the research team on a need-to-know basis. BHRIC was monitored and maintained by the Christine E. Lynn College of Nursing Information Technology Department.

The researcher had control of the data, which were stored according to the data management plan agreed upon with the Christine E. Lynn College of Nursing Information Technology Department. To protect participant confidentiality, consent forms were stored in a secured locked cabinet. Written notes were coded for each participant and kept in locked cabinets. Audio files were deleted after transcription and verification by the researcher and dissertation chair. Transcripts were stored using BHRIC. A coding system was used for the demographic data, which were stored in a separate locked cabinet to ensure confidentiality. All researchers associated with this study were able to view the data for peer debriefing. No parties outside of the Florida Atlantic University had access to the data. Written data from this research will be shredded after five years. Electronic data will be destroyed by deleting them after five years.
Strengths/Limitations of the Research Plan

One strength of this research plan was the satisfaction of participants knowing they contributed to a better understanding of the role registered nurses played in the coordination of their child’s care. This study also examined sources of support, particularly for those families who do not have a registered nurse assigned on their insurance plan. Additionally, a better understanding of the role registered nurses play will hopefully provide insight to the integral function nurses play in the lives of CSHCN. From a policy standpoint, the information obtained from this study will help the nursing profession meet the needs of families, which may also lead to better health outcomes.

The researcher has over 10 years of experience working with families of CSHCN. One limitation involved the researcher’s personal experience with a family member who has a child with special healthcare needs. This was further compounded by the researcher working with families of CSHCN for 12 years. It was especially important that the researcher remove any preconceived notions or ideas regarding the participants’ experience. Thus, any potential bias was recorded in a reflective journal and bracketing occurred throughout this entire experience. Another limitation to this research study was the number of participants used. Since only 16 parents participated, the findings from this study could not be generalized (Wiersma, 2000).

Timeline

This research study took approximately 14 months to complete. Table 1 illustrates the study timetable.
Table 1

Research Timeline

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Chapter Summary

This study used a qualitative design to describe the experiences of parents of CSHCN on both public and private insurance. Key partners in the community that serve CSHCN were used to recruit participants if permission was granted. Through phenomenology, the researcher identified common themes related to the phenomenon of interest. Semi-structured interview questions were used and the qualitative data were analyzed using Colaizzi’s (1978) method of analysis. Study rigor and ethical considerations were maintained throughout the process. The timeline for this study was approximately 14 months.
CHAPTER 4. FINDINGS

This chapter describes the findings of the lived experience of parents with CSHCN on public or private insurance. These findings include the demographic profile of parents and characteristics of CSHCN. The interpretation of data using Colaizzi’s (1978) method of data analysis is explained. Lastly, this chapter describes the five themes that emerged and each theme’s meaning. These themes were Struggle with Self-Preservation, Abandonment and Isolation, Self-Reliance and Advocate, Interdependence, and Lifeline.

Demographic Profile of Parents

Sixteen parents participated in this qualitative study. Table 2 describes the demographic profile of these participants. Approximately 87.5% of parents were female and 12.5% were male. The age of participants ranged from 36 to 62 years, with an average age of 43.5 years. Most participants were African American (50%), followed by Hispanic (25%), then Asian and Caucasian (12.5% and 12.5%, respectively). This study was conducted in South Florida and included three counties: Miami-Dade, Broward, and Palm Beach. Most parents resided in Broward County (50%), while the remaining participants resided in Miami-Dade or Palm Beach counties (25% and 25%, respectively). In terms of marital status, 62.5% of parents were married and 38.5% were either divorced or separated. Less than half of participants (43.8%) earned more than $50,000. Seventy-five percent of parents were employed; 81.2% were college educated or had some college education. Lastly, 37.5% of parents were Christian, 31.2% did not
disclose their religion, 18.7% were Catholic, 6.3% were Episcopalian, and 6.3% were non-denominational.

Table 2

Demographic Profile of Parents

<table>
<thead>
<tr>
<th>Demographic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td>n</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>87.5</td>
</tr>
<tr>
<td>Male</td>
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</tr>
<tr>
<td><strong>Ethnicity</strong></td>
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<tr>
<td>African American</td>
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</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
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</tr>
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<td>Hispanic</td>
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<td>25.0</td>
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<tr>
<td><strong>County</strong></td>
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<td></td>
</tr>
<tr>
<td>Broward</td>
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</tr>
<tr>
<td>Miami-Dade</td>
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<td>Palm Beach</td>
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<tr>
<td><strong>Marital status</strong></td>
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</tr>
<tr>
<td>Divorce/other</td>
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<td>37.5</td>
</tr>
<tr>
<td>Married</td>
<td>10</td>
<td>62.5</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
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<td></td>
</tr>
<tr>
<td>College or some college</td>
<td>13</td>
<td>81.2</td>
</tr>
<tr>
<td>Other (Master’s degree or higher)</td>
<td>3</td>
<td>18.8</td>
</tr>
<tr>
<td><strong>Income</strong></td>
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<td></td>
</tr>
<tr>
<td>$15,000-$24,000</td>
<td>1</td>
<td>6.3</td>
</tr>
<tr>
<td>$25,000-$34,000</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>$35,000-$49,000</td>
<td>3</td>
<td>18.7</td>
</tr>
<tr>
<td>More than $50,000</td>
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<td>43.8</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>3</td>
<td>18.7</td>
</tr>
<tr>
<td>Demographic</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>-------------------</td>
<td>----</td>
<td>-----</td>
</tr>
<tr>
<td>Employment status</td>
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<td></td>
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<tr>
<td>Employed</td>
<td>12</td>
<td>75.0</td>
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<tr>
<td>Other</td>
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<td>25.0</td>
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<tr>
<td>Religion</td>
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<tr>
<td>Catholic</td>
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<td>Christian</td>
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<td>37.5</td>
</tr>
<tr>
<td>Episcopalian</td>
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<td>6.3</td>
</tr>
<tr>
<td>Non-denominational</td>
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<td>6.3</td>
</tr>
<tr>
<td>None disclosed</td>
<td>5</td>
<td>31.2</td>
</tr>
</tbody>
</table>

Figure 1 describes the sources of support identified by parents. A total of 81.3% of parents identified their friends as a source of support, followed by their spouse/partner (68.8%), then their child’s teacher (62.5%), and then physical, speech, or occupational therapists (62.5%).

**Figure 1**

*Sources of Support*
Characteristics of Children with Special Health Care Needs

Table 3 describes the characteristics of children with special healthcare needs.

The age of children in this study ranged from 5 to 21 years, with an average age of 11.6 years. In terms of children’s gender, there were more males (87.5%) than females (12.5%). Regarding insurance, 57% of children were enrolled in a public insurance plans such as Florida Medicaid and Florida Kidcare, while 43% were enrolled in private insurance plans.

Table 3

Demographic Profile of Children

<table>
<thead>
<tr>
<th>Demographic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5</td>
<td>1</td>
<td>7.1</td>
</tr>
<tr>
<td>6-11</td>
<td>7</td>
<td>50.0</td>
</tr>
<tr>
<td>12-17</td>
<td>4</td>
<td>28.6</td>
</tr>
<tr>
<td>18-21</td>
<td>2</td>
<td>14.3</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>12.5</td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>87.5</td>
</tr>
<tr>
<td>Insurance Coverage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Florida Kidcare</td>
<td>1</td>
<td>7.1</td>
</tr>
<tr>
<td>Florida Medicaid</td>
<td>7</td>
<td>50.0</td>
</tr>
<tr>
<td>Private</td>
<td>6</td>
<td>42.9</td>
</tr>
</tbody>
</table>

Note. N 14; Average age was 11.6 years old.

Table 4 describes the different diagnoses of children and their corresponding parent code. Diagnoses included physical health conditions such as rare genetic diseases.
as well as neurobehavioral or developmental disorders such as autism and attention
deficit hyperactivity disorder (ADHD).

**Table 4**

**Diagnoses of Children**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Parent Code</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F1PI1WN1</td>
<td>ADHD, ADD, dysgraphia</td>
</tr>
<tr>
<td>2</td>
<td>F2PI2WN2</td>
<td>ADHD</td>
</tr>
<tr>
<td>3</td>
<td>F3PI3WN3</td>
<td>Beta-propeller protein associated neurodegeneration, autism, epilepsy, visually impaired/optic atrophy, global developmental delays, speech impairment</td>
</tr>
<tr>
<td>4</td>
<td>F4PI4WN4</td>
<td>Optic nerve hypoplasia of the right eye</td>
</tr>
<tr>
<td>5</td>
<td>F5PI5WN5</td>
<td>Achondroplasia, spinal stenosis, apnea, curvature of the spine, extreme short stature</td>
</tr>
<tr>
<td>6</td>
<td>F1PU1WN1</td>
<td>22Q13 Deletion Syndrome</td>
</tr>
<tr>
<td>7</td>
<td>F2PU2WN2</td>
<td>Scoliosis</td>
</tr>
<tr>
<td>8</td>
<td>F1PI1N1</td>
<td>Autism</td>
</tr>
<tr>
<td>9 &amp; 10*</td>
<td>F1M1PU1N1</td>
<td>Autism</td>
</tr>
<tr>
<td>11 &amp; 12*</td>
<td>F2M2PU2N2</td>
<td>Autism, ADHD</td>
</tr>
<tr>
<td>13</td>
<td>F1PU1N1</td>
<td>Autism, ADHD, receptive language disorder</td>
</tr>
<tr>
<td>14</td>
<td>F2PU2N2</td>
<td>Epilepsy, autism, developmental delays</td>
</tr>
<tr>
<td>15</td>
<td>F3PU3N3</td>
<td>Autism</td>
</tr>
<tr>
<td>16</td>
<td>F4PU4N4</td>
<td>Hemi-hypertrophy, legally blind – left eye, microcornea, ectopic atrial tachycardia, congenital ablasia, failure to thrive</td>
</tr>
</tbody>
</table>

*Note. *These are a couple.

**Phenomenological Data Analysis using Colaizzi’s (1978) Strategy**

One-to-one semi-structured interviews were conducted and lasted approximately
60-90 minutes. At the end of each interview, participants were notified that a follow-up
interview was necessary to confirm whether the study findings mirrored their personal
experiences. Data collection ended once saturation was reached and the three research
questions could be answered. In addition, saturation was determined based on agreement by the researcher and her dissertation chair, who is an experienced qualitative researcher.

The following eight steps from Colaizzi’s (1978) method of data analysis were followed:

1. Providing a vivid description of the phenomenon.
2. Collecting descriptions of the phenomenon from the participant and reading all these descriptions.
3. Reviewing the original transcripts.
4. Extracting important statements.
5. Creating codes, categories, and themes.
6. Integrating the findings of the study into an exhaustive description of the phenomenon.
7. Describing the structure of the phenomenon.
8. Validating the findings with research participants to compare the researcher's descriptive results with their experiences.

Original Transcripts

Interviews were transcribed verbatim by the researcher. Transcripts were read repeatedly to gain a sense of the parents’ lived experience. Preconceived ideas or thoughts from the researcher’s previous work as a nurse care coordinator were documented in a reflexive journal. Thus, this process of bracketing allowed the stories of the participants to be explored without assumptions from the researcher. Appendix H provides examples of original transcripts.
**Significant Statements and Phrases**

According to Colaizzi (1978), statements in the participants’ stories directly related to the phenomenon are considered significant. Colaizzi asserted that “several protocols may contain the same or nearly the same statements, thus repetitions can be eliminated” (p. 59). Appendix I shows examples of significant statements. Significant statements and phases related to the lived experience of parents were tracked and documented using Microsoft Excel. After reviewing the transcripts, 25 significant statements were extracted.

**Formulated Meanings and Themes**

Next, formulated meanings were created from the extracted statements and 25 meanings were created. Table J1 (Appendix J) provides the relationship between significant statements and formulated meanings.

The formulated meanings were then grouped into seven categories. Peer debriefing occurred when the dissertation chair and the researcher engaged in discussion about the interpretations and meanings of categories and themes. Member checking occurred when the researcher returned to participants to verify the accuracy of the themes. With the guidance of the dissertation chair, five themes emerged from this study: Struggle with Self-Preservation, Abandonment and Isolation, Self-Reliance and Advocate, Interdependence, and Lifeline.

**Theme One: Struggle with Self-Preservation**

The theme, Struggle with Self-Preservation, emerged with parents of children enrolled in private insurance without a nurse care coordinator. The burden of caring for a child with special healthcare needs did not allow for personal time, which led to
exhaustion for mothers. Similarly, Struggle with Self-Preservation was described as mothers having to forego their own care because they juggled all major responsibilities.

**Foregoing My Own Care**

Mothers neglected their own care because they placed their child’s needs in front of their own. One participant explained how the management of her daughter’s rare condition affected her own health:

> My physical health is absolutely taking a toll for the last two years. Lack of time - I mean no personal time. It is my goal right now to focus more on that but, at the same time, I’m fighting a disease that will kill my daughter one day and so I don’t have the luxury. (F3PI3WN3)

This participant also shared that she had not done any morning care and was still in her pajamas at the time of the interview. The mother explained how she worked almost 17 hours a day coordinating the care of her child with special healthcare needs and caring for other children.

Another participant discussed foregoing her own medical care because of coverage limitations by the private insurance. The mother explained that her private insurance was a health savings account (HSA) and she was only granted $2,400 per year for healthcare services. This allowance was allocated for only three members of her household although she had a four-member household. Due to limitations with this allowance, the mother explained that it was necessary to save money from the HSA in order to meet the needs of her child. The participant stated:

> My deductible is up there - it’s anywhere from $3000 to $5000. So, with that it’s like being in the dark - I’ve had to forego my procedures that I need because I’m
too worried about exhausting everything in that twelve-month period. Because anything can happen…I had to forego some non-preventative services for myself so the kids could have what they need. And God forbid, the word hospital is not you can’t have that in the picture, no. So, you have to choose wisely. 

(F5P15WN5)

**Theme Two: Abandonment and Isolation**

The theme, Abandonment and Isolation, emerged with parents of children enrolled in private insurance without a nurse care coordinator. In this study, Abandonment and Isolation refers to parents feeling socially isolated because of the demands of their child with special healthcare needs. Abandonment and Isolation also refers to parents being unable to identify support systems with their private insurance and within the healthcare system. Abandonment and Isolation were particularly acute when parents did not use the insurance, had inadequate coverage for their child, and were ineligible for supplemental programs.

First, parents of children enrolled in private insurance without a nurse care coordinator felt isolated from family and friends. Isolation and abandonment also came in the form of family and friends not understanding the mother’s unique situation. A participant described the disconnect she felt from family members and her husband:

We’re losing our friends left to right and as good hearted and as great as friends are, they just don’t understand. My husband as loving and supportive as he is, just doesn’t understand. Same for my mom. And I truly mean that in the best way possible. I think it’s like if you’re not in it, it’s just impossible. (F3P13WN3)
Another parent voiced similar concerns: “You know, like a couple of people, my mother-in-law didn’t get it either and I had to really explain it to her” (F1PI1WN1).

Another mother stated:

You know, initially, I felt like my friends and family did not understand. They were like oh you always take him to the doctor, you have to pray on it. Especially the grandparents. And it didn’t matter how many times you explained it.

(F4PI4WN4)

Overall, parents felt abandoned and isolated when they were unable to use the insurance, had inadequate coverage, and had increased out-of-pocket costs. Feeling abandoned and isolated was also evident when parents were determined to be ineligible for supplemental programs.

