Comparison of Telemedicine to Traditional Face-to-Face Care for Children with Special Health Care Needs: Analysis of Cost, Caring, and Family-Centered Care, Family Cost Survey, Caring Professional Scale, Measure of Processes of Care 20-Item Scale

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COMPARISON OF TELEMEDICINE TO TRADITIONAL FACE-TO-FACE CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: ANALYSIS OF COST, CARING, AND FAMILY-CENTERED CARE

By

Mary A. Hooshmand

A DISSERTATION

Submitted to the Faculty of the University of Miami in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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the requirements for the degree of
Doctor of Philosophy

COMPARISON OF TELEMEDICINE TO TRADITIONAL FACE-TO-FACE CARE
FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS:
ANALYSIS OF COST, CARING, AND FAMILY-CENTERED CARE

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Comparison of Telemedicine to Traditional Face-to-Face Care for Children with Special Health Care Needs: Analysis of Cost, Caring, and Family-Centered Care

Abstract of a dissertation at the University of Miami.

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It is estimated that one out of every five household with children in the United States includes a Child with Special Health Care Needs (CSHCN). Families of CSHCN face many challenges including financial burdens beyond that of other families and difficulty accessing much needed pediatric specialty care. Telemedicine provides a potential solution or, at the least, an alternative to the traditional system of care, for health care providers and communities to address access and financial concerns of families of CSHCN.

A quasi-experimental research design was used in this study to examine the differences in cost, caring, and family-centered care in relation to pediatric specialty services utilizing telemedicine technology compared to traditional face-to-face care. The study sample included a convenience sample of 222 parents/guardians of CSHCN residing in rural, remote and medically underserved areas of Southeast Florida enrolled in the Children’s Medical Services (CMS) program. The sample was comprised of two study groups: traditional ($n = 110$) which included families receiving traditional face-to-face pediatric specialty care; and the telemedicine group ($n = 112$) which included
families who have received telemedicine visits along with traditional face-to-face pediatric specialty care.

Measures of cost, caring, and family-centered care were obtained using three instruments including a Family Cost Survey, Caring Professional Scale (CPS), and Measure of Processes of Care-20 Item Scale (MPOC-20). Results indicated that there were no significant differences in family costs when telemedicine was available locally compared to traditional face-to-face care in the local community. Family costs were anticipated to be significantly higher if telemedicine was not available in their communities. There were no differences in the families’ perceptions of care as caring for the telemedicine and traditional groups. Results indicated significant differences between the groups in regards to family-centered care, with telemedicine group parents/guardians reporting more positive perceptions of the system of care as family-centered compared to families receiving traditional face-to-face pediatric specialty care.

These results together underscore the importance of assuring and facilitating access to pediatric specialty care for CSHCN and their families by further reducing their burdens and costs. The use of innovative systems of care such as telemedicine has promise to promote caring, family-centered systems of care in their home communities. Future research is recommended to further examine nursing roles and interventions in telemedicine programs, measurement tools, and family perceptions of systems of care across different populations.
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CHAPTER I

Introduction

Children with Special Health Care Needs (CSHCN) include “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (Marcin et al., 2004; McPherson et al., 1998). CSHCN and their families face significant challenges accessing health care services across our communities. These challenges are compounded for CSHCN and families residing in rural, remote and medically underserved areas.

Telehealth technology including telemedicine is increasingly being utilized to provide much needed health care services to individuals residing in these communities. The literature presents many different definitions of telemedicine which have evolved reflecting technological developments over the years. For the purpose of this paper, telemedicine for CSHCN is defined as the provision of health care utilizing an interactive communication system linking pediatric specialty providers to CSHCN, their families, and local providers in remote, rural, and medically underserved areas (Office for the Advancement of Telehealth, 2001; Thurmond et al, 2002). The interactive communication system used in telemedicine consists of high resolution, interactive videoconference equipment with audio and video capabilities; diagnostic cameras and clinical assessment equipment including medical instrumentation such as otoscopes, ophthalmoscopes, and digital stethoscopes (Harrison et al., 2006; Karp et al., 2000; Nesbitt et al., 2005; Rasmussen & Hartshorn, 2005).
Scope of the Problem

The 2006 National Survey of Children with Special Health Care Needs (CSHCN) estimates 13.9% of children ages 0 to 17 years in the United States and 13.4% of children in Florida have a special health care need, and 21.8% of households with children include at least one CSHCN (U.S. Department of Health and Human Services, 2007). Historically, services for CSHCN have been challenging for families and providers alike in terms of availability and access to appropriate health care services. Families frequently face multiple barriers to care including provider availability and access, financial, insurance, and geographic barriers to care (Healthy People 2010). The problem of access to pediatric specialty care is compounded by the fact that these children require more frequent routine and urgent health care (Marcin et al., 2004, p. 1).

Access to health care and particularly pediatric specialty care is especially challenging in rural communities. While one fifth of United States’ residents live in rural communities, these rural residents are faced with significant inequities in accessing health care compared with those living in urban and suburban communities (Thompson, 2001). Access to pediatric specialty care is an even greater challenge for families of CSHCN in these communities. CSHCN in rural and medically underserved communities experience disparities in access because there are fewer pediatric specialty services available, and the services are frequently available only at a distance from their community (Eberhardt, Ingram, Makuc et al., 2001; Marcin et al., 2004). This results in incredible hardships for the families and the CSHCN, and particularly impacts the most fragile children who are dependent upon life-sustaining medical equipment such as ventilators, supplemental oxygen, and feeding pumps. Transportation for medical appointments becomes a burden.
and is disruptive to the lives of these families. Special transportation arrangements are required to allow for wheelchairs or stretcher transport with the most fragile children.

Pediatric specialty appointments for families in rural areas can be costly ventures involving overnight travel costs and loss of pay which impacts all families, but particularly impacts those families of day laborers. These are burdens and costs they can least afford. “The availability of telemedicine as a means of improving access to specialty care services to underserved rural communities has become one increasingly viable solution to these problems” (Nesbitt, T.S., Marcin, J.P., Daschbach, M.M., & Cole, S.L., 2005, p. 80). One study of parents/guardians of CSHCN in a rural, medically underserved area reported major barriers to pediatric specialty care as travel time greater than one hour for appointments (83%) and missing work for appointments (96%). Ninety-eight percent of the parents/guardians indicated they wanted to continue to receive their consultations utilizing telemedicine versus traveling to the pediatric specialty center in the future (Marcin et al., 2004, p. 4).

Satisfaction with telemedicine.

Telemedicine, as a mechanism for providing access to health care services, is proving to be an acceptable solution to health care access issues for patients, families/caregivers, and providers alike. Research over the last nine years indicates positive patient/caregiver satisfaction with telemedicine services (Harrison et al., 2006; Karp et al., 2000; Marcin et al., 2004; McConnochie et al., 2005; Nesbitt et al., 2005; Thurmond et al., 2002; Williams et al., 2001). In two studies of telemedicine specific to CSHCN, the children and caregivers were found to be satisfied with telemedicine services (Karp et
al., 2000; Marcin et al., 2004). Studies examining provider satisfaction with telemedicine produced similar results indicating providers were highly satisfied with telemedicine (Karp et al., 2000; Marcin et al., 2004; Nesbitt et al., 2005). In fact, studies indicated that the more a physician worked with telemedicine, the more positive they were regarding telemedicine (Karp et al., 2000).

Research indicates care provided utilizing telemedicine is acceptable and does not pose any adverse risk when compared to traditional face-to-face care (Karp et al, 2000; Rasmussen & Hartshorn, 2005; Thurmond et al, 2002). In a study which included seven rural medically underserved communities, there was a community perception of improved quality of care and/ or higher opinion of local health care with telemedicine. (Nesbitt et al, 2005). While research indicates patient/caregiver satisfaction with telemedicine services (Harrison et al., 2006; Karp et al., 2000; Marcin et al., 2004; McConnochie et al., 2005; Nesbitt et al., 2005; Thurmond et al., 2002; Williams et al., 2001), research also indicates a need to evaluate telemedicine further with respect to perceptions of personal and human connection, caring environments, quality of care, and health outcomes (Thurmond & Boyle, 2002, p.27).

Cost and reimbursement for telemedicine.

With research regarding telemedicine indicating patient and provider satisfaction, perceived improvement in quality of care, and higher opinions of local health care, it might be expected that provider organizations would be actively implementing telemedicine programs in rural, remote and medically underserved communities. Financial concerns have posed a barrier to deployment of telemedicine with initial capital
investment appearing to be the most important financial indicator in the decision making process (Smith, 2005). Costs, including expense and reimbursement problems, are frequently cited as significant barriers to health care delivery utilizing telemedicine (Doolittle, Williams & Cook, 2003, p.108).

The lack of consistent insurance reimbursement has been a financial barrier in terms of deployment and sustainability of telemedicine programs. Currently, laws and policy are inconsistent across the United States in respect to insurance reimbursement for telemedicine services. As of 2003, five states had laws recognizing and assuring reimbursement for both public (Medicaid-Title XIX) and private insurance reimbursement for telemedicine services. In 27 states, there is limited coverage from Medicaid for telemedicine services (The Center for Telemedicine Law with the support from the Office for the Advancement of Telehealth, 2003). Likewise, some private insurance companies provide coverage in some but not all states. An example of this is Blue Cross and Blue Shield which reimburses for telemedicine in some plans but not universally across their individual plans. At the national level, Medicare does provide limited coverage for telehealth services. Reimbursement regulations are set by the states for both Medicaid and private insurance, while Medicare regulations are established at the Federal level. This explains the great variance among the individual states in reimbursement policy for telemedicine. In Florida, the Agency for Health Care Administration has approved a pilot project allowing reimbursement for telemedicine services in select areas including the six counties in the Children’s Medical Services Southeast Region.
Telemedicine for CSHCN in rural, remote and/or medically underserved areas is an increasingly frequent viable alternative for traditional face-to-face pediatric specialty care for this vulnerable population. Telemedicine projects are frequently initiated with grant and demonstration project funds. But it has been difficult to continue the projects as economically sustaining programs due to an inconsistent or lack of reimbursement by public and private insurance companies.