**Not Using the Private Insurance**

Participants stated the private insurance did not help cover their child’s needs and, therefore, they did not use it. One participant expressed the challenge of making multiple calls to the private insurance about a neuropsychiatric screening her child needed:

Um, the challenge was that I didn’t even use my insurance. There was no benefit to me to even use it. Nobody takes the insurance money because it’s such a low reimbursement that they don’t take it. They will literally not take it. I called like five different psychiatrists who do neuropsychiatric screenings/evaluations and none of them would accept insurance. They wouldn’t accept it. (F1PI1WN1)

Another participant explained that she could not rely on the private insurance company but instead relied on the support from grants:
So you can’t really rely on the health insurance. I dread them. Not only do I dread them I have a fear of them. Because you’re deciding life and death. You’re deciding the quality of life for my child. So rather than give you all the energy, I’m going to go to the non-profits because with non-profits all I need are a paper and pen and I’m done. That’s it. There’s one that I’m looking at for swimming lessons to help pay for it. I would rather do that then get a damn insurance company to help me pay for something therapeutic. (F5PI5WN5)

This parent went on to describe how she dedicates personal time in between family commitments to search for available resources through these grants:

I started looking online for grants and there’s a lot of them out there. So in 2015, so it was me and two people from two other states we were able to get her a step stool. And it cost $750 which I did not have. And I have this GMT time getting money time. And I’m blessed because people are like how did you know to go there and I tell them God. I owe it to him because I didn’t know to do that. I just started looking. And I started looking it grew and it grew and it grew.

On the other hand, when parents called the private insurance, they described getting very little help. One participant stated, “I mean they gave me names of people who accept insurance but none of them really accept insurance for this [neuropsychological evaluation]” (F1PI1WN1).

Parents also described having an impersonal experience when they called the private insurance company. One mother stated, “I call the 800 number on [name of private insurance company] and then whoever answers the phone is who you get” (F4PI4WN4). Another parent stated that private insurance company was uncaring:
I would just rather deal with a non-profit. I’m sorry. The way they handle the parents is much better. It’s more humane. The insurance does not see left, right, front, back. All they see is the money. That’s all they see. (F5PI5WN5)

When asked if there was a person on their child’s private insurance company that parents could call for help, one parent stated:

No, they do not assign any case manager because this is a PPO plan. It’s not like an HMO or Medicaid plan. So, when you call you get anyone. Because they don’t have a specific person - every time when you call you get different people. They do not have a specific extension to deal with this person directly. (F2PI2WN2)

When another parent was asked this question, she responded: “Nope! I had asked for one but they didn’t have one…” (F3PI3WN3).

Inadequate Coverage

Abandonment and Isolation emerged when parents stated the private insurance did not provide adequate coverage. For example, parents of children who have or are at risk of developmental delays received adequate therapy coverage through the Early Steps program, which offers early intervention services to children from birth to age 36 months (Florida Department of Health, n.d.). Parents expressed receiving therapy that was adequate and covered through this program. However, once the child turned 3 years old and graduated from Early Steps, parents faced struggles with the private insurance company. One parent described the challenges of paying a high deductible until the private insurance would cover services:

Every year since she turned three the burden on us is that we had to fork out $10,000 before any of her services could be covered. And with our insurance
policy, they’ll kick in for her but I need to continue to pay another $10,000 to meet the family deductible. (F3PI3WN3)

Another parent described the out-of-pocket costs for an evaluation not covered by the private insurance:

Well, what I couldn’t believe was that they wouldn’t pay any screenings for him. They can screen him at school but it’s not very comprehensive. But to get a real neuropsychiatric evaluation you had to pay out-of-pocket. We paid almost $2,000. (F1PI1WN1)

This mother went on to explain the out-of-pocket costs (co-payments for her son’s therapy sessions):

And then occupational therapy which I also had to pay um $50 a session and I would go twice a week for several months, so that’s $100 a week. And that’s what the neuropsych eval recommended. And that also doesn’t, there’s no coverage for that. That’s easily $400 a month for about 6 months he went. And this is with an in-network provider.

Another parent stated that she paid additional out-of-pocket costs for glasses for her child, who is legally blind in one eye:

….because his vision is so bad, there’s so much…even with insurance I pay $300 and I had to get two pairs because if he lost one he has the backup. He can only wear the thick frames because the lens in that right eye is so thick. So, because of that we have to get certain lenses. And they said that it’s because of the actual lens that’s why it’s so much money. So it’s the vision plan that they offer I guess it’s independent. So it’s each pair I paid $600. (F4PI4WN4)
Another parent explained how denials for services were a usual process when it came to her child with a rare, genetic condition: “And they don’t give you any timeframe just kinda refuse services so I just look at denials as part of the process for us. It’s no longer shocking, surprising or how dare they it’s kind of like, yup!” (F3PI3WN3). She continued to describe the out-of-pocket expenses based on her child’s policy:

And this insurance policy although it’s grandfathered in, they have no cap on how much they can increase the premium every year. So every year it’s gone up. Like this year it went from $1,081 per month to $1,340, I think. So, that’s quite a jump that’s almost $300 this year, per month that we are paying for our premium and then it would be the $10,000 in network deductible and then the $20,000 out of network deductible.

Lastly, one mother expressed that she offset the expenses of the private insurance by using other resources. She described the inadequacy of the insurance:

No, because I always get a bill. The $2400 that they give goes towards eligible expenses. So, when I go to the doctor’s office, there’s always going to be something for me to pay. There’s always going to be $100, $50 as long as it’s an eligible expense braces (dental), or if I need DME which will not happen with this insurance because I go through the non-profit for that, that’s why the non-profits are so important they’re grants because that’s how I’m able to offset some of the expenses. (F5PI5WN5)

**Ineligible for Supplemental Programs**

Parents also felt isolated and abandoned by the healthcare systems when they were found ineligible for supplements programs that would help their child. Due to
coverage limitations placed by the insurance, parents of children with private insurance without a nurse care coordinator felt it was necessary to seek other resources. One participant explained her frustration with applying for Social Security Income (SSI) and being denied due to her family’s income:

I even tried to get Medicare through Social Security (SSI) after a 10-year battle. When you get SSI for two years you qualify for Medicare and Medicare I don’t know if you have to choose one or the other but yeah. And that was a 10-year battle. My husband was unemployed, they didn’t want to give me SSI and I finally appealed right after my husband lost his job….

And with the SSI, there are six major areas of life activities. All you need to score is one marked severe my daughter scored four out of six severe with functionalities (to meet medical eligibility). And that didn’t qualify her because of my income and resources. She met the criteria with all the medical stuff.

(F5PI5WN5)

Another parent expressed a similar experience when she was denied SSI due to her income:

I tried to apply for SSI/disability and I was denied based on my income. So I wasn’t able to get any other resources for him. And people would tell me you should be able to get this and that because he had a tethered cord and had spinal surgery. And people would say, girl, you should qualify to get stuff. And then his weight at birth, but they were like no m’aam sorry but we go based on income and you make too much so based on that we’re gonna have to deny you. (F4PI4WN4)

This participant went on to explain that she only used one income instead of two:
And I only put my income on their not his dad’s and they were still like no. It was two household incomes and I applied for one. And I didn’t want to lie and say I had people living with me and look what happened still. It had to be like six to eight people for me to qualify. I’m like you have all these people who don’t work and stay home and you give them all the assistance. We work and do all this and y’all won’t give me nothing at all? And they were like no ma’am sorry.

This same participant also attempted to apply for free glasses through a local, non-profit organization, but was denied:

So someone told me to look into the [name of organization], and I applied for a program they had. I had an appt with the office in Downtown Fort Lauderdale. And they told me that he did not qualify because both eyes were not affected. And that it was only one eye the other eye is 20/20. And I said to myself gee whiz! I can’t catch a break! Do you know how much money I could have saved if they helped me? So there’s resources out there but you still end up not being eligible. I was so upset.

One parent who was able to receive supplemental help through the Med Waiver program described difficulties with obtaining information:

And we made like 17 calls but no Department at Medicaid (AHCA) could provide us with guidance. We were basically ping-ponged. And this is every single call. They are not familiar with Med waiver and so even basic information was not provided so when you call in you can’t speak to a basic Medicaid agent. When you call in can you ask for the adult waiver department even though you’re
talking about a child and then if the person on the other line doesn’t know what
the adult waiver department is then you’re stuck. (F3PI3WN3)

This same parent described her plight with respite care through the Med Waiver program:
The respite care issue is a huge burden. They don’t pay the respite enough and
therefore, you have respite that as soon as another job opportunity comes up
they’re out. You’re looking at people that are doing a really, really hard job,
you’re asking them to help with children that have multiple exceptionalities and
you’re paying them like $11.50, $12.50 and expecting them to show up and
literally do some really heavy lifting, etc. but you’re not willing to compensate. I
mean we just went through three or four of them in the last couple of months. It’s
just hard trying to keep them long enough to help us out. I mean you’re entrusting
someone with your child. That’s why I’m looking into just hiring someone on my
own. Because then I could just pay the person what I wanted.

Theme Three: Self-Reliance and Advocate

The theme, Self-Reliance and Advocate, emerged with parents of children with
special healthcare needs enrolled in private insurance without a nurse care coordinator. In
this study, Self-Reliance and Advocate is defined as parents depending on themselves
and going above and beyond to meet the needs of their child. For example, one mother
explained that the appeal process for denied therapy services was very time consuming:
I’ll have to make 6 calls because no one at the other end will actually understand
the process. And so it’ll take a few days just to do that. And then you’ll get the
paperwork back which is just like 80 pages long and then I’ll have to spend time
reviewing. (F3PI3WN3)
Another parent explained her efforts in making sure that all of her child’s physicians were on the same page:

I find myself telling them what I need and what to do. And this is the problem I have dealing with different specialists  Dr [XX] is the only doctor who, after the visit actually sends his report to the primary doctor [laughs]. The other doctors don’t do it. So I have to walk around with a binder so everyone knows what everyone is doing. Mmm hmm. And thank God this child does not have meds. (F5PI5WN5)

Parents with children enrolled in private insurance without a nurse care coordinator felt they could not rely on the pediatricians. One participant explained the need to direct the pediatrician in completing a form about school accommodations or special health concerns:

The pediatrician’s an idiot. I’m sorry. Can’t even do a yellow form correctly. I had to say to him, your putting on the form sir that she can participate in all these activities, I told you four or five times already that not’s true. (F5PI5WN5)

She continued to describe an instance where the pediatrician was unreliable with referring her to developmental services:

When I first went to my daughter’s pediatrician, he was pretty much clueless as far as the resources needed to address her physical…and to address her needs. I experienced what I like to call the blinking experience. I blink, the pediatrician blinks… it was a blinking game … I blinked, he blinked, we both blinked and no one there was no answer. He or she is entirely unaware of the resources. You’re
told that your child needs physical therapy, but no one seems to know the answer as far as where to go to receive these resources. (F5PI5WN5)

This participant also explained that she normally does not contact the pediatrician’s office for help. The mother described the plight of requesting help with durable medical equipment by calling the office for assistance:

And so one day as just a dare I put that I needed help with durable medical equipment. And [name of private insurance company] had some sort of outsourced company for that particular equipment. They [private insurance company] gave the medical assistant such a run around that she then comes to me and asked me if I could do it?! So, I was like you know what? I’m good. They are completely…I’ve said to parents over and over again if you put a child with a rare disorder in front of a pediatrician, whatever education they have, it goes right through the door.

This mother also played the role of advocate by working tirelessly to get her daughter the durable medical equipment through a grant:

I just started looking. And I started looking it grew and it grew and it grew and so that particular person the requirement was for me to get a letter from the doctor explaining what would be the benefit of my daughter having it. But the orthopedics don’t like to write and lawyers don’t like to do math. So every time I ask this doctor for a letter she would give me a script and so I would ask -- do you not know what a letter is? So finally I became the ghost writer and I would write it and bring it to the doc. But it took me from November to May because for this grant you have to do a summary of why it was needed before you even get the
application. Then the app came, you have to do your own research as far as the company that was going to give you this...And I had to call, email I was on the phone til seven in the evening with someone from the company...So I had to keep calling and then finally the two of them connected and in May we got the step stool. And all of this I think the nurse could definitely have helped me.

Another parent of a child diagnosed with a rare genetic disorder stated that she could not rely on healthcare providers:

I’ve had to dumb down everything to make it acceptable for doctors to understand. We’ve had eight neurologists. I try to make their jobs easier. They need to see multiple patients. I think it’s not in their benefit for them to see someone like me who requires in depth time for a disease that no one knows much about. (F3PI3WN3)

Parents with children enrolled in private insurance without a nurse care coordinator often took it upon themselves to search for answers. For example, one participant explained trying to gather information about the Med Waiver program for supplemental help:

The lack of misinformation that I have received along the way is the most spectacular fault with the system. The burden has been on the caregiver. It should not take 17 to 20 calls to get a very, very simple answer. And the process should be very, very simple. I should not have to go to state statutes, mandates, legislation and chapters and statutory codes but that is what I have to do every single time and it is without fail. (F3PI3WN3)
This participant explained having to spend a great deal of time researching her child’s therapy benefits:

So we started exploring what options we had and I read our insurance packet like back to back so whatever, like 100 pages, 120 pages, brochures and documents. It didn’t cover OT, it didn’t cover speech, they made no mention of behavioral services it just said it didn’t cover it within a certain framework…I understand that this is a marathon and not a sprint. But everyone’s not equipped to do a marathon [laughs]. But we are doing the best that we can.

One parent described her journey to keep going and work as her daughter’s advocate:

I was just living day-by-day doing task-by-task without understanding why…So now it’s up to me to understand. Because if I don’t understand everyone who deals with her won’t understand. So, it took a lot of initiative on my part to try to understand is this going to rule my family or am I going to take it by the horn and do what I need to do? Because it’s very consuming. (F5P15WN5)

When asked how their situation would have looked different if a nurse care coordinator was available, participants stated the nurse could follow up on issues or concerns. One participant stated: “So if I had a nurse care coordinator it would have kept me more calm. She could have guided me because you’re just lost” (F5P15WN5). One participant stated that it would have been helpful if the nurse care coordinator understood her child’s unique challenges:

It would’ve been great as long as the nurse was knowledgeable about the specifics of my case. The biggest thing with any of these networks is that you end up being
volleyed back and forth, it’s the biggest…I mean, who is doing the business planning? Do they feel it’s just better, have they made a financial study to see is it better to have 20 exchanges at 40 minutes a piece and pay people $12 bucks an hour? Then to have two nurse care coordinators that really know the cases that we pay better? (F3PI3WN3)

Another parent stated that a nurse care coordinator could have provided valuable information and guidance:

That nurse would have had that area of expertise and would have guided me. Because maybe she knew…So maybe there was somebody out there willing to do it on my behalf. Yeah, somebody who works in the field like a nurse care coordinator might know. (F1P1WN1)

One mother stated that having the nurse care coordinator understand the role of both parent and care coordinator would have helped:

Having someone at Med waiver and [name of private insurance company] that was willing to help me. Someone who was able to cut through the red tape and not look at me as just I feel like anytime I would call any place I felt that they were in an adversarial role instead of there to help us. But that’s not how they come across no one is pleasant, no one seems to want to help us. The system is made to fail us not help us. And people are always shocked and I’m like but that’s the reality. I’m no longer shocked about it. (F3PI3WN3)

**Theme Four: Interdependence**

The theme, Interdependence, emerged with parents of children with special healthcare needs enrolled in public insurance without a nurse care coordinator. This
theme also emerged with a parent of a young adult with special healthcare needs enrolled in private insurance with a nurse care coordinator. In this study, Interdependence was defined as parents relying on the expertise of friends in the field or healthcare providers such as their child’s physician’s office.