There have been limited studies on the cost of telemedicine visits compared to traditional face-to-face specialty care particularly from the family perspective. One study of eight clinical sites in rural Arizona reported telemedicine costs to be directly dependent on the number of telemedicine consults performed by site. The differences in cost were correlated to different utilization of services, with higher utilization resulting in lower costs (De la Torre et al., 2004). Several studies and reports indicate the need to further research the cost effectiveness and impact of telemedicine versus the cost of traditional face-to-face care within diverse and (De la Torre et al., 2004; Doolittle et al., 2003; Hailey, 2005; Marcin et al., 2004; McConnochie, 2005; Smith, 2005; Thurmond & Boyle, 2002). In fact, there is a gap in the research related to the cost to families, and particularly vulnerable populations such as families of CSHCN. The majority of the research has been focused on organizational and provider costs.

Caring and telemedicine.

Caring has long been a concept central to the focus of nursing care and certainly to the delivery of health care services in general. Swanson (2000) postulates that caring equals compassion and competence. The introduction of telemedicine as a mode of
health care delivery to traditionally ‘hard to reach’ populations residing in rural, remote, and medically underserved areas introduces concerns among health care providers and recipients alike regarding the potential loss of the human caring factor as well as competence of the provider delivering the health care service.

Family-centered care and telemedicine.

Families are intricately involved with their children’s daily lives and, in particular, they are very involved and recognized as key partners in caring for their child’s special health care needs. The federal Maternal Child Health Bureau (MCHB) recognizes the critical role of families and family-centered care for all children including CSHCN. In 2005, the MCHB recognized family-provider partnership as the foundation of family centered care and defined family-centered care as inclusive of the following principles: families and professionals working together in the best interest of the child with the child assuming a role in this partnership as they grow, respect of skills and expertise brought to the relationship from both families and professionals, trust, communication and sharing of information, decision making together, and a willingness to negotiate (Dendoba, McPherson, Kenney, Strickland, and Newacheck, 2006).

The importance of family-centered care has been recognized through several studies over the years. Dendoba et al. (2006) found family-centered partnership predictive of improved outcomes in respect to several health measures including access to specialty care, missed days from school, satisfaction, and unmet needs for services for the CSHCN and family. Family-centered models of care have also been found to be predictive of enhanced satisfaction with services by families of CSHCN (Trute, B., &
Hiebert-Murphy, 2007, p. 115). While telemedicine can assure access to pediatric specialty care, it is critical that research determine whether this delivery model meets the criteria of family-centered care for CSHCN.

Purpose

This research project examined the issues of cost, caring and family-centered care as they relate to telemedicine services for CSHCN in rural, remote and medically underserved areas of Southeastern Florida. Telemedicine technology is rapidly advancing and poses a solution or an alternative way to access care for vulnerable populations, particularly those in remote, rural and medically underserved communities. To promote acceptance by health care providers and recipients of health care, it is critical to provide research-based evidence that health care services provided via telemedicine are cost effective, caring, and family-centered.

The purpose of this research project was to examine cost, caring and family-centered care in relation to pediatric specialty services utilizing telemedicine technology compared to traditional face-to-face visits for CSHCN in rural, remote and medically underserved areas of Southeast Florida. Cost, caring, and family-centered care were examined from the perspectives of the parents/guardians of CSHCN.

Study Questions

The research questions are:

1. What are the differences in cost to parents/guardians when care is provided via telemedicine compared to traditional face-to-face care?
2. What are the differences in parents/guardians perceptions of the system of care as caring when care is delivered utilizing telemedicine compared to traditional face-to-face care?

3. What are the differences in parents/guardians perceptions of the system of care as family-centered care when care is delivered utilizing telemedicine compared to traditional face-to-face care?

Theoretical Framework

This study addressed the issues of cost, caring and family-centered health care from the perspective of the parents/guardians of CSHCN when care is provided via telemedicine. Three different frameworks were utilized to examine the constructs of cost, caring and family-centered care.

Cost.

Families of CSHCN face financial burdens beyond that of families of healthy children. The cost framework for this study is a cost-minimization analysis framework. Cost-minimization is a form of a cost-effectiveness analysis which presumes the effectiveness or outcomes of a program are similar but that the costs are different (Gold, M., Siegel, J.E., Russell, L.B., and Weinstein, M.C., 1996; Muennig, P., 2008). This framework focused on the difference in costs between the comparable interventions of traditional face-to-face care and telemedicine. This study focused on the cost difference from the perspectives of the family of the CSHCN, recognizing the importance of reducing financial burden and hardship for this vulnerable population.
Using the cost-minimization framework, the study examined cost from the family perspective comparing the costs of traditional face-to-face pediatric specialty care to care provided utilizing telemedicine. This included both direct and indirect costs as well as hidden costs recognized by the family but not evident to those outside the family or community health providers. Costs examined included travel, lodging, loss of wages, child care, and ancillary family costs such as food. The Family Cost Survey was developed for this research project to measure both direct and indirect costs for the purpose of this research.

Caring.

Historically, caring has long been a concept central to the practice of nursing and certainly to the delivery of health care services in general. The theoretical framework for caring guiding this study is the Swanson Caring Model. Swanson (2000) postulates that caring involves both compassion and competence in the delivery of care. The introduction of telemedicine as a mode of health care delivery to traditionally ‘hard to reach’ populations residing in rural, remote, and medically underserved areas introduces concerns among health care providers and recipients alike regarding the potential loss of the human caring factor as well as competence of the provider delivering the health care service.

Swanson’s (1991) phenomenologically derived middle range theory of caring describes five therapeutic caring processes which are separate but not mutually exclusive including: knowing (striving to understand the other’s experience), being with (emotionally present), doing for (as the other would do for the self if at all possible),
enabling (facilitating resolution by validating and informing), and maintaining belief (in the other’s potential to get through an event or transition and face a meaningful future).

Caring is defined as “a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility” (Swanson, 1991, p. 165). The Caring Professional Scale (Swanson, 2000) is an instrument consisting of two factor analytically derived subscales, the compassionate healer and the competent practitioner (Swanson, 2002). The Caring Professional Scale was utilized to measure the therapeutic processes of caring for the purpose of this research.

Family-centered care.

Family-centered care has been recognized as the standard of care for all children and particularly for CSHCN. The framework for family-centered care is based on the Maternal Child Health Bureau definition of family-centered care inclusive of the following principles: families and professionals working together in the best interest of the child with the child assuming a role in this partnership as they grow, respect of skills and expertise brought to the relationship from both families and professionals, trust, communication and sharing of information, decision making together, and a willingness to negotiate (Dendoba, McPherson, Kenney, Strickland, and Newacheck, 2006). The Measure of Processes of Care- 20 Item Scale was utilized to measure the domains of family-centered care for the purpose of this research (King, S., King, G., and Rosenbaum, P., 2004; King, S., Rosenbaum, P., and King, G., 1995; King, Rosenbaum, and King, 1997).
Overview of Framework

Figure 1 illustrates the framework of this study examining the constructs of cost, caring and family-centered health care from the perspectives of the parents/guardians when care is provided via telemedicine as compared to traditional face-to-face care.

Figure 2 illustrates the substruction of this study including the constructs of cost, caring and family-centered care and further delineating the related constructs, variables, and empirical indicators.

Figure 1. Framework of Study
Face to Face Care vs. Telemedicine
Substruction of Study

Figure 2. Substruction of the Study
Assumptions

Based on the framework for this study, the assumptions include the following:

1. Access to pediatric specialty care can be a challenge for CSHCN and families.
2. Access to pediatric specialty care can be a burden for CSHCN and families in rural, remote and medically underserved areas.
3. Pediatric specialty health care can be provided to CSHCN in rural, remote, and medically underserved areas utilizing telemedicine.

Definitions of Variables

**Children with special health care needs** (CSHCN) include “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (Marcin et al., 2004; McPherson et al., 1998).

**Telemedicine for CSHCN** is the provision of health care utilizing an interactive communication system (high resolution, interactive videoconference equipment with audio and video capabilities; diagnostic cameras and clinical assessment equipment) (Harrison et al, 2006; Karp et al, 2000; Nesbitt, et al, 2005; Rasmussen & Hartshorn, 2005) linking pediatric specialty providers to CSHCN, their families, and local providers in remote, rural, and medically underserved areas (Office for the Advancement of Telehealth, 2001 Thurmond & Boyle, 2002).

**Traditional face-to-face visits** include those clinical visits in which the CSHCN and their parents/ guardians are present in the room physically with the pediatric specialty provider. A **telemedicine visit** includes those in which the specialty provider is at a distance clinical site and examining and interacting with the CSHCN and their parent/
guardian through the use of telemedicine equipment. The **parent, guardian, or legally designated caregiver** is defined as the individual primarily responsible for care of CSHCN and physically present with child during clinical visits (telemedicine and face-to-face) with the pediatric specialist.

**Cost** is defined in terms of family costs to either attend a remote clinical site or to access pediatric specialty care with telemedicine technology. The family costs will be all inclusive examining both direct and indirect costs. For families, this can include travel, lodging, loss time at work for family members resulting in loss of wages, and child care costs. **Caring** is defined as a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility, and moreover, caring equals compassion and competence (Swanson 1991, 2001). In 2005, the Maternal Child Health Bureau recognized family-provider partnership as the foundation of family centered care and defined **family-centered care** as inclusive of the following principles: families and professionals working together in the best interest of the child with the child assuming a role in this partnership as they grow, respect of skills and expertise brought to the relationship from both families and professionals, trust, communication and sharing of information, decision making together, and a willingness to negotiate (Dendoba, McPherson, Kenney, Strickland, and Newacheck, 2006).

**Summary**

Families of CSHCN face many challenges including financial burdens beyond that of other families and difficulty accessing much needed pediatric specialty care. These challenges are compounded for families already vulnerable whether it is due to
their socioeconomic status, insurance issues, ethnic or racial background, or by living in a rural or medically underserved area. It is clear that systems of care for CSHCN should be accessible, reduce financial burden, and construed by the recipients of care as caring and family-centered in order to build family-provider partnerships, and optimize health outcomes for CSHCN and their families. Telemedicine provides a potential solution or, at the least an alternative to the traditional system of care, for health care providers and communities to address access and financial concerns of families of CSHCN.

This study proposed to examine the issues of cost, caring, and family-centered care services via telemedicine for a population of CSHCN residing in rural, remote and medically underserved areas as compared to those receiving traditional face to face pediatric specialty care. Measures of cost, caring, and family centered care will be obtained from the parents/ guardians of CSHCN. This chapter has provided an introduction to the significance, scope of the problem, purpose, study questions, and theoretical framework. Chapter II will provide a review of the literature relating to CSHCN, telemedicine, cost, caring, and family centered care.
CHAPTER II
Review of the Literature

This literature review presents a critical analysis of the current literature about the key concepts of CSHCN, telemedicine, cost, caring and family centered care. The review will be organized into four sections. The first section will discuss the definition of CSHCN and will provide an overview of literature relating to pediatric specialty care including access to pediatric specialty care and the particular challenges including financial burdens it poses to CSHCN and their families. The second section will provide an overview of telemedicine specific to the definition and utilization as it relates to CSHCN including cost perspectives. The third section will contain an overview of literature about caring and particularly as it relates to maternal child health and particularly pediatric populations. The fourth section will focus on family centered care.