Parents of Children with Special Healthcare Needs Enrolled in Public Insurance Without a Nurse Care Coordinator

First, parents of children enrolled in public insurance without a nurse care coordinator described feeling lost and confused during their child’s initial diagnosis. One parent described relying on a friend for advice for her adopted daughter diagnosed with a rare genetic condition: “It was a friend of mine who really told me what to do and questions to ask. He was an MD in his country and at the time he worked in a hospital” (F1PU1WN1). Another parent described how she relied on the advice of a friend for her son diagnosed with scoliosis:

The friend I was thinking about happens to be a nurse [laughs]. So it was discussing what the plan is, new information that’s out there about his diagnosis, and what was her experience in treating other kids that had scoliosis… And because she is an ARNP in pediatrics, she talked about the current practices and what to expect. (F2PU2WN2)

Also, parents of children enrolled in public insurance without a nurse care coordinator relied on help from healthcare providers such their child’s physician’s office or therapists. For example, one parent explained how she was facing the possibility of Medicaid reducing her daughter’s therapy hours. The mother stated “the owner of the ABA therapy company is really advocating though. She travels to Tallahassee to fight for
our hours and writes letters to politicians” (F1PU1WN1). The mother considered this a source of support for her family. Parents of children enrolled in public insurance without a nurse care coordinator also relied on individuals at different physician’s offices as support. One participant described how the medical assistant at the pediatrician’s office “helps with anything I need” and “rushes to get things done” (F1PU1WN1). This mother expressed comfort in knowing that the medical assistant knew her daughter and showed compassion.

Another parent described the efforts done by the orthopedics office with navigating the public insurance on her behalf before her child’s surgery:

…like the specialists, understood how insurance works and what it was that I should expect and said if you come across any problems with your insurance not covering you just let me know because we’ll file so and so. They were just telling me things that I didn’t know. And this was the specialist. Because they knew exactly how to work with the insurance companies especially with anything he needed that was mandatory. (F2PU2WN2)

She went on to discuss the support she received from the orthopedics office:

They (insurance company) never called or nothing. Everybody from the doctor’s office (orthopedics) called though all 3 ARNPs. I mean I think it got to the point where I spoke to everybody in their office. From the person who does insurance she’s the one that called me and said ok, we checked the insurance and blah blah blah, she just gave me everything as far as everything is fine, its approved, there’s nothing for you to do mom. Then the ARNP that prepped us before, after and during gave [child] her private telephone number that at any time he has a
problem that he needs to text her or call her. There was another ARNP and she was like the backup person and she said the same thing.

Parents with children enrolled in public insurance without a nurse care coordinator also discussed what they did not consider to be support. One parent described the response she received from the pediatrician’s office when her child was first diagnosed with scoliosis: “The primary, on the other hand, took it as oh, well, we just found it now this is what you need to do just go on and take care of it” (F2PU2WN2). The mother also went on to explain the lack of follow up from the pediatrician’s office after his corrective surgical procedure:

You know, after the surgery, the primary care doctor never even called me. Yeah, they didn’t call me. He was supposed to have regular visit and we just went in for the regular visit and I mentioned that he had the surgery. And she [the medical assistant] was like, ok. Actually, we didn’t even see the physician during the visit. Because when he went, it was for him to get his HPV shot so maybe that’s why.

So, the primary never laid an eye on him.

When asked what having a nurse on the public insurance would have looked like, one participant stated “I would have had somebody that wasn’t emotionally affected by what was going on [laughs] that would have said okay these are the things that’s coming up and how are you going to handle them, what are your concerns?” (F2PU2WN2).

Parent of a Younger Adult with Special Healthcare Needs Enrolled in Private Insurance with a Nurse Care Coordinator

Next, Interdependence was a theme that emerged for a parent of a young adult enrolled in private insurance with a nurse care coordinator. This mother, however, did not
use the nurse. Instead, this parent relied on the assistance of friends and colleagues she knew and worked with in the field of education. Due to her son’s autism and related behavioral problems, the parent formed a personal relationship with her child’s physicians, particularly the psychologist and psychiatrist. The mother first described how her friends served as a source of support for her son with autism:

…a lot of my friends were familiar with ESE so they were there from an academic point of view. Even though I knew the system but as mom sometimes we forget what the system can provide us. They would remind me hey, maybe we can get this or we can look at that for him. And so they were there for the academic part as well. Their friends and their friends who are in the education system. (F1P1N1)

This parent also explained how her own educational background and experience helped her son receive the necessary school accommodations. She recounted a meeting she had at an Individualized Education Program (IEP) meeting:

…they knew that when I came to the table, I knew exactly what he needed. I came to the table with everything. So, I’d tell them go ahead and write and I’ll tell you if I need more…I worked with the school board for 38 years my undergrad was speech pathology and my Master’s was in Learning Disabilities.

This participant also relied on her son’s healthcare providers. Although the parent had a nurse assigned, she relied more on behavioral health professionals to manage her son’s behavioral issues. The mother explained that both she and her son developed a personal relationship with the psychiatrists and psychologists over time:
At Miami Children’s Hospital, and this is where the insurance did help, they provided us psychiatrist and psychologist. He has been with him since he was three so even through now…Dr. P is really his cheerleader. And [child] has always had the personal phone numbers so if he needed to contact him at any time he could call him directly. So, he’s always had someone he can talk to as well.

Additionally, this participant stated that although a nurse was available with the private insurance, she often called her son’s behavioral providers for help and had their personal cell phone numbers. The parent felt they were able to help manage her son’s behavior related to his autism.

When asked how her situation would have looked different if she used the nurse care coordinator on the private insurance, this participant stated:

Well when he had his temper tantrums, there were times where I thought I would go to jail, but I called the police one time. So, I could lose my job because I work with the State. If I had used my nurse care coordinator then, I would have absolutely needed that at that time. That guidance, that advice, if I was feeling depressed to call, call that person to give you ideas and give me that calmness. If I knew I could have used her in that scenario, but I didn’t really know.

Overall, parents of CSHCN enrolled in public insurance without a nurse care coordinator and a parent of a youth enrolled in private insurance with a nurse care coordinator relied on the advice, guidance, and support of others. Specifically, parents of CSHCN on public insurance without a nurse care coordinator relied on the expertise of their peers in the medical and nursing field as well as healthcare providers. Meanwhile, a parent of a youth enrolled in private insurance with a nurse care coordinator relied on the
expertise of friends and colleagues in the field as well as behavioral health professionals. According to the parent, they were better versed about her son’s behavioral issues.

**Theme Five: Lifeline**

The theme, Lifeline, emerged with parents of children enrolled in public insurance with a nurse care coordinator. Hayles et al. (2015) examined the experience of healthcare for parents of children with cerebral palsy. “Meeting Needs through Partnership” was a theme defined as having “needs met was through a partnership with health care professionals” (Hayles et al., 2015, p. 1145). Similarly, Lifeline was defined as parents’ dependence on their nurse care coordinator during difficult situations. The nurse care coordinators were a valuable tool that mothers leaned on when navigating their child’s public insurance.

First, nurse care coordinators served as Lifelines for parents of children enrolled with public insurance by being available to them. One participant expressed that her child’s nurse care coordinator made home visits and inquired about her child’s well-being:

> Like now, that I’ve had someone visit me at home from the insurance and ask me questions, and want to meet my daughter…and super nice, super helpful…she came over and she’s been in touch with me…And she’s just awesome because whenever I need something for [child’s name], I can email her. (F4PU4N4)

Second, nurse care coordinators worked on the behalf of parents. One participant stated that her child’s nurse care coordinator was available for any issues with the insurance: “…because I know they’re there in case anything different than what’s usual happens…She helped me to remind me for some things. They’re just there for me to call
them when I need them which is good” (F1PU1N1). This parent also explained how her child’s nurse care coordinator helped with locating a specialist:

They called me, found me a neurologist, made the appointment for me. I remember when I made the decision to go back to a neurologist, they did that. They would tell me about the good ones, who has a good reputation and all that.

This mother went on to explain how the nurse care coordinator recommended a therapy that would help her child:

It’s a person [nurse] that’s there to answer your questions or maybe go the extra mile to make an appointment or suggest…Oh, for example, they suggested I do horse therapy for him and it was approved…She gave me information. They actually applied for me for the horse therapy which was great. That was pretty good.

Another mother in this study discussed how the nurse care coordinator worked on her behalf by providing information and guidance:

She would come with information -like oh I have a number for this or that, you can look there or here. She would ask if I have a concern and if I was nervous or doubtful, she would give me reassurance like yes you could take him to the neurologist or yes you can take him there. Like hey if you don’t feel comfortable here are some other choices. Because I never knew about the YMCA and she told me about it. She understood like okay you have some challenges. I mean she told me a whole lot of things. Just new information because I felt like I was in the dark. (F3PU3N3)
One mother stated how the nurse care coordinator helped with providing information necessary for her child: “…when I was able to get her on the phone she did give me some valuable information” (F1M1PU1N1).

Another participant described how her child’s nurse care coordinator helped in obtaining a special authorization to a specialty center:

…it’s been instrumental in making things go smooth, making sure it happens that she can go to the visit. Because sometimes when the parents call for a special authorization, it’s different from the nurse coordinator I guess her calling from the insurance company or doing whatever she does makes the process go faster. Yeah. I’m so grateful, I really am. (F4PU4N4)

This parent also described another instance in which the nurse care coordinator worked on her behalf to obtain a special authorization for custom shoes:

So, with [nurse coordinator’s name], we’re trying to get her, for the first time in 11 years, actual custom shoes. And all the insurance people it’s like, oh, we don’t have the right code because at the end of the day it comes down to money because then we don’t get paid. And so [nurse coordinator’s name] has been awesome because she’s trying to do a special authorization to get her the shoes because we have all the paperwork that her orthopedic doctor says it’s true like she needs it and it’s not for vanity. She’s phenomenal and I don’t know if it has anything to do with what’s going on [crackdown on Medicaid fraud] but I mean I’m definitely grateful. And I do see the difference in her healthcare. (F4PU4N4)

Parents in the study explained how the nurse care coordinator managed to resolve issues. The nurse provided direction and guidance for challenges encountered by parents:
Because sometimes when the parents call for a special auth, it’s different from the nurse coordinator. I guess her calling from the insurance company or doing whatever she does makes the process go faster. Yeah. I’m so grateful I really am. (F4PU4N4)

Another parent echoed a similar thought by stating, “They know the little tricks and tips” (F3PU3N3).

Parents of CSHCN enrolled in public insurance with a nurse care coordinator also discussed adequate coverage with Medicaid:

> With the insurance we have right now there’s actually no limits. I’ve heard other parents that have other insurances and they’ll be like oh, they only authorized this many hours [2 or 3] per week and I’m like what?! No! I have 20 hours or something like that the difference is big. So, the resources that Medicaid offers, you cannot compare to the other insurances... They are giving us what he needs. I’m able to get the stuff from the insurance. (F1PU1N1)

Another mother explained how her child’s public insurance adequately provided coverage: “The coverage is excellent. They pay the bills. I haven’t seen a bill yet” (F3PU3N3).

One participant also explained how the nurse care coordinator was there to monitor the progress of their child:

> At CMS I did have a nurse calling me and they still do to keep up with him. They would ask me if they had his shots, if there is any needs of the child… Because they’re on top of it. (F1PU1N1)

This mother continued by providing an example:
I never called about the neurologist it was actually the nurse who called me to check. They do call to check how’s your son doing? Did he follow up with the dentist? Did he have his yearly check up? They check those things. And she was always available so that’s good.

Another mother stated that monitoring happened in the form of a meeting: “Yes, she meets with me every six months to talk to me. And it’s for the insurance to make sure he still needs the therapy. It’s more the insurance and covering the hours” (F2PU2N2).

Another participant explained how the monitoring done by the nurse care coordinator was beneficial:

She used to call every so often ask me how are you doing, ask me if I need anything, and she’d say okay I’ll try to get on it as soon as possible. And then she’d call me back and follow up. And you know it was so much more easier, (F3PU3N3)

One other participant stated that the nurse care coordinator provided frequent follow up:

I mean I think I had someone that called me before her, occasionally and checks how my daughter is doing or asks me a couple of questions about her, but no one has ever come to my house and actually have a face to face and interview with me and met my daughter. (F4PU4N4)

Parents of CSHCN enrolled in public insurance relied on the expertise, guidance, and support of their nurse care coordinators. Participants expressed that the nurse care coordinator’s availability, information sharing, and frequent follow-ups provided
reassurance. Parents also stated feeling a sense of security knowing that someone was there to help navigate their child’s public insurance.

**Chapter Summary**

This chapter discussed the process of analysis and interpretation of the lived experience of parents of children with special healthcare needs enrolled in public or private insurance with or without a nurse care coordinator. Colaizzi’s (1978) eight steps of data analysis were used. Twenty-five significant statements were extracted from 16 interviews. Formulated meanings were created for each significant statement. Formulated meanings were sorted into categories, which were then created into themes. Five themes emerged from the data describing parents’ experiences on private or public insurance either with or without a nurse care coordinator. The following is a breakdown of the themes and the number of parents that fall into each category:

**Themes 1-3 – private without a nurse (n  5)**
- Struggle with Self-Preservation
- Abandonment and Isolation
- Self-Reliance and Advocate

**Theme 4 – public without a nurse (n  2) and private with nurse (n  1)**
- Interdependence

**Theme 5 – public with nurse (n  8)**
- Lifeline
CHAPTER 5. DISCUSSION

The purpose of this study was to understand the experiences of parents of CSHCN enrolled in public and private insurance. This chapter includes the discussion of major findings related to the experience of parents of CSHCN enrolled in public and private health plan with or without a nurse care coordinator assigned. Included in this discussion are literature supporting the findings as well as connections to a theoretical framework. This chapter ends with the limitations of the study and implications for nursing research, practice, and education, as well as recommendations for future research.

This chapter includes the study findings that helped answer the following research questions:

1. What is the lived experience of being a parent who has a CSHCN on a public health plan with or without a nurse care coordinator assigned?
2. What is the lived experience of being a parent who has a CSHCN on a private health plan with or without a nurse care coordinator assigned?
3. How does a parent who has a CSHCN experience support?

Interpretation of the Findings

Using a phenomenological approach, five themes emerged from this inquiry: Struggle with Self-Preservation, Abandonment and Isolation, Self-Reliance and Advocate, Interdependence, and Lifeline. These five themes described the overall lived experience of parents of CSHCN enrolled in a private or public health plan with or without a nurse care coordinator assigned. The three themes of Struggle with Self-
Preservation, Abandonment and Isolation, and self reliance and advocate applied to five parents with children enrolled in private insurance with a nurse care coordinator. The theme, Interdependence, applied to two parents with children enrolled in public insurance without a nurse and one parent with a young adult enrolled in private insurance without a nurse. Finally, the theme, Lifeline, applied to eight parents with children enrolled in public insurance with a nurse care coordinator.

Theme One: Struggle with Self-Preservation

The theme, Struggle with Self-Preservation, emerged with mothers of CSHCN enrolled in private insurance without a nurse care coordinator. Struggle with Self-Preservation answered the following research questions:

1. What is the lived experience of being a parent who has a CSHCN on a private health plan without a nurse care coordinator assigned?
2. How does a parent who has a CSHCN experience support?

Struggle with Self-Preservation was described as mothers having to forego their own care because they juggled all major responsibilities. Coffey (2006) conducted a metasynthesis that examined parenting of a child with chronic illness. Similar to Struggle with Self-Preservation was the theme of carrying the burden. Carrying the burden was described as mothers carrying most of the responsibilities and being the primary caregiver. Similarly, Struggle with Self-Preservation was described as mothers having to forego their own care because they juggled multiple responsibilities. A poor quality of life for a parent of a CSHCN can have significant impact on their health and well-being over time. Several findings explored the quality of life of parents of CSHCN and were
consistent with the theme, Struggle with Self-Preservation (Davis et al., 2009; Gregory et al., 2018; Kuhlthau et al., 2014).

Kuhlthau et al. (2014) examined the quality of life for parents of children with ASDs. Findings showed that parents experienced increased stress due to caregiver burden. These parents also neglected their own physical health. According to Kuhlthau et al., parents missed their medical appointments and avoided healthy eating habits because they prioritized their child’s needs. Parents also voiced exhaustion from a lack of sleep. One parent expressed, “My biggest worry is that I have to keep myself as healthy as I can, because he’s going to need me for a long time” (Kuhlthau et al., 2014, p. 1346). One parent in the current phenomenological study expressed her ongoing battle with maintaining her health: “It is my goal right now to focus more on that [personal time] but, at the same time, I’m fighting a disease that will kill my daughter one day and so I don’t have the luxury” (F3PI3WN3). This mother was aware that caring for her herself was important; however, her daughter’s needs outweighed her own priorities.

Davis et al. (2009) examined the quality of life of parents with children diagnosed with cerebral palsy. Findings showed that caring for a child with cerebral palsy had significant impact on parents’ physical well-being. Like Kuhlthau et al. (2014), Davis et al. (2009) found that parents also experienced impact to their physical health and experienced sleep interruptions. These impacts became more apparent as their child got older and gained weight. Also, sleep was disrupted from tending to their child’s need during the night. According to Davis et al., parents expressed having limited time each day. One parent explained how it took nearly 45 minutes to bathe her child with cerebral.
Similarly, in the current phenomenological study, one mother stated that she lacked sleep and worked 17 hours a day balancing household responsibility and coordinating her child’s care. Davis et al. (2009) also found that parents expressed concerns about their child’s long-term dependence because of their condition. One mother in the current study expressed the same concern with dedicating much of her time managing her daughter’s debilitating condition (F3PI3WN3). This finding in the current study was different because mothers foregoing their care was consistently seen for this insurance type with the lack of a nurse care coordinator providing support. This lack of support led to difficulty managing daily activities.

Gregory et al. (2018) examined the quality of life of parents with children diagnosed with congenital heart defects. When compared to parents with minor illnesses, parents had lower health scores due to “poorer physical health, difficulty sleeping, and differences in perceived physical health in maternal and paternal outcome” (Gregory et al., 2018, p. 365). There was also an impact on daily activities such as household tasks and responsibilities as well as attending medical appointments.

The theme, Struggle with Self-Preservation, can be compared to caregiver burden. The literature describes caregiver burden as the stress a person experiences with work and financial status and family relationships, as well as physical and emotional well-being (Pearlin et al., 1990). The current literature also examines parents’ health quality of life and the impact of caring for a CSHCN. However, there are limited studies that specifically examine the impact of parents navigating their private insurance without a nurse care coordinator. The current study highlighted this experience.
Overall, the findings from the literature were threaded throughout the current study for mothers with CSHCN enrolled in private insurance without a nurse care coordinator. These mothers found it challenging to adequately care for themselves while managing their child’s care. They often dismissed their own personal needs and prioritized their child’s needs first. Although mothers experienced struggles with self-preservation, they did not hesitate to carry out the necessary responsibilities. Ultimately, these mothers were their child’s primary caregivers and they continued to manage household tasks while caring for their other children.

Mothers tried their best to sustain their own health, but this was only compounded by the struggle to tackle complex insurance issues alone. These challenges were often overwhelming because of the amount of time they dedicated to coordinating their child’s care. Although mothers did not prioritize their own self-care, they persevered and pushed through despite their circumstances. Despite these demands, mothers maintained a sense of resilience to push forward despite the overwhelming duties. Their primary concern remained meeting the needs of their child. Unfortunately, this often came at the cost of sacrificing themselves.

**Theme Two: Abandonment and Isolation**

In this study, Abandonment and Isolation refers to parents feeling socially isolated because of the demands of caring for a CSHCN. This theme answered the following research questions:

1. What is the lived experience of being a parent who has a CSHCN on a private health plan without a nurse care coordinator assigned?
2. How does a parent who has a CSHCN experience support?
Abandonment and Isolation also referred to parents being unable to identify support systems with their child’s private insurance and within the healthcare system as well as to parents feeling socially isolated from family and friends. This theme was consistently found with several existing studies in the literature (Currie & Szabo, 2020; Kuhlthau et al., 2014; Pelenstov et al., 2016).

Currie and Szabo (2020) examined parents’ experience and perception of support for children diagnosed with rare neurodevelopmental disorders. Parents felt a disconnect from the healthcare system and a lack of understanding from their family and friends. In terms of the healthcare system, “all parents expressed frustration because of systemic barriers with episodic care models and lack of coordination services within medical and government systems” (Currie & Szabo, 2020, p. 5). Additionally, parents felt diminished and disregarded by the medical system. Families also expressed that government disability services were disjointed, and they could not rely on the guidance of government programs. Another parent expressed that they were left to figure out the ins and outs of the system on their own.

These findings aligned with those of the current study. Mothers of CSHCN enrolled in private insurance without a nurse care coordinator stated that they could not rely on the private insurance company for help - so much so that they did not use their child’s insurance. Parents expressed feeling frustrated because the private insurance company did not provide support when it was needed. This happened when parents called the insurance company for assistance or to obtain necessary information pertaining to their child. Mothers stated that the insurance company provided misinformation or a lack of information. To make matters worse, the impersonal interactions when they called the
insurance company made mothers feel even more abandoned. In addition to the
insurance, mothers felt abandoned by supplemental programs intended to help because
they did not meet eligibility requirements. Overall, the lack of care coordination from a
nurse had a significant impact and parents felt lost navigating their private insurance and
healthcare system.

The literature also revealed that parents felt abandoned and isolated by family and
friends. Currie and Szabo (2020) found that family and friends did not fully understand
the challenges of parents with CSHCN. Currie and Szabo referred to this as
“Incomprehension: very few people get what our life is like” (p. 6). Parents explained
that family and friends struggled to understand their daily challenges caring for a
CSHCN. Although family and friends wanted to be supportive, they did not fully
understand the extent of their daily battles. Similarly, mothers in the current
phenomenological study expressed that family members and friends did not understand
their challenges because they were raising typical children who were healthy. This lack of
understanding led to family and friends not supporting parents as needed. Mothers also
spent a great deal of time coordinating their child’s healthcare, which led to little time to
socialize. Overall, mothers found it difficult to be socially engaged because of the
increasing demands of caring for their child.

Pelenstov et al. (2016) conducted a systematic review and found that parents not
only needed the support of health professionals but also of family and friends. Parents
stated that having supportive family members and friends was important. Mothers and
fathers felt that other parents with a CSHCN understood their circumstances and
struggles better (Pelenstov et al., 2016). Social isolation was a major factor since friends
and family did not understand why parents were unable to attend social gatherings. Thus, parents felt excluded from society. Similarly, these findings were threaded throughout the current study in the stories of a mother of CSHCN enrolled in private insurance without a nurse care coordinator assigned. On the other hand, there were parents in the study who expressed that other parents with CSHCN were sources of support because they shared similar struggles and challenges.

Mothers of CSHCN enrolled in private insurance without a nurse care coordinator also felt abandoned and isolated because of inadequate coverage and increased out-of-pocket expenses. Mothers were left to fill in gaps when the insurance company did not help. Kuhlthau et al. (2014) stated that parents faced financial burdens with copayments for therapy sessions and physician appointments. Parents also struggled when the insurance did not provide reimbursement for their child’s speech, occupational, or behavioral therapies. In the current study, mothers expressed that their child’s insurance coverage was inadequate because of increased out-of-pocket costs from copayments, deductibles, and monthly premiums. Inadequate coverage was mentioned with therapy hours and medical equipment. Overall, these financial burdens only added to parents’ stress of managing their child’s daily care needs.

Feeling isolated and abandoned made the journey of caring for a CSHCN that much harder without the support of the private insurance company, supplemental programs, family members, and friends. Mothers were forced to balance the role of parent, spouse, and coordinator, all while caring for their child. Contacting the insurance company was, unfortunately, more of a burden than a benefit. When mothers did call the private insurance company for help, it resulted in feelings of stress, anxiety, and
frustration. Dealing with supplemental programs was often a dead end, resulting in no additional help for their child. Also, when applying for additional resources through supplemental programs, parents were honest about their salaries; however, this turned out to work against them because they were denied resources due to income. This was discouraging for parents, especially because their child needed the additional help. Furthermore, having family and friends who did not understand their child’s complex needs only added to their struggles. The financial burden of caring for their child led to mothers’ stress and caregiving load.

Many studies highlighted the overall experience of caring for a CSHCN, which includes isolation and abandonment. There are limited studies, however, that focus on the experience of this isolation and abandonment while navigating their child’s private insurance alone. The narratives in this study showed something different and unique. Parents expressed frustration when the dynamics of caring for a child with complex medical or behavioral condition were misunderstood. This was further complicated by the difficulties faced with the private insurance company. Parents were deterred from calling for help because they felt rejected. Mothers consistently expressed the difficulties they faced with deciphering the language and processes of the private insurance without a nurse care coordinator. This insurance type was the only category in this study where parents expressed a lack of support from the insurance company, supplemental programs, family, and friends.

When help was needed, mothers reached out to the private insurance company but were left disappointed. Due to unmet needs through the private insurance, parents sought the help of community healthcare resources but were denied. These circumstances were
further complicated when family and friends could not empathize. Hence, it was important for mothers to have a sense of belonging and feel part of a community of family and friends who understand their plight. Unfortunately, this was difficult because of the struggles associated with caring for their child with special healthcare needs.

**Theme Three: Self-Reliance and Advocate**

The theme, Self-Reliance and Advocate, emerged with parents of CSHCN enrolled in private insurance without a nurse care coordinator. This theme answered the following research questions:

1. What is the lived experience of being a parent who has a CSHCN on a private health plan without a nurse care coordinator assigned?
2. How does a parent who has a CSHCN experience support?

In this study, Self-Reliance and Advocate is defined as parents depending on themselves and going above and beyond to meet the needs of their child. Mothers of CSHCN enrolled in private insurance without a nurse care coordinator spent a great deal of time searching for information on their own. Overall, mothers felt that healthcare providers and the private insurance company provided inadequate information when it was needed. These findings were consistent with the current literature (Baumbusch et al., 2018; Pelenstov et al., 2016; Somanadhan & Larkin, 2016).

According to Pelenstov et al. (2016), parents of CSHCN searched for additional information about their child’s condition. Parents moved from the role of parent to expert. For example, participants searched for information about their child’s condition to answer questions. They also searched for information and resources related to their child’s condition. Overall, parents wanted information that was easily accessible and
meaningful (Pelenstov et al., 2016). In the current study, mothers of CSHCN enrolled in private insurance without a nurse care coordinator ventured into finding information online to obtain additional assistance. This was evident with their search for items such as durable medical equipment or searching for a basic understanding of their coverage and limitations under the private insurance company. Mothers also searched online to gather information to learn more about their child’s condition.

Baumbusch et al. (2018) explored the challenges that parents faced when accessing services. These challenges with healthcare providers led to strained relationships between the parent and the provider. One parent described feeling as if she was fighting with the physician in order to get services. Another parent voiced the frustration of dealing with physicians when they did not understand certain aspects of her child’s rare condition. This frequently led to providers’ inability to refer parents to the appropriate resources (Baumbusch et al., 2018).

Somanadhan and Larkin (2016) conducted a study with parents who shared similar concerns. Parents felt that the organization of their child’s healthcare was often disjointed. Specifically, they felt a lack of collaboration and communication among healthcare providers, thus making them feel vulnerable. Parents expressed frustration and disbelief toward the healthcare system and felt that providers do not have a general understanding of the daily challenges parents with special needs children experience (Somanadhan & Larkin, 2016).

Mothers in the current study shared similar concerns. Pediatricians are considered gatekeepers; however, mothers stated that some pediatricians as well as specialists did not understand the daily needs of their child. They worked hard to assure that physicians

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were on the same page. Mothers voiced frustration with having to guide and explain exactly what was needed from the physician. This constant battle with doctors left mothers feeling exhausted and misunderstood. This misunderstanding eventually led to physicians not meeting the needs of their child. This not only resulted in additional work for parents but also a distrust towards healthcare providers. Thus, parents felt disconnected and not an integral member of the healthcare team.

Mothers with CSHCN enrolled in private insurance without a nurse not only dealt with struggles to maintain their physical health, abandonment, and isolation, but they were forced to rely on themselves and to be an advocate for their child. Initially, mothers expressed feeling lost and scared when they received the news of their child’s diagnosis. This was compounded with feelings of sadness, frustration, and powerlessness. Over time, however, these feelings slowly dissipated and later transformed into feelings of empowerment. Due to their circumstances, mothers persevered - even in moments of doubt and uncertainty. Through this period, mothers learned to assume different roles when caring for their child. In addition to being an advocate, they were a parent, spouse, coordinator, and caregiver. Ultimately, mothers took matters into their own hands and began searching for solutions that could possibly help their child’s circumstances.

**Theme Four: Interdependence**

The theme, Interdependence, emerged with parents of children with special healthcare needs enrolled in public insurance without a nurse care coordinator. This theme also emerged with a parent of a young adult with special healthcare needs enrolled in private insurance with a nurse care coordinator. The mother of this young adult, however, did not use the nurse. Instead, she relied on the guidance and assistance of
friends and colleagues she knew and worked with in the education field. Additionally, this mother formed a personal relationship with her child’s physicians, particularly the psychologist and psychiatrist.

In this study, Interdependence is defined as parents relying on the expertise of friends in the field or the child’s healthcare providers. These healthcare providers included physicians, nurse practitioners, medical assistants, and administrative personnel such as front desk staff. This themed answered the following research questions:

1. What is the lived experience of being a parent who has a CSHCN with special healthcare needs on a private health plan without a nurse care coordinator assigned?

2. How does a parent who has a CSHCN with special healthcare needs experience support?

Findings in the current literature were consistent with this theme (Baumbusch et al., 2018; Drummond et al., 2012). Baumbusch et al. (2018) asserted that parents of children with rare diseases found informal peer support as a source of support. Participants affirmed that having an informal support network helped when they encountered issues navigating the healthcare system. Parents voiced that having this support was beneficial because they were a source of information.

Similarly, in the current phenomenological study, participants stated that seeking guidance from informal peer support was a primary source of information when it was needed. Parents felt a sense of reassurance by relying on the expertise of friends who worked in the medical and education field. These friends had first-hand experience working with children with disabilities. According to Baumbusch et al. (2018), many
parents were part of support or parent advocacy groups. Similarly, in the current study, one parent was part of a support group for parents of children diagnosed with 22Q13 deletion syndrome, a rare genetic disorder. Parents felt a sense of belonging and felt understood. Ultimately, mothers expressed feeling relieved knowing they could rely on these groups and peers for guidance.

Drummond et al. (2012) examined the medical home model and parental coping while raising a child with special healthcare needs. The medical home model was described as “a model of care that promotes holistic care of children and their families, provides management of both acute and chronic issues, and provides an ongoing relationship with a health care professional for each family” (Drummond et al., 2012, p. 267). According to the American Academy of Pediatrics (AAP, 2015), a medical home is an important component when coordinating the care of children with special healthcare needs. It is an approach delivered by pediatric primary care offices to provide comprehensive primary care to children with complex needs (AAP, 2015). Other than physicians, the medical home includes nurse practitioners, registered nurses, licensed practical nurses, and licensed clinical social workers. Findings showed that parents who communicated with their providers reported better coping. Ultimately, children who belonged to a medical home had parents who reported coping well (Drummond et al., 2012).

Similarly, in the current study, parents relied on their healthcare provider for support. The medical home model was evident within the pediatrician and orthopedic surgeon’s office. According to parents, support was experienced when the doctor’s offices completed tasks such as prior authorization paperwork or prepared preoperative
forms needed for their child’s surgery. Parents also appreciated help with medication issues when healthcare providers called the pharmacy. Support was shown when healthcare providers were available to answer questions and address concerns. According to Drummond et al. (2012), having support from a medical home meant that providers and support staff actively communicated with parents. In the current study, physician, nurses, medical assistants, and front desk personnel kept open lines of communication with parents. Overall, the medical home concept was most effective when healthcare providers worked as a team in collaboration with parents.