Children with Special Health Care Needs (CSHCN)

Definition of CSHCN.

The definition of CSHCN has evolved and has become more inclusive over the years. This definition has been linked with the evolving maternal child health programs at the federal and state levels focusing on “crippled children” in the 1930’s (related to polio outbreaks) to “handicapped children” in the 1960’s and 1970’s to CSHCN in the 1980’s (Newacheck, Rising, & Kim, 2006, p. 335). Three different approaches are described in the literature with respect to identifying and defining CSHCN. A categorical approach identifies conditions which are considered chronic and may or may not include a diagnosis (Beers, Kemeny, Sherritt, and Palfrey, 2003; Warfield and Gulley, 2006;
Children are identified as having special health care needs if they require health care services beyond that of other children (McPherson et al., 1998; Marcin et al., 2004; Muldoon, Neff, and Gay, 1997). Additionally, non-categorical or functional approaches are used to identify CSHCN in terms of limitations in functioning and/or ability to complete age appropriate activities of daily living (Warfield and Gulley, 2006).

The current definition of CSHCN, developed in 1997 through a consensus process led by the federal Maternal Child Health Bureau (MCHB), is more inclusive than previous traditional medical model definitions and integrates the physical as well as developmental, emotional and behavioral conditions (McPherson et al., 1998, p. 139; Roberts et al., 2004). This definition of CSHCN includes those children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998, p. 138). This MCHB workgroup included representatives from state and federal programs, health care professionals, families, epidemiologists and policy analysts involved with CSHCN. As a part of the workgroup process, a set of principles were established and the group assessed different approaches to defining CSHCN. Three definitional approaches were identified based on the presence of: chronic conditions, functional impairment, and the presence of elevated service needs (McPherson et al, 1998, p.138).

This more inclusive definition encompasses children with health as well as other special needs such as behavioral health and educational needs; and is inclusive of the family of the CSHCN recognizing their need for supportive services (McPherson and
Honberg, 2002, p. 23). In developing this definition, there was consensus that it is better to prevent a child from developing a special health care need than to treat the child after they had developed the special health care need. Therefore, at-risk children were included in the definition (McPherson et al, 1998; Newacheck, Rising, & Kim, 2006. This definition was widely accepted at a National Summit on Children and Youth with Special Health Care Needs in December 2001 by families, providers, professionals, national and state agencies, insurance company and managed care representatives, and professional organizations.

Prevalence of CSHCN.

Prior to 1992, there was variance in reports about the prevalence of CSHCN because of different definitions and methods used to collect the data. Studies reported estimates ranging from less than 5% to greater than 30% (Newacheck and Taylor, 1992). Newacheck and Taylor (1992) utilized data from a large population-based sample of children included in the 1988 National Health Interview Survey (NHIS) to examine prevalence of childhood chronic illness.

The NHIS is a national population-based survey conducted by the Bureau of the Census for the National Center for Health Statistics (NCHS) to collect information on the health status and health care services used by the population of the United States. In 1988, the survey included a supplemental questionnaire which included questions on child health. In their study, Newacheck and Taylor (1992) conducted interviews with households representing a sample of 17,110 children under 18 years old in order to identify those children with one or more chronic conditions. Results were that 20 million
or 31% of these children were affected by one or more chronic conditions, with 70% of these affected by one condition, 21% with two conditions, and 9% having three or more chronic conditions (Newacheck and Taylor, 1992, p. 365).

In 2001, the federal Maternal Child Health Bureau, in conjunction with the National Center for Health Statistics, conducted the first National Survey of CSHCN. The purpose of this survey was to provide estimates of the number of CSHCN, their characteristics and to provide an assessment of how well their needs were being met (van Dyck, Kogan, McPherson, Weissman, and Newacheck, 2004).

Estimates from the 2001 National Survey of CSHCN indicated 12.8% of children ages 0 to 17 years in the United States and 13.0% of children in Florida have a special health care need. (Blumberg, Osborn, & Luke, 2003; van Dyck, Kogan, McPherson, Weissman, and Newacheck, 2004). Estimates from the 2006 National Survey of CSHCN indicates that 13.9 % of U.S. children and 13.4% of Florida children have special health care needs, and 21.8 % of households with children include at least one CSHCN (U.S. Department of Health and Human Services, 2007). There is a modest increase in estimated CSHCN at both the national level and in Florida from years 2001 to 2006. A limitation of these surveys is that they are based on self-reports. Another limitation is that the population of ‘at risk’ children is excluded from the prevalence estimates included in these reports (U.S. Department of Health and Human Services, 2007). Therefore, the prevalence of CSHCN in the United States and Florida as determined by the current definition including at-risk children would be greater than the reported estimates of 13.9% and 13.4% of children in the United States and Florida respectively.
Szilagyi et al. (2003) used data from the Child Health Insurance Research initiative to determine the characteristics and measure the prevalence of CSHCN (0 – 18 years old) enrolled in State Children’s Health Insurance Programs (SCHIP) in four states including New York, Indiana, Kansas, and Florida. The state of Florida only included adolescents. Results of interviews conducted with parents of 5,296 children indicated prevalence rates in three of the states ranging from 17% in New York, 18% in Florida, and 25% in Kansas. There was no data available regarding prevalence in Indiana. A large percentage of these identified CSHCN, including 68% of those in Florida, had been uninsured for at least 12 months prior to enrollment in the SCHIP program. The prevalence rate among this population insured through SCHIP was greater than that of the general population identified through the National Survey of CSHN.

Access to care for CSHCN.

The literature indicates issues with access to pediatric specialty services for CSHCN. Families of CSHCN frequently face multiple barriers to care including provider availability and access, financial, insurance, and geographic barriers to care (Healthy People 2010).

Data on 57,553 children younger than 18 years included in the 1994-1995 National Health Interview Survey on Disability (NHISD) was analyzed using multivariate and bivariate analyses to assess the association of health insurance with access to care and use of services for CSHCN (Newacheck, McManus, Fox, Hung, and Halfon, 2000). Findings from this study indicated that 89% of these CSHCN had some form of insurance and those insured were more likely to have a usual source of health
care (96.9% vs. 79.2%). CSHCN with insurance were less likely to report unmet medical needs (2.2% vs. 10.5%). Those with insurance were more likely to have seen a physician in the past year (89.3% vs. 73.6%) and to have had more annual physician contacts than those without insurance (8.5 vs. 4.1). The researchers also found differences between the characteristics of the care received by CSHCN enrolled in public insurance compared to those enrolled in private insurance plans. Those CSHCN in public insurance plans were twice as likely to be without a regular clinical provider (18.9% vs. 9.1%, \( p < .01 \)) and to lack access after-hours to their regular source of clinical care (13.4% vs. 6.8%, \( p < .01 \)) (Newacheck et al., 2000, p.763). Jeffrey and Newacheck (2006) conducted a systematic literature review on the role of insurance for CSHCN and found strong evidence on the positive and substantial effect of insurance on access to care for CSHCN. These studies over the years point to the importance of health insurance including type of plan in terms of access to health care for CSHCN.

Newacheck, Hung, and Wright (2002) further analyzed the 1994-1995 NHISD data examining racial and ethnic differences in access and utilization of health services. Of the 57,553 children younger than 18 years of age, 17.7% were identified as having special health care needs. Their results indicated that minorities were more likely to be without health insurance coverage (13.2% vs. 10.3%; \( p < .01 \)), without a usual source of health care (6.7% vs. 4.3%; \( p < .01 \)), and report inability to obtain needed medical care (3.9 vs. 2.8%; \( p < .05 \)). While the researchers found disparities in access and utilization among all minorities, the gaps in access to primary care, specialty care, and ancillary health care services were greatest for Hispanic CSHCN.
Access and utilization of specialty care was much lower among Hispanics and non-Hispanic blacks even when controlling for chronic condition, insurance, and socioeconomic status. Access to specialty care was especially impacted among the near poor with those between 125% and 200% of the federal poverty level less likely to have access to care (Kuhlthau et al, p. e249).

Results from a study of the association between a parent’s language and access to care for CSHCN concluded that CSHCN with non-English speaking parents were more likely to experience barriers to access to care and to have unmet needs (Yu, Nyman, Kogan, Huang, and Schwalberg 2004). Porterfield and McBride (2007) identified parental income, education and insurance to be associated with access to specialty care. Their results indicated that parents of CSHCN with higher incomes and education were more likely to access services for their CSHCN. These studies point to the need to provide targeted outreach and education for vulnerable populations who require access to care for CSHCN.

Davidoff (2004) noted that almost 20% of low-income CSHCN experienced an unmet need in accessing some form of health care services. Further examination about unmet needs and problems in accessing care for CSHCN was done using data from a 1998-1999 survey of families of CSHCN in twenty states (Warfield and Gulley, 2006). They found that specialty services were the most frequently needed (86.3%) with 3% reporting that needs for specialty services went unmet. Among those families of CSHCN reporting a high level of needs (five or more services), 50.1% reported problems with finding providers with the necessary skills and experience and 44.6% reported difficulty in obtaining sufficient visits to these providers. The results indicated that as the number
of service needs increased for the CSHCN, reports of access problems and unmet needs increased significantly.

Access to care problems is especially compounded in rural communities. While one fifth of US residents live in rural communities, these rural residents are faced with significant inequities in accessing health care compared with those living in urban and suburban communities. (Thompson, 2001). Access to pediatric specialty care is an even greater challenge for families of CSHCN in these communities.

Challenges and burdens of CSHCN.

Families of CSHCN report challenges and burdens beyond that of families with healthy children. These challenges and burdens are supported throughout the literature. Access to care is frequently cited as an impacting factor in respect to burdens on families of CSHCN particularly as it relates to unmet needs. In their study of the NHIS data, Newacheck and Taylor (1992) reported that CSHCN and their families experienced substantial added burdens including increased school absences, physician contacts, and hospital days all related to their chronic conditions. These researchers estimated that the cost of hospital and physician care related to chronic conditions for these children to be $7.5 billion annually (Newacheck and Taylor, 1992, p.369).

In a secondary data analysis of the 1999 and 2000 Medical Expenditure Panel Survey (MEPS), researchers examined health care utilization and expenditure patterns for CSHCN finding that 7.3% of these children in the United States used significantly more services, had higher health care costs, and higher out-of-pocket expenditures than their healthy counterparts (Newacheck, P.W., Inkelas, M., and Kim, S.E., 2004). Health care
expenditures of CSHCN were four times the average of that of children without disabilities ($2669 versus $676, p < .001). Average out-of-pocket expenditures of CSHCN were found to be on the average 50% greater than children without disabilities ($297 versus $189, p < .001). Low-income families were found to be particularly vulnerable in terms of out-of-pocket expenses and financial burdens. The researchers found that families of CSHCN with incomes < 200% of the Federal Poverty Level (FPL) spent 172% more of their income on their CSHCN than families with incomes > 400% of the FPL (P < .001). Families of CSHCN have greater financial burden than other families and those with lower incomes have significantly greater financial burdens on their family related to the care of their CSHCN.

The 2001 National Survey of Children with Special Health Care Needs results indicated that almost 18% of CSHCN reported unmet needs for health care services (U.S. Department of Health and Human Services, 2004; van Dyck et al, 2004). In their 2004 study, Kuhlthau and colleagues (2004) examined the 1999 NHIS data utilizing a cross-sectional analysis design and multivariate analysis to examine patterns of specialist use among children and adolescents by presence of a chronic condition or disability, insurance and sociodemographics. Results of this study indicated that 13% of children were seen by specialists, with specialist visit rates twice as high for CSHCN compared to healthy children (26% vs. 10.2%). CSHCN with private or Medicaid insurance used a specialist more often than CSHCN who were uninsured. Szilagyi et al (2003) found that > 30% to 40% of CSHCN enrolled in SCHIP reported having unmet needs at enrollment including the need for specialty care, mental health care, dental care, and prescription medications.
Data from the 2001 National Survey of CSHCN were examined with bivariate and logit analyses to assess the prevalence of unmet needs for routine and specialty care and to identify factors associated with these unmet needs (Mayer, Skinner, and Slifkin, 2004). Results indicated that 74.4% of CSHCN reported needing routine physician care and 51.0% reported needing pediatric specialty care. The prevalence of unmet need was higher for specialty care with 7.2% reporting that they were unable to access these services. In comparison to the general population of children, CSHCN have a much greater perceived need (53% vs. 18%) for specialty care (Mayer et al.). This study found that predisposing factors related to having unmet needs for routine and pediatric specialty care included: African American children as well as those of multiracial backgrounds, mothers with less than a high school education, CSHCN without insurance, and near poor and poor CSHCN living below the federal poverty level. These characteristics also were associated with the prevalence of unmet needs for pediatric specialty services.

In their study of the prevalence and characteristics of CSHCN, van Dyck et al. (2004) noted the major impact on families to include: financial burden (20.9%), spending large amounts of time arranging for and/or providing care for the CSHCN (14.9%), and reduction or loss of employment due to the CSHCN’s condition and needs (29.9%). Families of CSHCN with more severe conditions were reported to be most impacted.

Using data from the 2001 National Survey of CSHCN, Chen and Newacheck (2006) examined the role of insurance coverage in protecting families of CSHCN from financial burdens associated with care. Insurance coverage was found to significantly reduce the chances of the families experiencing financial problems and burdens. In fact, continuous insurance coverage was found to have a protective factor in reducing these
burdens. The most vulnerable families were the near poor families with incomes between 100% and 200% of the Federal Poverty Level (FPL) versus families with incomes below 100% FPL. Oswald, Bodurtha, Willis, and Moore (2007) also examined data from the 2001 national survey to examine the relationship of underinsurance and key health outcomes for CSHCN. Their findings indicated that there are definite negative effects associated with underinsurance including poor outcomes related to impaired access to medical homes, community based systems of care, and transition related services. CSHCN who were identified as underinsured had poorer outcomes than those with insurance.

In respect to access to care, unmet needs, and burdens for families of CSHCN, there continue to be issues of concern across the United States and in Florida. In the 2005-2006 National Survey of Children with Special Health Care Needs (2007), parents reported 16.1% of CSHCN nationally and 21.8% in Florida as having unmet needs for specific health care services. Twenty percent of parents nationally and 23.9% in Florida paid more than $1000 in out-of-pocket in medical expenses per year for their CSHCN; 18.1% nationally and 21.9% in Florida reported family financial problems due to their CSHCN; and, 23.8% nationally and 30.1% of the families in Florida reported that they had to cut back or stop working due to the needs of their CSHCN. The literature is consistent and clear in respect to the burdens placed on families of CSHCN across our society. These burdens are further complicated and compounded when combined with access to care issues for CSHCN across our communities.
Telemedicine for CSHCN

Definitions of telemedicine.

Telemedicine is the use of electronic communication and information technologies to provide or support clinical care at a distance when distance separates the participants (Field, 1996; Office for the Advancement of Telehealth, 2001, p.1; U.S. Department of Commerce, 1997, p.1). Telemedicine should not be confused with telehealth which is a much broader concept defined as “the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration” (Office for the Advancement of Telehealth, 2001, p.1). There were several definitions of telemedicine identified throughout the literature, from simple to more complex and comprehensive definitions. Merriam-Webster’s (2005, p.1284) defines telemedicine simply as “the practice of medicine when the doctor and patient are widely separated using two-way voice and visual communication.” Other definitions in the literature provided greater detail and specifics regarding the nature of telemedicine. Consultative, diagnostic, or other medical services are delivered via telecommunications technologies to rural or underserved public, not-for-profit hospitals, and primary health care facilities in collaboration with an academic health center and associated teaching hospitals or tertiary center (Purcell, 1998). Telemedicine is the use of telecommunications technology to send data, graphics, audio, and video images between participants who are physically separated (i.e. at a distance from one another) for the purpose of clinical care (Brecht & Barrett, 1998).
In several articles, there were no stated definitions of telemedicine but the authors did provide descriptions of the telemedicine projects included in the studies. There were definite commonalities in both the descriptions and the definitions. The telemedicine communication system includes high resolution, interactive videoconference equipment with audio and video capabilities; designated secure ISDN and/or IP lines; diagnostic cameras which may include hand held cameras; and medical instrumentation. (Harrison et al, 2006; Karp et al, 2000; Nesbitt, et al, 2005; Rasmussen & Hartshorn, 2005).

Historical overview of telemedicine.

The majority of the research articles identified were in the late 1990’s through 2006. However, there is historical discussion linking telemedicine to Alexander Graham Bell’s invention of the telephone in 1875 because he was working on devices for the reproduction and transmission of sound to assist the hearing impaired (Smith, 2005). The first initiation of telemedicine can be described as the use of the plain old telephone system (POTS) in 1877 for communication between physicians and the local drug stores of the time (Lee et al, 2000; Thurmond & Boyle, 2002). The first officially recognized uses of telemedicine were in the very late 1950’s and early 1960’s in a neurology clinic at the University of Nebraska and Indian Health Service clinics and hospitals sponsored by the National Aeronautic and Space Administration and the United States Public Health Service (Smith, 2005). During the 1970’s and 1980’s, there was little advancement or development of telemedicine primarily due to costs. Since that time, technological advances in communication, electronic, and computer sciences have resulted in new, improved technologies with new capabilities and lower costs (Smith, 2005). This has
resulted in a resurgence of telemedicine programs since the late 1990’s, particularly as a mechanism for addressing access to health care issues for hard to reach, vulnerable populations.

Telemedicine and access to care.

In all of the research literature, the authors consistently note the role of telemedicine as a mechanism for addressing access to care issues linking specialty providers to patients in rural, remote and medically underserved communities (De la Torre et al., 2004; Harrison et al., 2006; Karp et al., 2000; Marcin et al., 2004; McConnochie et al., 2005; Nesbitt et al., 2005; Rasmussen and Hartshorn, 2005; Smith, 2005; Thurmond and Boyle, 2002). Results of an integrative literature review suggested that patients are amenable to telehealth interventions as part of their health care (Thurmond and Boyle, 2002). In underserved rural communities, telemedicine availability has been credited as a means of improving access to specialty care services for particularly vulnerable populations. It is seen as an increasingly viable solution effectively addressing access to care problems (Nesbitt, Marcin, Daschbach, & Cole, 2005). Specifically, a study was done examining perceptions of residents in seven rural, underserved communities in California before and after telemedicine programs were implemented in their localities. Telemedicine consultations included 182 total consultations in sixteen different clinical specialty areas. Findings indicated a higher opinion of local health care quality and satisfaction by providers and families alike for those who had experienced telemedicine compared to those who traveled outside their community for health care (Nesbitt et al., 2005).
The primary goal of the Arizona Telemedicine Program, a university-based statewide program founded in 1996 by the state legislature, was to increase access to specialty health care for all citizens of Arizona (Lopez, Avery, Krupinski, Lazarus, and Weinstein, 2005). Since implementation of the program, there have been over 97,000 telemedicine visits covering multiple specialty areas including pediatric specialists. Results of satisfaction surveys indicated high patient satisfaction with the telemedicine services and the overwhelming majority (75 – 96%) indicated that it was as good as face-to-face care.

Studies indicate that telemedicine is increasingly being utilized as a mode of health care delivery which improves access to care particularly for vulnerable populations living in rural and remote communities. A systematic review of the literature suggests that telemedicine has been implemented in a variety of settings, provides access to care, and that patients and families are receptive to and satisfied with telemedicine (Mair and Whitten, 2000). Methodological deficiencies identified in these studies included small sample sizes, low response rates, and simple survey tools without evidence of reliability and validity. The researchers note the need for further studies examining communication issues and the provider-patient relationship.

Telemedicine and children.

Since 2000, the literature includes a progression of articles describing demonstration projects related to telemedicine and children both within and outside of the United States. These telemedicine projects have ranged from services including all
children in communities and schools to those particularly focused on access to pediatric specialty care for CSHCN.

Telemedicine projects have been implemented into school health and day care programs. In 1997, the University of Kansas Medical Center partnered with the United School District to implement a telehealth project, TeleKidCare, initially within four inner-city schools and then expanding to 31 schools (Mackert and Whitten, 2007; Whitten, Kingsley, Cook, Swirczynski, and Doolittle, 2001). Results of interviews and focus groups indicated that teachers, nurses, and administrators involved all supported telemedicine as a mechanism to deliver health care to underserved children in their schools. A subsequent case study examining success factors in this telemedicine project concluded that the project changed the way health care was being delivered to children within the school system.