The theme, Interdependence, described parents’ dependence on others to help fill the gaps in their child’s care. Mothers with CSHCN enrolled in public insurance sought comfort from individuals who worked in their physician’s office. Having someone who knew the insurance process and provided guidance removed some of the burden. Unlike mothers enrolled in private insurance without a nurse, mothers with CSHCN enrolled in public insurance without a nurse had the support of friends with medical experience. Having a child with a rare genetic disease was overwhelming in the beginning, especially at the time of initial diagnosis. Confiding in a friend with extensive medical training provided comfort and reassurance during a time filled with uncertainty. Also, having a child undergo surgery for the first time can be a stressful time in a parent’s life. A pediatric nurse practitioner offered advice to one parent to ease the fear and anxiety a parent in the current study experienced.

Although a mother of a young adult with special healthcare needs enrolled in private insurance had a nurse care coordinator assigned, the mother voiced not using the nurse. Over time, this mother formed a close relationship with her son’s psychologist and
psychiatrist. The mother’s decision to not use the nurse could be explained in two ways. First, the mother stated that she was unaware that she had a nurse. However, when the mother had knowledge of this, she expressed confiding in her child’s mental health providers instead. Second, because of the child’s diagnoses of autism and developmental delay, the mother may have confided in the psychologist and psychiatrist for professional guidance on how to manage her son’s behavioral problems. Overall, mothers who experienced the theme, Interdependence, found in necessary to seek the guidance of those they trusted.

Theme Five: Lifeline

The theme, Lifeline, emerged with parents of CSHCN enrolled in public insurance with a nurse care coordinator assigned. Lifeline, in this study, is defined as parents’ dependence on their nurse care coordinator during difficult situations. This theme answered the following research questions:

1. What is the lived experience of being a parent who has a CSHCN on a public health plan with a nurse care coordinator assigned?
2. How does a parent who has a CSHCN experience support?

Hayles et al. (2015) examined the experience of healthcare for parents of children diagnosed with cerebral palsy. Like Lifeline, the theme, “Meeting Needs through Partnership,” was defined as having “needs met was through a partnership with health care professionals” (Hayles et al., 2015, p. 1145). This partnership was established by creating a family-centered approach in which parents were actively involved in their child’s care. According to Hayles et al.,
[by] using this approach, health care providers work in partnership with families, involve the family in the identification and prioritization of their child’s needs and the development and evaluation of services for their child, and provide flexible services to meet their individual needs. (p. 1139)

Thus, meeting needs through partnership also assured that healthcare providers filled any gaps in the child’s care and concerns from the family were addressed.

Through meeting needs through partnership, healthcare providers developed a relationship with families. Hayles et al. (2015) noted that the values, attitudes, and processes of healthcare providers affected the interactions with parents. For example, parents felt valued when their child’s healthcare providers showed mutual regard and respect. Parents also conveyed that having healthcare providers who listened to their concerns was important. Parents felt that their interpretation of their child’s needs should be considered, and they should be the primary decision makers (Hayles et al., 2015).

The theme, Lifeline, was defined as parents’ dependence on and partnership with their nurse care coordinator. Care that was coordinated and consistent with frequent monitoring was considered a source of support for parents with a nurse. First, monitoring was a care coordination activity completed by the nurse. Nurse care coordinators contacted parents telephonically or visited the home to follow up on the child’s progress or to identify gaps in care. Home visits, particularly, made the interactions between the nurse and parent more personal.

Cady et al. (2014) examined the characteristics of advanced practice registered nurses (APRN) and care coordination for medically complex children. Findings showed that APRN’s care management included multiple phone calls to parents and providers to
develop an appropriate plan of care. Similarly, in the current study, mothers of CSHCN with public insurance voiced satisfaction when the nurse care coordinators called frequently and went the extra mile. Parents appreciated when nurse care coordinators were available, especially when an issue occurred.

Collectively, mothers of CSHCN enrolled in public insurance expressed that it was easier to handle challenges with the support of their nurse care coordinator versus attacking the issue alone. Mothers also stated that the ability to solve issues on their child’s public insurance was handled differently for nurse care coordinators than parents. Nurse care coordinators had the knowledge and experience with public insurance policies and procedures. Mothers, therefore, found the nurse care coordinator to be an asset. Thus, parents did not have to carry the extra burden of problem-solving insurance issues or coordinating their child’s care.

Nurse care coordinators had better insight into the challenges of navigating health insurance processes and procedures. These challenges included obtaining prior approvals for diagnostic or surgical procedures, obtaining equipment, and making appointments with busy physician practices. Nurse care coordinators were also instrumental when they provided resources and information that may benefit the child. Often, a child was eligible for services of which parents were not aware. Most importantly, parents felt that nurse care coordinators were better equipped to help when they understood the needs of their child. Overall, nurse care coordinators were Lifelines who were instrumental in closing gaps in care.
Swanson’s (1991) theory of caring was chosen as the theoretical framework for this study because it highlighted how registered nurses should care for and provide support to parents of CSHCN. It also described the role that registered nurses play in the lives of parents navigating public and private health insurance. Swanson’s theory includes five basic processes: knowing and understanding, being with and in the moment, doing for, enabling, and belief.

**Knowing** required that the registered nurse understand the parents’ plights and difficulties when navigating their child’s health insurance. This meant being empathetic and understanding of parents’ frustrations. Parents of CSHCN enrolled in public insurance expressed that their nurse care coordinator understood the struggles of navigating the plan. For example, parents expressed having difficulty obtaining prior authorizations; however, the nurse care coordinator assisted with this. Parents stated that because the nurse care coordinators understood the insurance process, navigation was not as difficult.

Next, **being with** and **in the moment** go one step further than knowing. According to Kavanaugh et al. (2015), “‘being with’ meant physically and emotionally engaging with parents in an unhurried manner and establishing a meaningful connection” (p. 150). Mothers of CSHCN enrolled in public insurance expressed not feeling alone when their nurse care coordinators came to the home. Mothers felt connected when nurses frequently called them if a home visit was not possible.

Next, **doing for** entails “doing for the other what he or she would do for the self if it were at all possible” (Swanson, 1991, p. 163). **Doing for** meant that the nurse
anticipated challenges parents may face as they navigated the insurance. Parents of CSHCN enrolled in public insurance with a nurse care coordinator expressed that *doing for* happened when nurses worked on their behalf to meet their child’s needs. *Doing for* occurred when the nurse attempted to resolve issues or followed up with parents about any concerns. *Doing for* was also seen when nurse care coordinators located providers and scheduled appointments for the parent.

Next, *enabling* occurred when the nurse care coordinator provided guidance, information, and explanations when insurance language was unclear. Nurses must assist with tasks that are too difficult for parents to manage on their own. The nurse also provides emotional support and validates parents’ feelings (Swanson, 1991). *Enabling* in this study occurred when the nurse care coordinator provided information and guidance whenever it was needed. Mothers of CSHCN enrolled in public insurance felt supported when their nurse offered information about services from which their child could benefit.

Lastly, *maintaining belief* is continuing to have faith that parents can get through an event and “face a future with meaning” (Swanson, 1991, p. 162). Nurses should believe in the ability and capability of the parent to navigate their child’s health insurance plan; however, they need to understand the challenges. According to parents of CSHCN enrolled in public insurance, *maintaining belief* happened when the nurse care coordinator provided reassurance during difficult times. Mothers expressed difficulty with juggling the demands of caring for their children and that nurses’ reassurances made it easier to face the day.

Overall, Swanson’s (1991) theory of caring provided a foundation of how registered nurses could best support parents of CSHCN. The five basic processes set a
premise for showing caring actions towards families. This phenomenological study showed how implementing these actions can help support parents.

**Implications for Nursing**

**Nursing Research**

The findings of this phenomenological study have implications for nursing research. Many health insurance plans offer nursing care coordination services to help parents with CSHCN navigate a very complex healthcare system. Unfortunately, this may not always be the case for some parents with CSHCN enrolled under public and private insurance. Nursing care coordination and its impact on individuals and families should be examined further. Additional research is needed to examine the differences between public and private insurance when nursing coordination is included as a benefit to a health plan. In cases where nursing care coordination is provided, further research should focus on methods to best deliver care coordination that is effective and serves the needs of families. This phenomenological study highlighted some of the differences between public and private insurances as they relate to nursing care coordination and a lack thereof.

**Nursing Practice**

The findings of this study have implications for nursing practice. According to ANA (2012), care coordination is “foundational to the health care reform goals of improving the quality of care for individuals and populations via the efficient and effective use of resources.” AHRQ (2018) outlined the responsibilities of care coordination as helping families with referrals; assessment that is comprehensive; planning of care; client and family participation; and monitoring, follow-up, and referral
to community partners. Findings of this study highlighted the impact that care coordination had when these responsibilities were delivered by a nurse care coordinator.

AHRQ (2018) asserted that care coordination assures that the needs of the client are met over a period of time. Care coordination is a valuable tool in healthcare. Registered nurses serve as advocates for their patients even more so for families of CSHCN. It is important that nurse care coordinators fully understand their role and implement interventions needed to help parents. Furthermore, models centered on care coordination can be used as a mechanism to guide nurse care coordinators in practice. It is imperative that registered nurses and healthcare providers understand the challenges that parents of CSHCN face while navigating their child’s public and private insurance. Understanding the types of social support available may also identify how best to help parents cope.

**Nursing Education**

The findings of this phenomenological study have implications for nursing education. Nursing curriculum should include concepts about nursing care coordination, particularly in pediatric and public health nursing courses. This content should focus on the roles and responsibilities of nurse care coordinators not only in acute care settings but also in the community. Furthermore, clinical experiences for pediatric and public health nursing courses should include clinical sites such as insurance companies and community-based organizations where nursing care coordination may be available. These clinical experiences will allow nursing students to work and collaborate with families, nurse care coordinators, and various members of the healthcare team. Through partnerships such as these students can learn about the challenges that families face.
Finding clinical placements in the community, however, may be challenging. Barriers such as poor community partnerships and limited agency sites may contribute to the lack of available clinical agency sites for nursing students (Pringle, 2017; Shaw-Flach & Hoy, 2016). Simulation education is an instrumental strategy that supplements clinical training. Reaves et al. (2020) developed two public health scenarios that provided hands-on experience in a home and school setting. These scenarios focused on caring for a child with special healthcare needs. Students played the role of a nurse care coordinator and worked with families in closing gaps in care. This included care planning and referring to community resources. Simulation is an effective education modality that allows nursing students to gain exposure to various principles of nursing care coordination in a community setting. Hence, nursing students will have a foundation of care coordination as they venture into the professional nursing arena.

**Nursing Policy**

Lastly, the findings in this phenomenological study have implications for policy. ANA (2012) has asserted that “nurses are central to coordinating the patient experience, targeting both cost efficiencies and improved care outcomes for diverse patient groups.” However, many policy implications exist since some health plans are not required to assign a nurse care coordinator to families of CSHCN. Nursing care coordination should be considered an added benefit for both privately and publicly covered children. Providing this type of care coordination support could help lessen the caregiver burden. This is especially true for children categorized in higher acuity categories who suffer from complex conditions with greater needs.
Nurse care coordinators from insurance plans can also help to lighten the burden from physician offices. Nurse care coordinators can assist with a variety of tasks including scheduling appointments, providing health education and anticipatory guidance, and assisting with the pre-certification process. Registered nurses are vital members of the healthcare team who can work in partnership with physicians, support staff, and parents.

Also, nursing care coordination has significant contributions in terms of improved health outcomes. According to ANA (2012), care coordination resulted in reductions in emergency department visits, significant savings per patient, and improved quality of care, as well as overall improved patient satisfaction. ANA also affirmed that care coordination contributed to “significant increases in survival with fewer readmissions, increased patient confidence in self-managing care and improved clinical outcomes and reduced costs.” Hence, there are paramount benefits to adding nursing care coordination for both public and private health plans. These benefits not only result in healthcare savings for insurance companies but in better health outcomes for its enrolled members.

Lastly, it is important that policies around eligibility criteria be examined, especially in regard to income. Many parents in this study searched for community resources as a means of additional support. Unfortunately, parents were determined ineligible for these programs although their child met the medical criteria. Additionally, a very close analysis of the issues that families face with both the quality of care and services received should be examined.
Limitations

There were several limitations with this study. First, purposive sampling was used so participants were selected with the intent of meeting the eligibility criteria. Although this study met Creswell’s (2012) recommended number of participants, the sample did not represent all parents with CSHCN enrolled in private and public insurance. Differences between public and privately enrolled children with or without a nurse care coordinator should be explored with a larger sample. Next, to be included in this study, the required primary language was English; therefore, the perspectives of non-English speaking participants were not included. Also, more mothers (14) than fathers (2) participated; therefore, this study lacked ample male points of view. Lastly, since participants lived in three different counties in South Florida, the experiences of parents may have differed based on their geographic location. Specifically, the types of community resources and support networks may differ based on where participants lived.

In terms of CSHCN, only certain medical and neurodevelopmental disorders were represented in this study. Acuity levels differed with more children falling into the low or medium categories depending on the complexity of the child’s condition. As a result, the amount of support needed and experiences with insurance may differ. Also, in regard to insurance type, more CSHCN were enrolled in Medicaid and only one child was enrolled in Florida Kidcare.

Recommendations for Research

Conducting additional research about this phenomenology can help develop new knowledge and understanding. This phenomenological study revealed several recommendations for future research. First, additional research is needed to explore the
experiences of fathers of CSHCN enrolled in private or public insurance. The quality of life of parents over time should also be explored. Future research should include parents of CSHCN enrolled in other private and public health plans not included in this study. Lastly, this study included one young adult; therefore, future research should explore the healthcare experiences for parents with young adults (18 years and older) enrolled in public and private insurances.

Chapter Summary and Conclusion

The purpose of this phenomenological study was to understand the experiences of parents of CSHCN enrolled in public and private insurance. The five themes that emerged from this study included struggle for self-preservation, Abandonment and Isolation, Self-Reliance and Advocate, Interdependence, and Lifeline. These themes were threaded throughout the analysis of data. This chapter also discussed other findings with similar studies of parents with CSHCN.

The findings of this phenomenological study highlighted the major differences of parents navigating their child’s health insurance. These differences were dependent on the type of insurance and sources of support available. For example, the experience of parents who had a nurse care coordinator differed from parents without a nurse. Parents of CSHCN enrolled in public insurance with a nurse care coordinator considered the nurses to be a primary source of support in many circumstances with insurance. Having a nurse care coordinator available lessened the workload on parents. Nurse were instrumental in resolving problems and roadblocks with the public insurance. Hence, this allowed parents to focus on other tasks. Parents also discussed that constant monitoring of their child’s condition and follow up done by their nurse care coordinator was
beneficial. They also voiced that nurses were helpful when they referred them to resources in the community as well.

On the contrary, parents with CSHCN enrolled in private insurance without a nurse care coordinator took on this additional burden. This study suggests that if a nurse care coordinator was available, parents may have had more time to address other needs (such as self-care) and other responsibilities. The availability of a nurse care coordinator may have made a difference when navigating insurance as well as locating additional resources and programs for the child.

There were also differences in terms of overall support. Parents of CSHCN enrolled in private insurance with a nurse care coordinator and parents of CSHCN enrolled in public insurance without a nurse relied on peer support and the support of healthcare providers such as doctors’ offices. Members of their child’s physician office as well as friends with medical and nursing backgrounds were key sources of support. Parents sought the professional advice about their child’s condition and possible treatment options from friends who were in the field. Parents of CSHCN enrolled in private insurance without a nurse voiced a lack of support from family, friends, and physicians’ offices. Perhaps having this type of support in addition to a nurse may have lessened the burden of coordinating their child’s care.

Also, there were noticeable differences in parents’ satisfaction with the adequacy and cost of their child’s health insurance. Parents of CSHCN enrolled in private insurance voiced dissatisfied with higher costs associated with their child’s plan. Higher out-of-pocket expenses such as monthly premiums, copayments, and deductibles were additional financial burdens for these families. Parents also stated the private insurance was
inadequate because of coverage limitations. On the other hand, parents of CSHCN enrolled in Medicaid were not concerned with out-of-pocket expenses because they were covered. These findings are consistent with the current literature.