In 2001, a telemedicine project, Health-E Access, was implemented at five inner-city child care centers in Rochester, New York. A before-and-after design study using historical and concurrent controls examined the impact of telemedicine on absences from child care due to illness (McConnochie et al., 2005). Findings indicated a 63% reduction in absences due to illness was attributable to telemedicine. In fact, telemedicine remained the strongest predictor after adjusting for confounding variables such as age, insurance status, yearly and seasonal trends. Parent surveys indicated that, of the problems managed through telemedicine, 91.2% allowed them to stay at work and, without telemedicine, 93.8% of the parents indicated that the problem would have resulted in an office or emergency room visit for their child.
McConnochie et al. (2006) designed a telemedicine model for diagnosis of common acute childhood illness to compare telemedicine and traditional face-to-face evaluations on reproducibility of diagnosis and treatment. Findings indicated that the reproducibility of the telemedicine diagnosis did not differ from the traditional face-to-face evaluation with the exception of children with upper respiratory infections and ear symptoms. There was a significant difference in this group which was attributed more to disagreements about the diagnosis of acute otitis media itself than to the mode of care delivery resulting in the recommendation for further study. The researchers indicated that telemedicine allows for a more comprehensive look at the eardrum with larger, clearer images compared to an in-person ear examination which may not allow for the same clarity in image. Overall, these findings present providers with evidence of the reproducibility of diagnosis using telemedicine compared to traditional face-to-face pediatric visits.

Telemedicine and CSHCN

Karp et al. (2000) described a demonstration telemedicine project in Georgia for CSHCN implemented in 1995 connecting pediatric specialists at a tertiary clinic with a rural clinic 177 miles away. This project was developed to improve access and reduce burdens on families and CSHCN in the rural community. Results indicated caregiver and provider satisfaction with telemedicine, and that the more providers used telemedicine, the more positive they were about telemedicine. As well, they found that telemedicine was more successful when it was part of an integrated service delivery model compared to telemedicine only visits.
In a telemedicine project for CSHCN in an underserved rural community in California, Marcin et al. (2004) found that prior to implementation of telemedicine families faced significant barriers and hardships accessing specialty care. These barriers and hardships included extensive travel time, lost time from work, and frequent reliance on local emergency departments, and parental self-regulation of their child’s medications. In a three year period from 1999 to 2002, 55 CSHCN received 130 consults by pediatric specialists using telemedicine. Results indicated providers and families of CSHCN were highly satisfied with telemedicine. In fact, the overwhelming majority of parents (98%) stated that they wanted to continue receiving pediatric specialty visits via telemedicine versus traveling to the tertiary center. Telemedicine was found to reduce the travel, work loss, and financial burdens on the families. Additionally, the frequency of telemedicine visits increased over time. These results further emphasized the importance of telemedicine in reducing access to care issues for CSHCN in these communities presenting a viable solution for rural communities.

Malasanos (2005) provided an overview of a telehealth program funded by the Florida Department of Health, Children’s Medical Services, to provide care for children with diabetes and other endocrine disorders in remote and rural areas. Results indicated family satisfaction, decreased mean interval between visits (from 149 days at onset to 89 days in year 2), reduction in emergency room visits (from 8 to 2.5 per year), decreased hospital days/length of stay (from an average of 13 per year and 47 days to 3.5 a year for 5.5 days), and total program cost savings of $27,860 per year (Malasanos, Burlingame, Youngblade, Patel, and Muir, 2005). A telemedicine network also was established in Florida to provide rapid clinical assessments of children when there were allegations of
child abuse connecting nurses and physicians at community hospitals with experts at the major medical center hub site (Foster and Whitworth, 2005). An anecdotal evaluation based on guided interviews with three nurses and one nurse practitioner reported that, while the nurses went through phases of adjustment including initial apprehension, they soon became comfortable with the technology and felt it did not interfere with the nurse-patient relationship.

Telemedicine is increasingly being used for delivering behavioral and mental health services to children. Researchers in Australia examined the feasibility of a tertiary child and adolescent psychiatry outreach pilot program to rural health centers (Dossetor, Nunn, and Eggleton, 1999). They concluded that telemedicine provided access to effective tertiary psychiatric services for those children and adolescents living in isolated rural areas and resulted in cost savings while supporting the rural health professionals in these communities and enriching the rural mental health services. Harper (2006) describes a project providing interdisciplinary telemedicine evaluations for CSHCN in rural Iowa. This project included treatment protocols for CSHCN with physical as well as behavioral conditions. Researchers evaluated the efficacy and found that parents of CSHCN in the telemedicine group thought telemedicine was as effective as those receiving face-to-face consultations. In a pilot project at the University of Kansas, researchers evaluated cognitive-behavioral therapy (CBT) treatment for childhood depression delivered via telemedicine compared to traditional face-to-face care (Nelson, Barnard, and Cain, 2006). Results indicated that all parent and child CBT skills were successful via telemedicine and the remission rates from depression did not differ between the telemedicine and face-to-face treatment groups. The Indian Health Service
regional mental health clinic used telemedicine to provide behavioral health services to American Indian children and adolescents residing in Iowa through the Center for Native American TeleHealth and Telemedicine project at the University of Colorado (Savin, Garry, Zuccaro, and Novins, 2006). Findings from this demonstration project indicated that it was successful in providing access to behavioral health care and families were both receptive to and satisfied with services.

A telepediatric program in Queensland, Australia provided over 1500 specialty consultations during its first three years to 25 pediatric subspecialty areas. There was improved access to specialty care clinics, increased specialty visits, and high satisfaction (Williams and Smith, 2004). A Belfast telemedicine study of 66 newly diagnosed CSHCN with major Congenital Heart Disease (CHD) examined the feasibility of home support following hospital discharge via videoconferencing compared to telephone support (McCrossan et al., 2007). Results of this randomized controlled study indicated that providing videoconferencing support for families of children with CHD is technically feasible and safe. In addition it was noted that videoconferencing offered additional benefits to telephone support including reassurance to families and the ability to make clinical management decisions.

Cost and telemedicine.

Costs, including expense and reimbursement problems, are frequently cited as significant barriers to health care delivery utilizing telemedicine (Doolittle, Williams & Cook, 2003, p.108). Financial factors have been identified as playing a major role in deployment of telemedicine with initial capital investment appearing to be the most
important financial indicator in the decision making process (Smith, 2005). There have been limited studies on the cost of telemedicine visits as compared to traditional face-to-face specialty care. A systematic review of cost effectiveness studies of telemedicine interventions identified 55 of 612 articles which presented actual cost benefit data (Whitten, Mair, Haycox, May, Williams, and Hellmich, 2002). While many of the articles note that telemedicine is cost effective, they equated benefits with cost savings for the program or clinic site. The majority of the studies were small scale, short term duration, and pragmatic evaluations of telemedicine projects across varying, different health care systems. Several of the studies relied on single point estimates of cost. These limitations made it difficult to generalize findings from the individual studies.

Recent studies note the cost-effectiveness of telemedicine including reducing the burden of disease and pointing out that costs are reduced as utilization of telemedicine increased in clinical sites. One study of eight clinical sites in rural Arizona reported that telemedicine costs were directly dependent on the number of telemedicine consults performed by site. De la Torre et al. (2004) used a cost analysis framework to measure program costs including calculating average or incremental costs and, in the case of telemedicine, this includes direct and indirect costs to the family. The differences in cost were correlated to different utilization of services with higher utilization resulting in lower costs (De la Torre et al., 2004). In a cost analysis study of ten school clinical sites and a university medical center pediatric ambulatory site, the results suggested that telemedicine was cost competitive, costing equal or less than traditional clinics, when 200 or more consults were completed (Doolittle, Williams, and Cook, 2003). In a cost-effectiveness study using telemedicine for ophthalmology, researchers found
telemedicine to be cost effective in reducing the burden of eye disease in terms of cost per Disability Adjusted Life Year (DALY) averted (Johnston, Kennedy, Murdoch, Taylor, and Cook, 2004). DALY’s measure the years of healthy life lost from the burden of disease in terms of disability and potential for premature death (Johnston et al., 2004; Muennig, 2008).

Several studies and reports indicate the need to further research the cost effectiveness and impact of telemedicine versus the cost of traditional face-to-face care within diverse and underserved populations (De la Torre et al., 2004; Doolittle et al., 2003; Hailey, 2005; Marcin et al., 2004; McConnachie, 2005; Smith, 2005; Thurmond & Boyle, 2002).

Studies are sparse about the cost burdens on families as it relates to traditional face to face versus health care delivered utilizing telemedicine. Karp et al. (2000) examined the costs using a case example for one family. The family’s out-of-pocket travel costs for a telemedicine visit versus the traditional visit at the tertiary center were compared. Their findings indicated monetary costs for the family were reduced when receiving telemedicine versus traditional visits, thereby reducing the financial burden on the family. This case study only examined one family’s travel costs (Internal Revenue Service mileage rate), food, and parking. Results of an economic evaluation of the Queensland pediatric telemedicine program suggested that telemedicine reduced the burdens on the family with decreased travel time, out-of-pocket expenses, and lost time from work (Williams and Smith, 2004; Smith et al., 2003). In Iowa, Harper (2006) examined cost data from 83 cases looking at time and travel costs for professionals and family out-of-pocket costs. Results indicated that telemedicine provided a cost savings to
the professionals as well as the family with an average savings in family out-of-pocket costs (mileage and meals only) of $125 per session. The Indian Health Service telepsychiatry demonstration project in Iowa examined the cost of the telemedicine against the cost of transporting the child and family to the clinical site noting that it was $200 per month less to provide the services utilizing telemedicine (Savin et al., 2006). The sparsity of studies in the literature regarding the family cost burden component of cost effectiveness for telemedicine compared to face-to-face care is evident pointing to the need for further research in this area.

Caring

Caring theories abound in the nursing literature and date back to the 1970’s. There are several different theories of caring and prominent nursing theorists have described caring as the essence of nursing (Benner, P., and Wrubel, 1989; Watson, 1979, 1985; Leininger, 1984). While there are several different perspectives and caring theories, it is noted that caring itself transcends all theories and is acknowledged as central to nursing as a discipline.