Lastly, the interactions with the insurance for privately insured children without a nurse and publicly insured children with a nurse varied greatly. The parents of publicly insured children reached out to the insurance company and contacted the nurse when issues arose. Parents of privately insured children felt discouraged because of unhelpful actions that deterred them from using the insurance or calling again. Perhaps if a nurse who knew and understood their child’s needs was available, parents would feel comfortable discussing their issues or asking for guidance.

Health insurance companies can use this information to make policy changes within the health plan infrastructure. Nursing curriculums can include a discussion within courses such as pediatrics and community health about nursing care coordination. Likewise, clinical experiences can include sites where nurse case management occurs. Pediatric practices can involve nurse care coordinators from health insurance plans to help coordinate the care of CSHCN. This study helped to unveil new understanding of being a parent of a CSHCN enrolled in public or private insurance with or without a nurse care coordinator.
Appendix A. Swanson’s Theory of Caring

Figure A1

Swanson’s Theory of Caring

Appendix B. Letter of Cooperation

(Date)

To Whom It May Concern:

Please note that Regine Placide Reaves has permission of (agency) to recruit participants for her research at our organization for her study, “The Lived Experience of Parents of Children with Special Healthcare Needs on Public and Private Insurance: A Phenomenological Study.” The purpose of this study is to understand the experiences of parents with children diagnosed with special health care needs on both public and private insurance. Regine Placide Reaves has shared with me the details of her project.

We understand that the Mrs. Reaves will use key personnel in our office to identify and select potential families. She will recruit parents by leaving flyers as an invitation to participate in the study. Neither participating, nor declining to participate in this study will affect families’ services in any way. (Agency) requests that the agency name and identifiers of its clients be kept completely confidential in the research results.

I give her permission to conduct her study at our agency.

If there are any questions, please contact me.

Sincerely,

[Signed by an official of the agency]

[Individual signing the letter with their official title]
Appendix C. Recruitment Flyer

Florida Atlantic University

The Lived Experience of Parents of Children with Special Healthcare Needs on Public and Private Insurance

The purpose of this study is to understand the experiences of parents with children diagnosed with special healthcare needs on public and private insurance.

Am I eligible?

- You are eligible to participate if you are a parent of an infant, child or young adult aged 12 months to 21 years of age
- You are 18 years or older
- Your child has been diagnosed with a medical, behavioral, emotional or intellectual condition and you reside in Miami-Dade, Broward or Palm Beach County, Florida.
- Your child is enrolled in a public health plan with/without an RN coordinator managing their care or
- Your child is enrolled in a private health plan with/without an RN coordinator managing their care
- You are not eligible to participate if you do not speak English

How long will the study take?

The study may take up to two meetings, each lasting up to 90 minutes. If the study cannot be completed in the first interview, you may be asked to participate in a second interview.

Where and when will the study take place?

Interviews will take place at the time and location selected by you.

Are there any incentives for participating?

You will receive one (1) $15 Publix gift card at the end of the interview.

Who should I contact for questions?

You may contact Régine P. Reaves, MSN, RN at [1]
Appendix D. Informed Consent

ADULT CONSENT FORM

Version 3.0 – October 13, 2018

1) **Title of Research Study:** The Lived Experience of Parents of Children with Special Needs Children on Public and Private Insurance: A Phenomenological Study

2) **Investigator(s):** Lingyu Chiang Hanisko, PhD; Regine Placide Reaves, MSN Ed, MPH, RN

3) **Purpose:** The purpose of this study is to understand the experiences of parents with special health care needs on both public and private insurance.

4) **Procedures:**
   As a participant in this study, you will be interviewed by the researcher.
   - The study may take up to two meetings, each lasting up to 90 minutes.
   - You will receive one (1) $15 Publix gift card at the end of the interview.
   - If the study cannot be completed in the first interview, you may be asked to participate in a second interview.
   - If you are asked to participate in a second interview, you will receive an additional $15 Publix gift card at the end of the interview.
   - The time and location of the interview will be selected at your discretion.
   - The interview will be recorded using two digital recorders and transcribed.
   - You will be asked about your experience of having a child with special healthcare needs on public or private insurance. You will also be asked about your demographic information and sources of support.
   - You may ask to not have the interview recorded.
   - You will be provided time to ask any questions.
   - You may ask to stop the interview at any time.
   - You may choose to withdraw from the study at any time.

5) **Risks:**
   There will be no harm experienced during the interviews. However, discussing your child’s condition may bring about feelings of frustration, sadness or depression. Should this occur, the researcher will assess the situation and end the interview. The researcher will refer to Henderson Community Health’s Youth and Family Services program located in Broward County at 2900 West Prospect Rd, Tamarac, FL 33309, (954) 731 5100 for additional assistance. Also, as a registered nurse, I am a mandatory reporter by the State of Florida. Therefore, I would be obligated to report any disclosure of sexual, physical or emotional abuse.

6) **Benefits:**
   It is not known if participants will receive any direct benefits by taking part in this study. Healthcare providers may be able to provide relevant care to families of children diagnosed with special health care needs. Healthcare providers may also gain better insight on how to improve coordination of care for children with special healthcare needs.

7) **Confidentiality/ Data Collection & Storage:**
Two digital recorders will be used during the interview. All information provided will be transcribed verbatim. Only the researcher and faculty advisor will have access to the data. Any information collected about you will be kept confidential and secured and only the researcher and faculty advisor working with the study will see your data, unless required by law. To protect your confidentiality, consent forms will be stored in a secured locked cabinet. Only the researchers will be able to access to these locked cabinets. Audio files will be deleted after transcription and verification by the researcher and faculty advisor. Written data from this research will be shredded after five years. Electronic data will be destroyed by deleting them after five years. Sometimes researchers need to share information that may identify you and your research records with people that work for the University, the Institutional Review Board (IRB), Research Integrity staff, regulators or the study sponsor. These people are responsible for making sure the research is done safely and properly. If this does happen, we will take precautions to protect the information you have provided. We may publish what we learn from this study. If we do, we will not let anyone know your name/identity unless you give us permission.

8) **Contact Information:**

- If you have questions about the study, you should call or email the researcher, Regine Placid Reaves at [redacted] or [rplacid@health.fau.edu](mailto:rplacid@health.fau.edu) or faculty advisor, Lingyu Chiang-Hanisko, PhD, RN at 561-297-2937.
- If you have questions or concerns about your rights as a research participant, contact the Florida Atlantic University Division of Research, Research Integrity Office at (561) 297-1383 or send an email to researchintegrity@fau.edu.

9) **Consent Statement:**

*I have read or had read to me the information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. I have received a copy of this consent form.*

I agree  I do not agree  be audiotaped/ videotaped.

**Printed Name of Participant:**

**Signature of Participant:**  **Date:**

**Printed Name of Investigator:**

**Signature of Investigator:**  **Date:**
Appendix E. Participant Demographic Form

All information provided on this form will be kept confidential and will only be used for the purposes of this class assignment.

Child’s gender: ___ Male ___ Female

Child’s age: ______________

Parent’s Ethnicity:  ___ Asian American ___ Black or African American ___ Hispanic or Latino ___ Native Hawaiian and Other Pacific Islander ___ American Indian and Alaska Native ___ Other

City/State:  _________________________________________________

Marital Status: ___ Never Married _____ Married ___ Divorced /Separated ___ Widowed

Parent’s Highest Educational Level:

___ Some High School or Less
___ High School Graduate
___ College Graduate

Parent’s Income:

___Less than $15,000 ___ $15,000-$24,999 ___ $25,000-$34,999
___ $35,000-$49,999 ___ More than $50,000

Parent’s Employment:

___ Employed ___ Looking for work ___ Unable to Work ___ Other
Appendix F. Sources of Support

Please circle the terms below that you consider sources of support.

<table>
<thead>
<tr>
<th>Non-Professional</th>
<th>Professional</th>
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<tbody>
<tr>
<td>Church</td>
<td>Child’s Teacher</td>
</tr>
<tr>
<td>Friend</td>
<td>Counselor/Licensed Therapist</td>
</tr>
<tr>
<td>Grandparent</td>
<td>Doctor</td>
</tr>
<tr>
<td>Neighbor</td>
<td>Health Insurance</td>
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<tr>
<td>Other Family Member</td>
<td>Home Health Agency</td>
</tr>
<tr>
<td>Parent</td>
<td>Physical, Occupational, or Speech Therapist</td>
</tr>
<tr>
<td>Sibling</td>
<td>Support Group</td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>Social Worker</td>
</tr>
</tbody>
</table>
Appendix G. IRB Approval

DATE: November 7, 2018
TO: Lenny Chiang-Hanisko, PhD
FROM: Florida Atlantic University Social, Behavioral and Educational Research IRB
PROTOCOL #: 1253135-2
SUBMISSION TYPE: New Project
REVIEW CATEGORY: Exemption category # A3
ACTION: DETERMINATION OF EXEMPT STATUS
EFFECTIVE DATE: November 6, 2018

Thank you for your submission of Response/Follow-Up materials for this research study. The Florida Atlantic University Social, Behavioral and Educational Research IRB has determined this project is EXEMPT FROM FEDERAL REGULATIONS. Therefore, you may initiate your research study.

We will keep a copy of this correspondence on file in our office. Please keep the IRB informed of any substantive change in your procedures, so that the exemption status may be re-evaluated if needed. Substantive changes are changes that are not minor and may result in increased risk or burden or decreased benefits to participants. Please also inform our office if you encounter any problem involving human subjects while conducting your research.

If you have any questions or comments about this correspondence, please contact Donna Simonovitch at:

Institutional Review Board
Research Integrity/Division of Research
Florida Atlantic University
Boca Raton, FL 33431
Phone: 561.297.1383
researchintegrity@fau.edu

* Please include your protocol number and title in all correspondence with this office.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within our records.
Appendix H. Examples of Original Transcripts

Original Transcript (F3P13WN3)

1. What source of support do you use as a parent who has a child with special healthcare needs?
2. How does this type of support help in caring for your child?

Friends
I would say more emotional than anything. I think with complex care of a child it’s very difficult. Even more so for me because the needs change and they vary.

Neighbor
I would say minimally – they came only to the degree that – it’s more so emotional again.

Parents
Yes, I do get some support from mother but she is older – she’s 81 and uh you know she tries as best as she can but she’s physically not able to – because my daughter has gotten so big. So she’s here on a couple times out the year. Like today, she’ll be coming over with my aunt, her sister, to take her and the girls to the park. So that’s an opportunity where I feel she herself will be safe. Because there’s physical concerns with my daughter – she’s ambulatory she can get around – she’s completely nonverbal so it does make it a little more complex trying to you know. So that is the extent of family support – I hate to say it.

Spouse/Partner
I think that’s one of the biggest challenges – trying to divvy up the workload and there’s a lot between – we have a dynamic household – we have a 12, a 10 and 7 year old. And so being able to provide her with adequate level of care while maintaining an entire household and providing adequate support to the rest of the family is always a challenge – but we try and do our best. I think the best thing for us is trying to figure out – because we had changes in income – because we went from a two income household to a one income household because of the level of care that we need – I think that would be a challenge just in general for a household with three kids – who are at 3 separate schools so that’s been a big thing – 3 drop offs everyday. But that is what we chose to do – we do whatever we need to make it work. So its managing financial needs – and the logistics of our household. We do our best, it is challenging, I’m not gonna lie about that. Struggling to figure out financial – we both had our businesses and so I have actually shut down my company completely the last year so I could devote more of my time to providing support to her and learning more about her disease. I run a foundation – the only one in the US for her disease. It’s a sacrifice, otherwise trying to get adequate medical care is almost impossible. But we’ll get into that later lol. But the medical insurance and what we have to do with that – even this week – I’m gonna have to somehow squeeze it into my schedule and just getting adequate services. And they don’t give you any timeframe just kinda refuse services so I just look at denials as part of the process for us. It’s no longer shocking, surprising or how dare they – it’s kind of like, yup! My specialty is to research the medical care, I have to find the doctors, set up the appointments, um, because I am at home. I do a lot of the transporting to activities, just basic household but just even, I mean, we are at a deficit especially now since we’ve been without respite for an entire week…

Original Transcript (F2PU2WN2)

Interviewer: Do you get any follow up from anyone at Kidcare?

No, no body calls. Just the doctor (orthopedic surgeon). They (Kidcare) never called or nothing. Everybody from the doctors office called though – all 3 ARNPs. I mean I think it got to the point where I spoke to everybody in their office. From the person who does insurance – she’s the one that called me and said ok, we checked the insurance and blah blah blah, she just gave me everything as far as
Everything is fine, it’s approved, there’s nothing for you to do mom. Then the ARNP that prepped us before, after and during – gave (child) her private telephone number that at anytime he has a problem that he needs to text her or call her. There was another ARNP and she was like the back up person and she said the same thing. They even go in contact with the radiology department in their office (laughs) So if I had a question about how many x-rays is he gonna need because I’m concerned about the radiation. And he went into an explanation about the new machine that they use and he said, remember when they did his bone age? I said yeah, he said they did a separate thing for that and they had to cover up all the other parts of his body. And I said – unh hunh. And he said this new machine that we have not only does it takes a picture of his spine but it also does the bone age and it’s a very low density radiation which is why we can repeat it. Because the second time remember you weren’t covered – it doesn’t emit like the other things. I was so impressed.

So everybody in that office spoke to me at some point.

Interviewer: Was there an RN at the office that reached out at the office?

Mom: No, they were all ARNPs.

You know, after the surgery, the primary care doctor never even called me. Yeah, they didn’t call me. He was suppose to have a regular visit and we just went in for the regular visit and I mentioned that he had the surgery. And she was like, ok. Actually we didn’t even see the physician during the visit. Because when he went in it was time for him to get his HPV shot so maybe that’s why. So he went in just to get that done then I mentioned to the person that he had the surgery and they said, ok we’ll see him next year for his physical. So the primary never laid an eye on him.

But the surgeon was amazing. My thing was is I always wondered when something is that important or could get to that point – like remember when you said what would a nurse have helped me with? It would have helped me to understand that was my responsibility before the surgery happened, to prepare me, I didn’t have that. And when he was with Kidcare and I was talking to the doctor, and he asked me what insurance do you have, okay great, they just knew. They knew what they would cover, they’re going to do this, they’re going to ask for this. They did all the talking with the insurance company. When it came to my leave time at my job, the office called them and took care of everything – all the paperwork, all they asked for was my consent. And she said I’ll always fax it to you first to review it before I submit it. So, am I upset with Humana? I was but I think I’m more upset with myself for not realizing that there was more information out there for me find. But I eventually got it. But I’m just sitting here wondering about other parents that have commercial insurance – how do the commercial insurance think that parents can afford this when it’s unexpected? And I’m a nurse! Think of the parents who aren’t.

Original Transcript (F3PU3N3)

1. What source of support do you use as a parent who has a child with special healthcare needs?
2. How does this type of support help in caring for your child?

Friends
They watch him and do a good job with that. They will come by the house because I can’t go too many places. If I need something at the grocery store and I don’t want to deal with the tantrums, I can call them and they will bring it for me. If I can’t pick him up on time because we have to get up at a certain time, then they’ll get him and bring him for me. They help a lot.
Therapy
Right now he’s doing ABA therapy because he has behavior issues. And I see that the behavior is going down, so first I wanted the therapy to start at the school because then he’s not learning. And so I notice the bad behavior when he comes home. When it’s time to eat or if I need to do something I can’t. If I tell him to not jump on the bed as oppose it use to be a meltdown. So I think that’s working.

Interviewer: so they give you strategies to help with the behavior and that helps?

Mom: Yes. And this is something new. They now come once a week.

Interviewer: Is that the only therapy provider he has?

Mom: Yes, but I’m looking for someone to do OT with him. But they have to do it in the afternoon for like one hour and to the house and the weekend. Because I can’t take him back and forth – it’s only me. And I have to work. So I’m looking for someone and that’s hard. So someone to come to my house to do it with him for the one hour. I’m also looking for ST - but he’s getting ST at school and his speech therapist said he’s doing excellent and I see it too. With me he don’t really talk because I knows what he wants but with his sister he’s forced to talk – you know he’s forced to say what he wants.