This review will focus on the Swanson middle range theory of caring which was empirically developed and has been applied in diverse nursing settings including hospital and community health (Swanson and Wojnar, 2004). Swanson’s (1991) theory of caring, philosophically congruent with the works of Benner, Watson, and Leininger, defines caring as “a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility” (Swanson, 1991, p. 164). Furthermore, Swanson identifies five therapeutic caring processes that provide meaning to nursing acts
and are essential components of the healing relationship and relationship based care. These therapeutic caring processes which are separate but not mutually exclusive include: *knowing* (striving to understand the other’s experience), *being with* (emotionally present), *doing for* (as the other would do for the self if at all possible), *enabling* (facilitating resolution by validating and informing), and *maintaining belief* (in the other’s potential to get through an event or transition and face a meaningful future) (Swanson, 1991). In essence, nursing is viewed as informed caring for the well-being of others with the five therapeutic caring processes proposed as common features of caring and ultimately strengthening all caring and healing relationships including patient-nurse, family-patient nurse and other such relationships (Swanson, 1993; Swanson and Wojnar, 2004).

Swanson’s caring theory was derived through three phenomenological studies in three separate perinatal contexts with parents and professionals (Swanson, 1991). These studies included women who miscarried, neonatal intensive care unit (NICU) caregivers, and socially at-risk mothers receiving long-term public health nursing interventions. The first study was a phenomenological study of twenty women who had experienced miscarriages. The women were interviewed on two occasions and the five caring processes were identified with preliminary definitions. The guiding question for these interviews was “What constitutes caring in the instance of miscarriage?” (Swanson, 1991; Swanson-Kauffman, 1986a, 1986b). Swanson’s second study, caring in the Newborn Intensive Care Unit (NICU), examined what it was like to be a provider of care in the NICU through participant observation of care, interviews with providers of care including professionals and parents, and attendance at ethical grand rounds over the course of a year (Swanson, 1990, 1991). The results of this second study confirmed the
five caring processes and refined the definitions. Swanson’s third study, caring and the clinical nursing models project, examined caring among young women at high social risk who were recipients of an eighteen month public health nursing intervention targeting pregnant young women and their infants. As a result, the caring processes were confirmed, sub-dimensions of each process were identified, and an empirically derived definition of the concept of caring was proposed (Swanson, 1991; Swanson-Kauffman, 1988).

In the Miscarriage Caring Project, Swanson (1999) examined the effect of a caring intervention consisting of nurse counseling (trained in the Swanson Caring Model) on women who had experienced miscarriages. The objective of the study was to test the effects of caring-based counseling (nurse counseling based on Swanson’s Caring Theory), measurement (immediate versus delayed measures), and time on the impact of miscarriage, integration of loss, and women’s emotional well-being in the first year after miscarrying (Swanson, 1999). The sample included 185 women (242 enrolled but 185 completed the program). The caring-based counseling intervention was based on the findings of the three earlier phenomenological studies and this study tested the caring constructs within Swanson’s Caring Theory. Results of this randomized, longitudinal study indicated that caring was effective in reducing overall emotional disturbance, anger and depression; and concluded that the receipt of caring, completion of outcome measures immediately after loss, and the passage of time had some positive and significant effects on integration of loss and enhancement of well-being during the first year following the loss (Swanson, 1999).
Swanson’s NIH funded study (2000) predicting depressive symptoms after miscarriage was also used for development and testing of the Caring Professional Scale. The primary purpose of this study was to develop and test a theory-based path model which would enable prediction of the intensity of women's depressive symptoms at 4 months and at 1 year after miscarriage (Swanson, 2000). Swanson (2000) hypothesized that women most at risk for increased depressive symptoms after miscarriage are those who attributed high personal significance to miscarriage, lacked social support, had lower emotional strength, used passive coping strategies, had lower incomes, and did not conceive or give birth by 1 year after loss. The sample size was a subgroup of the larger Miscarriage Caring Project (185 women) and consisted of 174 women whose pregnancies ended prior to 20 weeks gestation (mean = 10.51, SD = 3.32) and who received care from a nurse midwife and/ or physician at the time of pregnancy loss (Swanson, 2000, p.196). Path analysis employing a series of stepwise, multiple regression equations was used to test the hypothesized model. Findings confirmed the hypotheses (Swanson, 2000, p. 191).

In a meta-analysis of approximately 130 data-based publications on caring, Swanson reviewed 67 interpretive studies (total number of participants= 2,314) that qualitatively described caring and were compatible with Swanson’s five caring processes further validating and lending credibility to the Swanson Caring Theory beyond the original context (Swanson, 1999). This meta-analysis further clarified the definition and meaning of caring as it is used in nursing and the consequences of caring. This included both intentional and unintentional outcomes of caring and non-caring behaviors from the perspectives of patients and providers. Consequences and outcomes for the patient
related to caring based interventions included positive effects on satisfaction with care, self esteem, self efficacy, and physical healing. Consequences of practice-based caring interventions for the professional included enhanced clinical judgment, empathy, intuition, capacity for caring and work satisfaction. Consequences of non-caring behaviors for recipients of care included feelings of humiliation, fear, despair, isolation, and lingering negative memories of the particular health care experience. Most significantly the research points to prolonged physical healing when patients experience health care encounters which are perceived as non-caring. Providers themselves also are negatively impacted by non-caring behaviors. Non-caring can result in nurses becoming depressed, hardened, weary, fearful, and robotic (Swanson, 1999, p.53). Caring interventions impact the development of positive caring relationships which ultimately can contribute to positive health outcomes for the recipients of care and positively impact the providers as well.

Family-Centered Care

One of the six core national goals for CSHCN and their families identified in Healthy People 2010 is family-centered care. This is not a new concept to those in maternal child health but is one that has now taken center stage in the care of CSHCN in across our communities both in the United States and internationally. The concept of family-centered care appears in the literature over thirty years ago when the Nursing Clinics of North America presented an issue containing eight articles relating to family-centered care, children and families (Betz, 2007; Beatty, 1972). This issue presented articles introducing the philosophical concept of family-centered care as it applied to
health care for children in a variety of practice settings. At Children’s Hospital of Los Angeles, they had adapted the philosophy of patient centered nursing care to allow for parent involvement and embraced the family and the family’s needs in their model of care. Themes revolved around the inclusion of families in the care of their child and in defining objectives to meet the health care needs of the child. During this time, there was a beginning shifting in paradigms for care of children from an institutional approach to consideration for a patient and family–centered approach. While family-centered care was beginning to be recognized as important for healthcare to children, it was recognized as particularly beneficial for children with special health care needs and their families (Ireys, 1981).

In the 1980’s, Surgeon General C. Everett Koop, the MCHB, the Association for the Care of Children’s Health, and other organizations together with families collaborated to advance the concept of family-centered care, with a particular focus on CSHCN in hospitals and community programs (Conway et al., 2006). The momentum has continued since then with further refinement of the definition and principles of family-centered care. In 2001, the Institute of Medicine issued a sentinel report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which identifies patient and family-centered care as a key recommendation for improving the quality of health care in the United States (Institute of Medicine, 2001). Additionally, family-centered care has been endorsed as a standard of care and priority by other major health care organizations including the American Academy of Pediatrics, American Hospital Association, American Nurses Association, Association of Maternal Child Health Programs, National Association of Children’s Hospitals and Related Institutions, Federal agencies, Joint
Commission on Accreditation of Healthcare Organizations, National Committee for Quality Assurance, Institute for Healthcare Improvement, and other organizations across the United States and internationally.

Definition and principles of family-centered care.

In a seminal document on family-centered care, Shelton, Jeppson, and Johnson (1987) defined eight key elements along with a framework for providing family-centered care to CSHCN and their families. These key elements and the framework were developed in coordination with parents and professionals from across the United States. The elements constituted a move towards a new philosophy of care from an institutional and agency-oriented approach which then became child centered, to a family-centered approach for the care of CSHCN. This new philosophy of care recognized the family as the constant in the child’s life, and that family and professional partnership was required. Increasing evidence pointed to the need for a change in philosophy because the family environment has the greatest influence on a child’s life, including meeting physical necessities, and providing emotional support and stimulation needed to promote growth and development (Shelton et al., 1987). This philosophy of care recognizes and supports the family as the natural caregiver of the child and builds upon the strengths of the family. The framework, revised further in 1995, incorporated cultural diversity and presented the elements of family-centered care in order of importance based on feedback from families and professionals (Shelton and Smith Stepanek, 1995).

In a concept analysis on family-centered care, Hutchfield (1999) noted Shelton’s work and indicated that this provided a clear framework which could be translated into
practice. Results of this concept analysis identified the components of family-centered care. These include parent-professional partnership, parents as primary caregivers involved in their child’s care, and ultimately parents being recognized as the experts in all aspects of care for their child.

In 2003, recognizing the benefits of family-centered care for families of CSHCN in terms of improved quality of services and health outcomes, the Maternal Child Health Bureau supported a project to assess the status of family-centered care in the United States. The purpose of the project was to provide recommendations to the MCHB regarding advancing implementation across programs and communities (McPherson, 2005). Over the course of two years, researchers reviewed the literature and met with families and professionals. The outcome of this effort included recommendations for a refined definition of family-centered care and a set of principles which reinforce the importance of partnerships between families and professionals as the foundation of family-centered care. In 2005, the MCHB recognized family-provider partnership as the foundation of family-centered care and defined family-centered care as inclusive of the following principles: families and professionals working together in the best interest of the child with the child assuming a role in this partnership as they grow, respect of skills and expertise brought to the relationship from both families and professionals, trust, communication and sharing of information, decision making together, and a willingness to negotiate (Dendoba et al., 2006). These have since been accepted as the standard of care by the Maternal Child Health Bureau for CSHCN. The definition and principles of family-centered care have been widely accepted and have been endorsed by the American Academy of Pediatrics, Family Voices and other national groups.
Family-centered care and outcomes.

Family-centered care has become the standard of care for CSHCN and has been associated with improved outcomes for both CSHCN and their families. Research has shown that parents want to be partners in their child’s care and that when parents receive information, feel prepared, and are present during procedures, there is decreased anxiety for both the parents and the child (Blesch and Fisher, 1996; LaRosa, Nash, and Murphy, 1997; Powers and Rubinstein, 1999; Wolfram and Turner, 1996). Family-centered care has been associated with both improved satisfaction with care and perceptions of well-being among parents of CSHCN (King, G., King, S., Rosenbaum, P., and Goffin, R., 1999). In a study of medical homes for at-risk children, Nelson et al. (2005) found a positive association between parental ratings of the clinician’s family-centeredness and parental reports of satisfaction with anticipatory guidance regarding illness and injury prevention. Family-centered care was evaluated in a qualitative study with 32 families of children hospitalized at a Swedish Children’s Hospital (Lundquist and Nilstun, 2007). Families reported having their dignity, self esteem, and self respect intact when care was perceived as family-centered.

Mothers of hospitalized pre-term infants (n= 55) who described their relationships with primary care providers as family-centered reported higher levels of satisfaction and psychological well-being; and were more likely to ask for assistance from health care providers (Van Riper, 2001). The effectiveness of an intervention to improve parent and professional collaboration for parents of premature infants (n= 154) in two neonatal intensive care units was tested. The intervention group received education and support
using a progress chart to record observations of their infant’s development. Parents in the intervention group reported higher satisfaction with the decision making process, their input and shared decision making (Penticuff and Arheart, 2005). Researchers studying 103 mothers of children with developmental and cognitive disabilities found that family-centered care was strongly associated with positive satisfaction with services even when controlling for the relational dimension of the working alliance between the parent and professionals (Trute and Hiebert-Murphy, 2007).

Over the years, health care institutions have come to recognize the important role of families in the provision of health care. Family-centered care principles are now integrated into health care policies and standards of care for families in an effort to improve quality, satisfaction and health outcomes, particularly for vulnerable populations. A care coordination project based on family-centered principles for at risk pregnant women in Wisconsin had reported decreased rates of tobacco and alcohol use during pregnancy, increased birth weights and gestational age, and reduced neonatal intensive care unit days (Solberg, 1996). Following implementation of a transitional care center based on family-centered care principles for families of hospitalized children, a children’s hospital in Ohio reported a 30% to 50% decrease in length of hospital stays, fewer rehospitalizations, decreased use of the emergency department, improved parent satisfaction, and decreased parental anxiety (Forsythe, 1998).

Health care systems across the United States have implemented family-centered care programs particularly for CSHCN with positive results. Since 1993, the Medical College of Georgia (MCG) Health System has integrated family-centered care through out their system. They report significant positive outcomes particularly in the
neurosurgical unit including increased patient satisfaction (from the 10th to 95th percentile), decreased length of stay by 50%, discharge rates increased by 15.5%, and reduction in medical errors by 62% (Sodomka, 2005; Conway et al., 2006). The Center for Medical Home Improvement in New Hampshire has established and supported medical homes in pediatric primary care practice settings based on family-centered care principles. Quality improvement results after two years indicated reduced the number of hospital days by 8%, decreased parental worries, and reduced school absences by more than half (Conway et al., 2006; Cooley C. Center for Medical Home Improvement, 2006).

While health care providers and organizations have made strides in terms of promoting family-centered systems of care for CSHCN, results of an analysis of the 2001 National Survey of CSHCN indicates there are still gaps. Dendoba et al. (2006) found that while 85.8% of families reported usually or always feeling like a partner in their child’s care, vulnerable families such as those living in poverty, racial and ethnic minorities, those lacking health insurance, and those with functional limitations were at greater risk of not feeling like a partner in their child’s care. The researchers found that a sense of partnership was predictive of positive outcomes related to satisfaction with care, access to specialty care, missed days from school, and unmet needs. They point to the need for developing strategies to improve access to family-centered systems of care for at risk and underserved families so they too can feel like partners in their child’s health care.
Summary

The review of the literature substantiates the challenges facing families of CSHCN in terms of financial burdens and access to pediatric specialty care. These challenges are compounded further when combined with such issues as poverty and residing in rural, medically underserved areas of the country. It is clear that systems of care for CSHCN should be accessible and construed by the recipients of care as caring and family-centered in order to build family-provider partnerships and optimize health outcomes for CSHCN and their families. Systems of care for CSHCN should be designed to be caring, family-centered and to reduce financial burden on families of CSHCN.

Telemedicine is increasingly being utilized as a mode of health care service delivery to promote access to care for CSHCN in rural and medically underserved communities. To date, there is a lack of research regarding telemedicine as compared to traditional face-to-face care in respect to family financial burden/cost, caring and family-centered care for CSHCN. This warrants further investigation as we design systems of care for CSHCN with the ultimate goals of being caring, family-centered and reducing cost burdens from the family perspective. This research compared telemedicine to traditional face-to-face care examining cost, caring and family-centered care from the perspective of the families of CSHCN. Chapter III will provide a description of the methods for this study.
CHAPTER III

Methods

Study Design

This project was a prospective, quasi-experimental research design to analyze cost, caring, and family-centered care related to a health care delivery system of care utilizing telemedicine compared to traditional face-to-face care.

Setting

The Florida Department of Health Children’s Medical Services (CMS) Program, the Title V Program in Florida serving CSHCN and their families, provides a statewide managed system of care linking community-based primary care with pediatric specialty care services at regional and tertiary centers such as children’s and university-based hospitals. The system of care also includes nursing care coordination, social work and family support services including family health partners, a lay parent support program. Eligibility for the program is two-fold: first, a child must meet the clinical eligibility which is based on the Federal definition of a CSHCN and the second criterion is financial eligibility. Financial eligibility has three categories: Medicaid (Title XIX), Florida KidCare (Title XXI), and safety net. CSHCN enrolled in Medicaid and Florida KidCare, the State Children’s Health Insurance Program (SCHIP) in Florida are financially eligible for CMS. Additionally, CSHCN with family incomes greater than 200% of the Federal Poverty Level (FPL) but have medical costs which spend the family down to the Medicaid financial eligibility levels are considered financially eligible and are identified as safety net enrollments. This third category of safety net includes CSHCN without any
other form of insurance considered ineligible for Medicaid or SCHIP programs due to legislative restrictions for enrollment in these programs.

As of July 2007, there are over 65,000 children enrolled in CMS across the state with 11,000 (17%) residing within the Southeast Florida Region which has implemented a regional telemedicine program for pediatric specialty care (Florida Department of Health, 2007). Pediatric specialty services provided by telemedicine are determined by needs in the local community and availability of specialty providers. In the southeast region, the telemedicine program provided over 1,100 pediatric specialty visits from November 2005 through May 2008 (Florida Department of Health, Children’s Medical Services Southeast Region, 2008).

Sample

The study sample included a convenience sample of parents or legal guardians of CSHCN enrolled in Children’s Medical Services in the Florida Southeast Region receiving pediatric specialty care for one year or more prior to onset of the research project. The sample was comprised of two subject groups: families receiving traditional face-to-face pediatric specialty care and families who have received telemedicine visits along with traditional face-to-face pediatric specialty care. Traditional care was provided either at the remote CMS clinical site or through travel to the tertiary center (children’s hospital, university-based or medical center clinical/hospital site, or private office). If pediatric specialty care was not available within the local community at the CMS clinical
site, the family was provided a choice as to whether they receive the care through telemedicine or travel to the tertiary center.

Because of the variety of clinics and the need to control for differences across pediatric specialty areas, it was determined that only those clinics which provided the pediatric specialty care through both modalities (traditional and telemedicine) were included in the sample. Table 1 provides an overview of the unduplicated patient count for CSHCN receiving traditional face-to-face visits and telemedicine care for each pediatric clinical specialty team for 2008.

Table 1

Children’s Medical Services Southeast Florida Region
Potential Study Sample- Unduplicated Patient Counts (UPC)
January 2008 – December 2008

<table>
<thead>
<tr>
<th>Specialty Team</th>
<th>Traditional UPC</th>
<th>Telemedicine UPC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dermatology (UM Team)</td>
<td>69</td>
<td>69</td>
</tr>
<tr>
<td>Diabetes (UF Team)</td>
<td>107</td>
<td>107</td>
</tr>
<tr>
<td>Neurology (Private Provider Team)</td>
<td>114</td>
<td>114</td>
</tr>
<tr>
<td>Nutrition (UM Team)</td>
<td>130</td>
<td>130</td>
</tr>
<tr>
<td>Orthopedics (Private Provider Team)</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Total Potential</td>
<td>445</td>
<td>445</td>
</tr>
</tbody>
</table>
The sample for this study was recruited from participants in the nutrition and neurology clinics, all of which have both traditional and telemedicine components. Recruitment of participants was done through letters (Appendix A) to those families who received pediatric specialty care at the identified CMS telemedicine clinic and traditional face-to-face specialty clinical sites in the previous three months. Flyers (Appendix B) also were posted in the CMS clinical sites participating in the study. The letters were sent by the respective clinical site advising families of the study and inviting them to participate. Letters and recruitment flyers also were distributed at the respective clinical sites. Families were invited to contact the principal investigator and research assistant to learn more about the study. The letters included a form as well as a self-addressed, stamped envelope to be returned to the clinical site giving permission for the research team to contact the family. If parents were interested in participating in the study, the principal investigator or research assistant contacted them and reviewed the inclusion and exclusion criteria to assure they met the criteria for enrollment. Face-to-face appointments were then scheduled for those determined eligible to enroll in the study.

Inclusion criteria included:

1. The parent / guardian of a CSHCN enrolled in CMS for one year or greater.

2. CSHCN has received pediatric specialty care at CMS clinic within one year of data collection.
3. Telemedicine group included only parent/guardian of CSHCN who had received greater than two visits utilizing telemedicine technology. Most recent telemedicine visit must have been within 90 days of participation in study.

4. Traditional face-to-face group included only parent/guardian of CSHCN who had received two or more CMS clinic visits. Most recent clinic visit had to have been within 90 days of participation in study.

5. The ability of the parent/guardian to read and/or speak English.

Exclusion criteria included:

1. Any parent/guardian of a CSHCN enrolled in CMS receiving all of the CSHCN’s pediatric specialty care from external providers outside of the CMS clinical structure. (For example, CSHCN received care from pediatric specialist in private office.)

2. Foster parent/guardian of CSHCN who has had placement of enrolled CMS child for less than one year period.

Sample and Power

A convenience study was recruited for this study. To determine sample size, a power analysis was used to estimate the sample size needed to obtain significant results. Power analysis is a method for reducing the risk of Type II errors, accepting a null hypothesis when it is false (Cohen, 1988; Keppel and Wickens, 2004; Polit and Beck, 2004). In the case of a Type II error, the researcher concludes that no relationship exists
when there actually is a relationship. Power analysis consists of four components: significance level ($\alpha$), sample size (n), effect size ($\gamma$), and power (1-$\beta$).