Child’s Father
Well the daddy help to but don’t get me wrong – he’s not a bad person, he helps to but he doesn’t take it as serious as me. He thinks it’s going to go away or he’s just going to be okay. He has a different idea of what’s going on.

Interviewer: Is he accepting of the diagnosis?

Mom: I don’t think so. He tells me he does but I don’t think so. If I tell him, hey can you pick him up because I don’t want my anxiety to go up and he’ll say but you know I’m working and blah blah blah. But for me I’ll be like okay, I have to work I still have to get him. But for him it’s an excuse and for me it’s not. We are not on bad terms and he is not a bad person. I just think that his priorities are not right and he think’s (child’s name) is a typical child. If you live the life, you’ll see it.

Original Transcript (F1PU1N1)

1. What source of support do you use as a parent who has a child with special healthcare needs?

2. How does this type of support help in caring for your child?

Friends
Well I unfortunately for me, have very little support. What I have is friends who listen to me, basically. And maybe give me an idea of what they think I should do. I don’t have time to go to no ---- And I consider my younger child as support bc he actually pushes my older child who has the condition. I divorced three years ago. Before I had some support now I have zero support from the parent. He does not believe that the child has anything. He doesn’t wanna act on it basically. It’s been really hard right now for my oldest one who has the conditions. He’s now allowing some therapy but it’s under his terms basically. Everything is under his time whatever he can do and all that. Um regarding speech therapy he doesn’t allow at all. He doesn’t believe in
it, he doesn’t think that the therapist is good and he just doesn’t want to put the time to it. He was in denial in the beginning, now he’s under the impression that, oh I accept him for who he is so I don’t need to make any changes.

And that must be hard for you..

Mom: Super, super hard because it’s two different personalities at the end of the day. It just has a lot to do with that dynamic of how we separated. We don’t get along. So anything to do the contrary to what I say - regardless of what happens to the children. He’s a person who suffers from addiction so I believe he’s trying to quit and one of his things is controlling. So he wants to have them all the time. Just him – not to share them with therapists during his time.

**Family**

I have a cousin and she has a child with receptive language disorder. And he has not been diagnosed as obsessive but he’s very much in the same spectrum. So, he’s way older, like he already graduated. One of the reasons why I say this is because he was diagnosed for something else but he was given the neurologist that my child has (which my husband does not agree with) suggested for him to start some kind of medication because he’s at a good age to start. His brain is already developed and there’s some risk of cause many damage = this is Vyvanse. He suggested and thought it would benefit in school, learning, focusing. And dad disagreed and he said no – and that’s frustrating for me – very. But then my friend, my cousin, she just gave me a lot of information, she used the same medication, she still uses that medication. So I get a lot of information from her.

**Therapist (Speech & ABA)**

They give me ideas. I get information from them. They are very open, they come to the house so we become close. The ST has been with him for ten years. He’s really advanced a lot and she’s really good with him. And the ABA therapist we just recently started doing (after fights and fights). It’s been really hard because I have trouble finding a therapist that would agree to such a weird scheduled. But every time I get with them we talk about him, we talk about what we can do, what we should push for and all that.

I have CMS for him. They are awesome. I was able to get – and this is where it goes confidential – because I had no support and I had to always put I was single handling the kids, even though I was married. Because when I tried to apply for insurance through United, not United – I tried several private insurances. They would not accept my child – and that was before Obamacare. And since that happened, I’ve been in Medicaid, thank God. And in those time, I was still married. And right now that’s what we have.
Interviewer: What challenges did you face or what challenges are you currently facing on your child’s insurance?

Mom: Oh God. Back then I worked for the county and the county had an HMO where you paid X amount of money – I think you paid $57 per pay period and they pretty much covered everything. I rarely had to come out of pocket – it was with Humana and I also had Avmed. So those two insurances – thank God – I had it my first year and thank God – that was heaven sent. So then the county switched to a popular item called the Health Saving Account where the county gives you $2400 and that money is for three members of your household and it has to last the whole year. So any hospital stays, I forgot what the minimum out pocket and you have to reach a deductible. So I’ll give you an example – my daughter had an MRI and it cost $500 and it was at a free standing facility because they don’t want you go to any hospital because once you go to a hospital you’re talking about $1000 or more. So what I’m finding is the contracted amount that’s being charged, and what I’m being charged by the provider are not always – they’re jipping me basically. So I’m having to go BACK and get the difference. With that insurance I have to be very very very careful on how I spend because my daughter also has braces, my oldest daughter has braces, so I have to be careful. They’re terrible, absolutely terrible. And I can’t have Kidcare because I have ---. I tried to put my eldest daughter because she has no disability on Kidcare – and they told me basically no – she basically has to either have Kidcare or the county insurance. So back to UHC, until you reach the deductible, the provider does not pay 80% of the cost. My deductible is up there – it’s anywhere from $3000 to $5000. So with that It’s like being in the dark – I’ve had to forego my procedures that I need because I’m too worried about exhausting everything in that 12 month period. Because anything can happen.

Early on with the insurance I didn’t have that many challenges. I can’t recall because so much of it was done through Early Steps so I didn’t have that many challenges. But as she got OLDER it became a juggling match. I had to forego some non-preventative services for myself so the kids could have what they need. And God forbid, the word hospital is not – you can’t have that in the picture, no. So you have to choose wisely and I have a host of medical bills. So my credit would not have taken the hit that it has if it weren’t for these medical bills. So next year I think I will put my oldest on Kidcare and not put her on the county insurance. Because although the count is only taking $10 per pay period – the county makes it look like you’re not paying anything because it’s only $10 so that’s not nothing. But on the back end you’re paying a lot for that $10. Because of my income, because this country bases everything off income, you know government assisted programs and resources are based off income, I would have to incur $230 per month on Kidcare.

Interviewer: Does the insurance take care of all your needs as far as coverage?

Mom: No, because I always get a bill. The $2400 that they give goes towards eligible expenses. So, when I go to the doctor’s office, there’s always going to be something for me to pay. There’s always going to be $100, $50 – as long as it’s an eligible expense – braces (dental), or if I need dme which will not happen with this insurance because I go through the non-profit for that, that’s why the non-profits are so important – they’re grants – because that’s how I’m able to offset some of the expenses.

Interviewer: and there’s no other insurance options that you can choose from?
Mom: Nope, it’s either UHC or no insurance. Well, no, there’s another plan but it’s worse. I don’t remember the name. It’s a consumer driven health plan.

Interviewer: If you run into a problem, is there anyone at the insurance that you can call for help?

Mom: No, I just call the 800 number on Cigna and then whoever answers the phone is who you get.

Interviewer: Do you have any limitations with providers, coverage?

Mom: No not with Cigna

Interviewer: Are there any challenges in general, with the insurance?

Mom: I have school issues with school with him. Because he qualifies for IEP – so he gets more time for testing. So they pull him out and for students who have an IEP they test them different. So they give him large prints and before they didn’t do that. So I would notice his grades were affected. And he would say oh it’s because I can’t see the printout. So I would have to go to the school and complain a couple of times about it.

Interviewer: Is there anyone at the school that helped you?

Mom: Right now it was the IEP counselor. She’s pretty good. We had a meeting the other day and she told me that she’s always asking (child’s name) if he had any questions in class, do you need more time with assignments. Because you know it’s his first year in middle school so she said it can be very challenging because you have different teachers and different classes. As opposed to one teacher in elementary school teaching the different subjects. And although they give him the time to test, he has issues trying to keep up with stuff. So she’ll ask do you have any questions. It happened a couple of time with the accommodations issue but it didn’t get to the point where it was ridiculous. So the day he didn’t have time to finish the test, she allowed him the next day to come before class to make up whatever he didn’t do to make up the time. So now they do accommodate him.

Interviewer: When he was first diagnosed, did you face any challenges?

Mom: He was home schooled at first and the lady first noticed that he was having vision problems. So I made an appt and found out there was an issue. And the doctor said we have to start patching his eye. It’s the nerve and not the muscle. So patching might work. He would run into things and run into something. A couple of hours a day. And I only did it at home. I tried to apply for SSI/disability and I was denied based on my income. So I wasn’t able to get any other resources for him. And people would tell me – you should be able to get this and that because he had a tethered cord and had spinal surgery. And people would say, girl you should qualify to get stuff. And then his weight at birth, but they were like no m’aam sorry but we go based on income and you make too much so based on that we’re gonna have to deny you. And I only put my income on their – not his dad’s and they were still like no. It was two household incomes and I applied for one. And I didn’t want to lie and say I had people living with me and look what happened still. It had to be like 6-8 people for me to qualify. I’m like you have all these people
who don’t work and stay home and you give them all the assistance. We work and do all this and y’all won’t give me nothing at all? And they were like no m’aam sorry.

Interviewer: If you had a nurse case manager from Cigna to help you with the challenges you just spoke with you do you think it would look differently? If so, how?

Mom: (mom takes a few seconds to think) It probably would’ve been a lot easier for me. She could follow up on any issues or concerns as far as like that who payment issues and things of that nature. And with the SSI denial maybe gave me some other options or resources that she knows of.

Original Transcript (F1PI1N1)

Interviewer: In what ways do you feel you were able to cope?

Mom: My faith. I had to learn how to work as a team with my husband also. We didn’t agree on how to discipline the kids at one point. And he chose to leave and go to his parents one time. And the kids were looking for their day. And I realized that sometimes you have to swallow your pride and find a median way. Because children need their dads. And as a sibling it’s hard for them because the spotlight is on the one child with special needs. So I learned once I deal with this one I need to focus my attention on the other one. Or I take one and my other husband takes another one. As time went along that’s how we learned to work as a team. We had family members who would say, that’s not from our family. We didn’t do that on our side or behave like that on our side. Or they would say, he’s a little crazy. And I’d say, no, he’s autistic. And then I’d give them information about it. You know many times he wouldn’t be invited to parties. Sometimes they were invited period. And he would ask how come I can’t go. This is family and friends now. And I’d say you know they’re doing their family stuff and so I’d try to change the subject and say come on let’s get in the car and go bowling. And so we just become our own family of 4 where we did everything together, entertain each other because the outside world – they look at you differently. They’re acceptable – to a certain point. It’s all about tolerance and acceptability. And that’s why we always had our own parties at the house where we invited kids from his class and only a few kids from the neighborhood and their parents.

You know we used to do Dan Marino’s walks and that was great. A lot of studies were being done. So times are changing.

Interviewer: If you were to rate yourself on a scale of 0 to 10, how do you feel you were able to navigate the insurance plan to meet his needs?

Mom: I would say an 8. Because there are some things that I should have investigated more. Like the nurse and those type of things. I did use the nutritionist because they did send info about good eating.

Interviewer: What went well

Mom: Being knowledgeable about the things he needed, knowing the ins and outs of health insurance specifically the mental health component. Many people will not utilize mental health.

Interviewer: Had you used the nurse on the insurance would your experience have looked different you think?

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Mom: Well when he had his temper tantrums, there were times where I thought I would go to jail but I called the police one time. So I could lose my job because I work with the state. If I had used my nurse case manager then I would have absolutely needed that at that time. That guidance, that advice, if I was feeling depressed to call, call that person to give you ideas and give me that calmness. IF I knew I could have used her in that scenario but I didn’t really know.

Interviewer: Any issues with the school? As far as accommodations?

Mom: No because they knew that when I came to the table, I knew exactly what he needed. I came to the table with everything. So I’d tell them go ahead and write and I’ll tell you if I need more.

Interviewer: So you’re experience, background, education definitely helped?

Mom: Oh yeah. I worked with the school board for 38 years – my undergrad was speech pathology and my master’s was in learning disability.

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**Original Transcript (F4PU4N4)**

1. What source of support do you use as a parent who has a child with special healthcare needs?

2. How does this type of support help in caring for your child?

**Health insurance**

I don’t know if it’s because of the Presidency or what is going on but this is the first time, like now, that I’ve had someone visit me at home from the insurance and asks me questions, and want to meet my daughter and super nice. Super helpful. I have my own little theory like maybe they’re trying to crack down on fraud. My daughter had nursing when she was little because she had so much medications, so many machines that I needed nurses. And the nurses would tell me, oh, we’ve gone to houses where they have mansions and boats and there’s a bunch of fraud going on. And I said, well we’re just trying to be honest people and get what we need. We’re not trying to get more than that. This nurse coordinator, her name is (nurse coordinator’s name), she came over and she’s been in touch with me. And I actually switched my son over to the insurance. So she’ll be at my house next week. And she’s just awesome because whenever I need something for Sophie, I can email her. And for any reason if I need a special authorization or something that’s happening fast enough – like ok, one of her huge issues is she has one leg bigger than the other – like significantly bigger visually – width and length. So, we’ve never been able to get her shoes like shoes that actually fit her. So we have to get shoes that are a bigger size but then one of them fits and the other the one doesn’t fit. Or one of them fits and the strap isn’t long enough but if you see her legs you’ll understand. So, with (nurse coordinator’s name), we’re trying to get her, for the first time in 11 years, actual custom shoes. And all the insurance people it’s like, oh, we don’t have the right code – because at the end of the day it comes down to money – because then we don’t get paid. And so (nurse coordinator’s name) has been awesome because she’s trying to do a special authorization to get her the shoes because we have all the paperwork that her orthopedic doctor says it’s true – like she needs it and it’s not for vanity. This is just like a daily thing that we all don’t even think about like shoes. It’s not a big deal to most but for her it’s been such a mission. She’s phenomenal and I don’t know if it has anything to do with what’s going on but I mean I’m definitely grateful. And I do see the difference in her healthcare.

Interviewer: How long have you worked with the nurse coordinator?
Mom: I would say maybe a year or more. I mean I think I had someone that called me before her, occasionally and checks how my daughter is doing or asks me a couple of questions about her, but no one has ever come to my house and actually have a face to face and interview with me and met my daughter. I think they’re cracking down on people abusing the welfare and the Medicaid system.

Interviewer: Great. Is there anything else that she does that you find very helpful?

Mom: She just asks if I need anything, like help with appointments or special authorizations. There was a shift with Bascom Palmer. My daughter goes to Bascom Palmer and something happened where now they weren’t taking CMS insurance but my daughter had been there since birth and she has a very unique eye issue where I really wanted to stay there. So its not that she’s not there anymore but whenever I go I have to get a special auth so that she can have her visit there. So she’s been instrumental in making things go smooth, making sure it happens – that she can go to the visit. Because sometimes when the parents call for a special auth, it’s different from the nurse coordinator – I guess her calling from the insurance company or doing whatever she does makes the process go faster. Yeah. I’m so grateful I really am.

Original Transcript (F1M1PU1N1)

3. What challenges did you face early on or what challenges are you currently facing?

Mom: Um, there were many challenges in Broward. First off, trying to find a speech therapist that can fit him onto the schedule – occupational therapist, the speech therapist that I did find when he was around 3 - they were terrible. They were people who came to the home, they did nothing but play with him. It was not a good experience in Broward at all, whatsoever. Not with the school system, not with Early Steps. We feel that they didn’t care enough and they were limited and uh yeah, he had very inconsistent therapy sessions with occupational and speech in Broward County.

Dad: Yes, the inconsistency with him because there has been so many changes. We had to change the school several times. He’s been going through that since he’s been two.

Mom: Yeah.

Dad: So, to have a sense of consistency that is huge. To see the same person, you know. Because my son doesn’t really do well with sudden, constant changes. Even now, you know, the young lady that comes to do the ABA they were talking about the possibility of changing her a few times and then somebody else and I was a little concerned about that. He works very well with her.

Interviewer: So these challenges that your telling me about – did you have anyone helping you through it?

Dad: Honestly, my wife is sort of like a, she’s to me, like, the biggest advocate. I don’t think my son would be where he is right now if my wife wasn’t so involved. In terms of always seeking things out, finding things out, things that are out there. She found out just by attending different um fairs and stuff like that, autism walks. Because there are resources that just aren’t, you know, um, pretty much handed to you. There are resources that you kinda have to seek out. And she’s
done a wonderful job of just being on top of things and being his advocate and telling people what he needs and what he’s lacking.

Interviewer: And so dad, you feel like, mom has had to go out and find information and resources?

Dad: oh yes, definitely. One thousand percent, yes.

Interviewer: What challenges are you currently facing?

Mom: Um, I think the only challenge we're facing right now is the school.

Dad: Yes, the school.

Mom: I’m going back with the ESE department because he’s zoned for a really good school but unfortunately that school doesn’t have a cluster so they had to transfer him to a school that we don’t like that’s considered a reject school. It is very unorganized, I’ve never seen anything like it.

3. What challenges did you face early on or currently on the insurance?

Mom: I have a very close relationship with the ABA owner/therapist. She started her own company. And she let me pay oop what I could until the insurance covers it. And it’s because we have a personal relationship. And If you ask me she’s definitely a source of support. She’s amazing. She helps us out so much and makes sure we have good therapist. Before I found her, I kept being placed on waiting lists for therapy. Like 6 months. Especially behavioral. And so another parent I know with special needs helped me find this place.

Unfortunately, the don’t pay the same rates as the private insurance. That’s could be an issue but I don’t have to deal with that thank goodness. I hear it all the time – she turns Medicaid clients away all the time because her therapists most times won’t take it. I’m lucky because I got in early. She watches out for me because (child’s name) was basically her first client. But the biggest challenge in the past is when Medicaid would change plans on us and then he’d be left uninsured. There was a lapse because they decided just to change.

Medicaid at one point was going to stop covering ABA last year and my advocate that I told you about, they went up to Tallahassee and a whole bunch of people went to fight it and they put it on hold. So that’s why this year I don’t know what it’s going to bring with that. She also has a 14 year old non verbal son. I think when you’re getting a place like for the money but it’s a different scenario when they have their own child with the same thing. Their personally invested in it. And they understand it more.

Interviewer: Did you go without services during the lapse?

Mom: Well what happen was the Speech and OT they called me and said we tried to bill the insurance and we can’t bill. And then I would call the insurance and would be told oh we changed it over to another insurance. And they never told me. Then you would have to have a whole new evaluation for the new insurance or they won’t cover. And then they take their time to do it so. He
didn’t have ST and OT for a couple of months and I had to pay oop for behavioral. And that was like $800. And I couldn’t do with the speech and occupational because we didn’t have the money.

Husband: I’ll give you a great example. So I’m an insurance agent and I’ve been doing that for 19 years. Here’s the weird thing with a state of Florida. When it comes to ABA therapy, we see better results with it. So the insurance pays for the ABA therapy which is tough. You know they wanna limit the hours and so forth. If I owned my own company and had 50 or more employees, by Florida law they have to give you ABA under a group policy. But if you bought an individual insurance policy through the ACA or something outside of ACA like Cigna, Aetna, etc., they don’t cover any ABA therapy because they say it’s not a medical necessity. So I’m trying to understand how the state of Fl can mandate it for 50 more employee plans but individual plans say you can’t because it’s not medically necessary. You can’t have it both ways. It’s mind boggling. How does the state mandate that? And my son is only getting 20 hours a week.
Appendix I. Examples of Significant Statements

1. I don’t even have time sometimes to brush my teeth. In fact, I haven’t brushed it today, I’m still in my pajamas. I work about 17 hours a day.

2. My physical health is absolutely taking a toll for the last two years. Lack of time I mean no personal time. It is my goal right now to focus more on that but at the same time, I’m fighting a disease that will kill my daughter one day and so I don’t have the luxury and I’m sure that’s a choice that other families have chosen to either do something or not. I’ve had to forego my procedures that I need because I’m too worried about exhausting everything in that 12-month period. Because anything can happen.

3. I’ve had to forego my procedures that I need because I’m too worried about exhausting everything in that 12 month period. Because anything can happen.

4. I mean, if I died, if push came to shove, he probably could do it but I’m doubtful. I can’t say yes with 100% certainty. I just don’t know if he’s not capable because he doesn’t have to be or bc it would be a challenge because they’re would be some slipping through the cracks on my child’s behalf because he wouldn’t be on top of it the way I am.

5. I have to find the doctors, set up the appointments, um, because I am at home. I do a lot of the transporting to activities, just basic household but just even, I mean, we are at a deficit especially now since we’ve been without respite for an entire week.

6. I’ll have to make 6 calls because no one at the other end will actually understand the process. And so it’ll take a few days just to do that. And then you’ll get the paperwork back which is just like 80 pages long and then I’ll have to spend time reviewing.

7. I find myself telling them what I need and what to do. And this is the problem I have dealing with different specialists – Dr. – is the only doctor who, after the visit – actually sends his report to the primary (laughs). The other doctors don’t do it. So I have to walk around with a binder so everyone knows what everyone is doing. Mmm hmm. And thank God this child does not have meds.

8. I tried to apply for SSI/disability and I was denied based on my income. So I wasn’t able to get any other resources for him.

9. And they told me that he did not qualify because both eyes were not affected. And that it was only one eye – the other eye is 20/20. And I said to myself – gee whiz! I can’t catch a break! Do you know how much money I could have saved if they helped me? So there’s resources out there but you still end up not being eligible.

10. And with the SSI, there are 6 major areas of life activities. All you need to score is one – marked severe – my daughter scored 4 out of 6 sever with functionalities. And that didn’t qualify her because of my income and resources. She met the criteria with all the medical stuff. So it always goes back to

11. Um, the challenge was that I didn’t even use my insurance. There was no benefit to me to even use it.

12. or if I need dme which will not happen with this insurance because I go through the non-profit for that, that’s why the non-profits are so important – they’re grants – because that’s how I’m able to offset some of the expenses.

13. So you can’t really rely on the health insurance. I dread them. Not only do I dread them I have a fear of them. Because your deciding life and death. You’re deciding the quality of life for my child. So rather than give you all the energy, I’m going to go to the non profits
because with non-profits all I need are a paper and pen and I’m done. That’s it. There’s one that I’m looking at for swimming lessons to help pay for it. I would rather do that than get a damn insurance company to help me pay for something therapeutic. Can you imagine what I have to go through? It’s too much, I can’t.

14. a lot of my friends were familiar with ESE so they were there from an academic point of view

15. My best friend is an assistant principal for a school so moments where I thought I was going to lose it I would call her and she understood.

16. because I knew so many people in the district… I wanted someone who was not familiar with me or familiar with him. So I had the head psychologist of ASD to do the testing

17. It was a friend of mine who really told me what to do and questions to ask. He was an MD in his country and at the time he worked in a hospital.

18. The friend I was thinking about happens to be a nurse (laughs). So it was discussing what the plan is, new information that’s out there about his diagnosis, and what was her experience in treating other kids that had scoliosis. She is a pediatric nurse.

19. And because she is an ARNP in pediatrics, she talked about the current practices and what to expect. These are the things that you should expect.

20. They’re just there for me to call them when I need them which is good.

21. Yes, they switched case managers now that I have Well Care (health plan) and Well Care requires case managers to meet with families in person and she’ll ask if I have any questions. I meet with her at my son’s OT sessions.

22. So she’ll be at my house next week. And she’s just awesome because whenever I need something for (name of child), I can email her

23. They called me, found me a neurologist, made the appointment for me. I remember when I made the decision to go back to a neurologist, they did that. They would tell me about the good ones, who has a good reputation and all that.

24. ...when she called periodically she would know I was busy and would ask me if I had any concerns. She would come with information - like oh I have a number for this or that, you can look there or here. She would ask if I have a concerns – and if I was nervous or doubtful, she would give me reassurance like yes you could take him to the neurologist or yes you can take him there. Like hey if you don’t feel comfortable here are some other choices. Because I never knew about the YMCA and she told me about it. She understood – like okay you have some challenges. I mean she told me a whole lot of things. Just new information

25. She just asks if I need anything, like help with appointments or special authorizations.
### Appendix J. Significant Statements with Formulated Meanings

#### Table J1

**Significant Statements and Formulated Meanings**

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I don’t even have time sometimes to brush my teeth. In fact, I haven’t brushed it today, I’m still in my pajamas. I work about 17 hours a day.</td>
<td>1. Mother is so busy coordinating her daughter’s care that she neglects her own basic needs.</td>
</tr>
<tr>
<td>2. My physical health is absolutely taking a toll for the last two years. Lack of time I mean no personal time. It is my goal right now to focus more on that but at the same time, I’m fighting a disease that will kill my daughter one day and so I don’t have the luxury and I’m sure that’s a choice that other families have chosen to either do something or not.</td>
<td>2. Mother’s physical health is not a priority and taking care of her daughter’s health needs is her only concern at the moment.</td>
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<tr>
<td>3. I’ve had to forego my procedures that I need because I’m too worried about exhausting everything in that 12-month period. Because anything can happen.</td>
<td>3. Mother postpones her own medical procedures for fear of running out of benefits for her daughter.</td>
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<tr>
<td>4. I mean, if I died, if push came to shove, he probably could do it but I’m doubtful. I can’t say yes with 100% certainty. I just don’t know if he’s not capable because he doesn’t have to be or be it would be a challenge because they’re would be some slipping through the cracks on my child’s behalf because he wouldn’t be on top of it the way I am.</td>
<td>4. Mother bears most, if not all, responsibilities of her child alone and doubts her husband could jump in and help if something happened to her.</td>
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<td>5. I have to find the doctors, set up the appointments, um, because I am at home. I do a lot of the transporting to activities, just basic household but just even, I mean, we are at a deficit especially now since we’ve been without respite for an entire week.</td>
<td>5. Despite the lack of extra help, mom manages to juggle and coordinate her daughter’s care and the entire household.</td>
</tr>
<tr>
<td>6. I’ll have to make 6 calls because no one at the other end will actually understand the process. And so it’ll take a few days just to do that. And then you’ll get the paperwork back which is just like 80 pages long and then I’ll have to spend time reviewing.</td>
<td>6. Due to denial issues for therapy, mom spends much of her time on the phone with the insurance to request medical records and notes from the reviewer. Once received, mom reviews them on her own.</td>
</tr>
<tr>
<td>Significant Statements</td>
<td>Formulated Meaning</td>
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<tr>
<td>7. I find myself telling them what I need and what to do. And this is the problem I have dealing with different specialists. Dr. is the only doctor who, after the visit actually sends his report to the primary (laughs). The other doctors don’t do it. So I have to walk around with a binder so everyone knows what everyone is doing. Mmm hmm. And thank God this child does not have meds.</td>
<td>7. Mother often guides the physician on what her daughter with a rare disease needs.</td>
</tr>
<tr>
<td>8. I tried to apply for SSI/disability and I was denied based on my income. So I wasn’t able to get any other resources for him.</td>
<td>8. Mother cannot get extra help financially due to how much she earns.</td>
</tr>
<tr>
<td>9. And they told me that he did not qualify because both eyes were not affected. And that it was only one eye the other eye is 20/20. And I said to myself gee whiz! I can’t catch a break! Do you know how much money I could have saved if they helped me? So there’s resources out there but you still end up not being eligible.</td>
<td>9. Mother believed her child was eligible for resources due to his condition; however, it was determined that he did not meet the medical criteria.</td>
</tr>
<tr>
<td>10. And with the SSI, there are 6 major areas of life activities. All you need to score is one marked severe my daughter scored 4 out of 6 severe with functionalities. And that didn’t qualify her because of my income and resources. She met the criteria with all the medical stuff. So it always goes back to that.</td>
<td>10. Mother believed that her child met the medical criteria but did not because of her income.</td>
</tr>
<tr>
<td>11. Um, the challenge was that I didn’t even use my insurance. There was no benefit to me to even use it.</td>
<td>11. Mother believed that the private insurance did not help in meeting her child’s needs so she did not use it.</td>
</tr>
<tr>
<td>12. or if I need DME which will not happen with this insurance because I go through the non-profit for that, that’s why the non-profits are so important they’re grants because that’s how I’m able to offset some of the expenses.</td>
<td>12. Mother feels that non-profit grants are better than using the child’s private insurance.</td>
</tr>
<tr>
<td>Significant Statements</td>
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<td>13. So you can’t really rely on the health insurance. I dread them. Not only do I dare them I have a fear of them. Because your deciding life and death. You’re deciding the quality of life for my child. So rather than give you all the energy, I’m going to go to the non profits because with non-profits all I need are a paper and pen and I’m done. That’s it. There’s one that I’m looking at for swimming lessons to help pay for it. I would rather do that then get a damn insurance company to help me pay for something therapeutic. Can you imagine what I have to go through? It’s too much, I can’t.</td>
<td>13. Mother believes the process with non-profit agencies are more reliable and less stressful than dealing with her child’s private insurance.</td>
</tr>
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<td>14. …a lot of my friends were familiar with ESE so they were there from an academic point of view.</td>
<td>14. Mother consults with peers in the education field.</td>
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<tr>
<td>15. My best friend is an assistant principal for a school so moments where I thought I was going to lose it I would call her and she understood.</td>
<td>15. Mother confides in friends she knows in administration during difficult times.</td>
</tr>
<tr>
<td>16. … because I knew so many people in the district … Mother knows many I wanted someone who was not familiar with me or familiar with him. So I had the head psychologist of ASD to do the testing.</td>
<td>16. Mother knows many people in the field that she sought an outside person for testing.</td>
</tr>
<tr>
<td>17. It was a friend of mine who really told me what to do and questions to ask. He was an MD in his country and at the time he worked in a hospital.</td>
<td>17. Mother shared concerns and questions with a friend who was a physician in his native country.</td>
</tr>
<tr>
<td>18. The friend I was thinking about happens to be a nurse (laughs). So it was discussing what the plan is, new information that’s out there about his diagnosis, and what was her experience in treating other kids that had scoliosis. She is a pediatric nurse.</td>
<td>18. Mother asked for advice from a friend who worked in the pediatric nursing field.</td>
</tr>
<tr>
<td>19. And because she is an ARNP in pediatrics, she talked about the current practices and what to expect. These are the things that you should expect.</td>
<td>19. Mother received guidance from a friend who was a pediatric nurse practitioner.</td>
</tr>
<tr>
<td>20. They’re just there for me to call them when I need them which is good.</td>
<td>20. Mom can call the nurse care coordinator for help.</td>
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<td>21. Yes, they switched case managers now that I have Well Care (health plan) and Well Care requires case managers to meet with families in person and she’ll ask if I have any questions. I meet with her at my son’s OT sessions.</td>
<td>21. The nurse care coordinator visits with families and parents can ask her questions.</td>
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<td>22. So she’ll be at my house next week. And she’s just awesome because whenever I need something for (name of child), I can email her.</td>
<td>22. The nurse care coordinator makes visits to the home and parents can ask her questions.</td>
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<td>23. They called me, found me a neurologist, made the appointment for me. I remember when made the decision to go back to a neurologist, they did that. They would tell me about the good ones, who has a good reputation and all that.</td>
<td>23. The nurse care coordinator worked on the mother’s behalf.</td>
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<td>24. ...when she called periodically she would know I was busy and would ask me if I had any concerns. She would come with information - like oh I have a number for this or that, you can look there or here. She would ask if I have a concerns and if I was nervous or doubtful, she would give me reassurance like yes you could take him to the neurologist or yes you can take him there. Like hey if you don’t feel comfortable here are some other choices. Because I never knew about the YMCA and she told me about it. She understood like okay you have some challenges. I mean she told me a whole lot of things. Just new information.</td>
<td>24. The nurse care coordinator provides new information and reassurance to mom.</td>
</tr>
<tr>
<td>25. She just asks if I need anything, like help with appointments or special authorizations</td>
<td>25. The nurse care coordinator offers to help.</td>
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