To determine an estimate of sample size using power analysis, it is necessary to have an estimate of the other three components ($\alpha$, $\gamma$, 1-$\beta$). Conventional standards for studies typically set significance at a two-tailed alpha of < 0.05 and power (1-$\beta$) at 0.80 (Cohen, 1988; Keppel and Wickens, 2004; Polit and Beck, 2004). Significance referred to as alpha ($\alpha$) is associated with Type I error which is the probability of rejecting the null hypothesis when it is true (Cohen, 1988; Keppel and Wickens, 2004; Polit and Beck, 2004). For this study, the alpha was set at a two-tailed alpha of < 0.05 which is the conventional standard and controls for Type I error. Power was set at 0.8 which is the conventional standard indicating an 80% chance of rejecting the null hypothesis and a 20% chance of Type II error accepting the null hypothesis when it is false (Cohen, 1988; Keppel and Wickens, 2004; Polit and Beck, 2004).

Effect size can be estimated either through a pilot study which can be quite costly or based on findings from similar research or studies of similar problems. In the case of telemedicine, the literature specific to both children and CSHCN was very limited in terms of results particularly as it relates to effect size estimates useful for power analysis (McConnachie et al., 2006). In a pilot study of forty adult patients receiving psychiatric services, researchers examined differences in traditional face-to-face and telemedicine services in respect to satisfaction (Stevens et al., 1999). While this study examined a different population from parents or guardians of CSHCN, the participants in this study are also a vulnerable population facing many of the similar challenges including access to
specialty services for those living in underserved communities. The researchers reported the means and standard deviation for patient satisfaction as follows: traditional face-to-face group ($M = 1.59, SD = .69$); telemedicine group ($M = 1.87, SD = .63$); and total group ($M = 1.73, SD = .67$). Calculation of effect size is possible using the means and standard deviation information using the formula for Cohen’s $d$ (Cohen, 1988; Keppel and Wickens, 2004). Since the study did not report effect size but did report means and standard deviation information relating to satisfaction for the two groups, it was possible to calculate effect size using the formula for Cohen’s $d$ as follows:

$$d_{12} = \frac{\mu_1 - \mu_2}{s_{12}}$$

Therefore, effect size was estimated to be .42 which indicates a moderate effect size.

Based on an effect size of .42, alpha of .05, and power of .80, the estimated sample size was calculated to be 89 per group totaling 178 subjects. For this study, the research team recruited a sample of 222 subjects including 110 in the traditional face-to-face group and 112 in the telemedicine group.

Human Subject’s Protection

This project proposal was submitted to the Human Subject Research Office at the University of Miami and the Institutional Review Board of the Florida Department of Health. Written informed consent (Appendix C) was obtained from the family member who participated in the study. A signed copy of the consent form was given to the
participants and included contact information for the principal investigator for questions and a contact for complaints.

Prior to enrollment in the study, participants were advised of the study goals to examine the system of care for CSHCN from the perspectives of families as it relates to cost, caring and family-centered care. They received written and verbal information and instructions from the principal investigator or research assistant which included information about the type of data being collected and the procedure for data collection. Participants were asked to provide approximately one hour of their time to complete the questionnaire booklet on one occasion. Participants were advised that they could withdraw consent at any point in time and that the care their CSHCN receives through CMS would not be compromised by their decision to withdraw from the study. Each participant completing the questionnaire booklet received a letter thanking them and a gift card for Publix valued at $20 as appreciation for their time. They were advised verbally by the principal investigator or research assistant, as well as in writing, that results of the study would be posted in the CMS clinical site waiting area and could be sent to them upon request.

The IRB determined this a minimal risk study. There were no direct benefits to parents who participated in this study. The proposed study did have potential benefits to society and particularly to CSHCN and their families as well as their providers. Telemedicine technology is rapidly advancing and poses an answer and, at the least, an alternative to access to care issues for vulnerable populations including CSHCN and their families. To promote acceptance by health care providers and recipients of health care
alike, it is critical that we provide research-based evidence that compares health care services provided via telemedicine versus traditional face-to-face care and examining issues such as cost, caring and family-centered care from the family perspectives.

Measurement Tools

This study used three instruments including: Family Cost Survey, Caring Professional Scale (Swanson, 1998, 2000), and the Measure of Process of Care- 20 Item Scale (King, Rosenbaum, and King, 1997, 2004). In addition, demographic data were collected using a Family Demographic Form. These instruments were packaged into one booklet with instructions incorporated into the booklet (Dillman, D.A., 2007). See Appendix D.

Measure of family cost.

The Family Cost Survey (Appendix D) was developed for this study and examined family direct and indirect costs related to pediatric specialty visits for their CSHCN. This survey collected information regarding travel, lodging, food, child care, and loss of wages related to a child’s visit to the CMS clinical site for traditional as well as telemedicine care.

Measure of the caring model.

There are a number of tools that have been developed to measure caring and many are based on the Watson theoretical framework of caring including the Caring Behaviors
Inventory, Caring Assessment Tool, and the Caring Nurse- Patient Interaction Scale (Wolf, Giardino, Osborne, and Ambrose, 1994; Duffy, Hoskins, and Seifert, 2007; Cossette, Cote, Pepin, Ricard, and D’Aoust, 2006). The majority of these tools measuring the construct of caring have primarily been utilized in adult patient populations with both adult recipients of care, nursing students, and nursing professionals. The Caring Professional Scale (Swanson, 1998, 2000) was the only tool identified that has measured caring in a maternal-child health population. It also was the only caring tool that has been used to measure caring about different health care providers other than nursing. The Caring Professional Scale (Swanson, 1998, 2000) was used in this study. See Appendix D.

The Caring Professional Scale, developed by Swanson (Swanson, 1998, 2000), is conceptually and theoretically based on Swanson’s caring theory (1991). The Caring Professional Scale is an instrument consisting of two factor analytically derived subscales, the compassionate healer and the competent practitioner (Swanson, 2002). The revised scale consists of 15 items constructed on a 5-point Likert scale (Swanson, 2002). The respondents are asked to rate the items on the extent to which their health care provider was comforting, informative, caring, supportive, clinically competent, technically skilled, respectful, and an attentive listener to name a few but not all of the items listed in the scale (Swanson, 2002). Higher scores on each subscale indicate that the health care provider is competent and caring from the perspective of the participant. Table 2 illustrates the two subscales and the possible range of scores for each of these subscales.
Table 2
Caring Professional Scale

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item #'s</th>
<th>Scale Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassionate Healer</td>
<td>1, 5, 6, 7, 8, 12, 13, 14</td>
<td>1 – 40</td>
</tr>
<tr>
<td>Competent Practitioner</td>
<td>2, 3, 4, 9, 10, 11, 15</td>
<td>1 – 35</td>
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</table>

The Caring Professional Scale can be adapted to rate the care provided by a variety of health care professionals. The Caring Professional Scale was used in the Miscarriage Caring Project which studied the effect of a caring intervention consisting of nurse counseling (trained in the Swanson Caring Theory) for women who had experienced miscarriages. The objective of the study was to test the effects of caring-based counseling developed from the caring constructs of Swanson’s Caring Theory (Swanson, 1999). The sample included 185 women who completed the study. Results of this randomized, longitudinal study indicated that caring was effective in reducing overall emotional disturbance, anger and depression; and concluded that caring and time had some positive and significant effects on integration of loss and enhancement of well-being during the first year following the loss (Swanson, 1999, p289). When used to rate caring for multiple providers, Cronbach’s alpha estimates for internal consistency ranged from .74 to .96 for advanced practice nurses, .97 for nurses, and .96 for physicians indicating internal consistency and reliability (Swanson, 1999).
Swanson’s NIH funded study (2000) predicting depressive symptoms after miscarriage also employed the Caring Professional Scale. The sample size was a subgroup of the larger Miscarriage Caring Project (n=185) and consisted of 174 women whose pregnancies ended prior to 20 weeks gestation ($M = 10.51$, $SD = 3.32$) (Swanson, 2000, p.196). In describing concurrent criterion validity of the Caring Professional Scale (CPS), Swanson reported that CPS scores were correlated with the empathy subscale of the Barret- Lennart Relationship Inventory ($r = .61$, $p < 0.001$) supporting concurrent criterion validity (Swanson, 2000, p. 197). Using a path analytic model, while women’s assessment of provider caring at the time of miscarriage was not found to significantly impact women’s depression, the following variables did: attributing high personal significance to miscarriage, lacking social support, having low emotional strength, using passive coping strategies, having low incomes, and not conceiving or giving birth by 1 year after loss (Swanson, 2000). While the Caring Professional Scale has not been applied to telemedicine, it has been applied and tested with maternal-child health populations and particularly those who are vulnerable due to special health care needs. This instrument has both theoretical and empirical validity and is clinically relevant across health care settings and populations (Swanson, 2002).

Measure of family-centered care.

Three instruments were identified that measure family-centered care specifically focused on populations of families with CSHCN. The Measure of Processes of Care-20
item scale (MPOC-20) was used in this study to measure family-centered care (King, King, and Rosenbaum, 2004; King, Rosenbaum, and King, 1995, 1997).

The Family Professional Partnership Scale measures the family-professional partnership based on a family’s perception of the skills and attitudes professionals need in order to achieve a positive relationship with families and has been utilized in the United States primarily in special education environments (Summers et al., 2005).

Family Voices released their Family-Centered Care Self-Assessment Tools for providers and families in October 2008 (Family Voices, 2008). These instruments are based on the family and provider perceptions and self-assessments of care as family-centered care. These tools have not been tested as of yet for reliability and validity.

The Measure of Process of Care Tools (MPOC-56 and MPOC-20) measure the domains of family-centered care based on the family’s perception of their health care professional and the health care organization providing services to the CSHCN (King, King, and Rosenbaum, 2004; King, Rosenbaum, and King, 1995, 1997). In essence, these tools measure the domains of family-centered care based on the family’s perceptions of the system of care versus the individual provider or clinical site. The MPOC tools have been widely used throughout Canada, the United Kingdom and other countries outside of the United States and have strong psychometrics to support reliability and validity (King, King, and Rosenbaum, 2004).

The MPOC-56 is a questionnaire consisting of 56 items covering five domains: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for child and family, and respectful
and supportive care (McConachie & Logan, 2003). Initial development included extensive review of the literature, focus groups involving item generation, pretesting, item reduction through pilot testing, and factor analysis.

The MPOC- 20 (Appendix D) was developed from the original 56- item MPOC and retains the same five subscales that represent fundamental components of family centered practice. The scale consists of 20 items constructed on a 7-point Likert scale. Higher scores indicate that families perceive the system of care as more family-centered. Table 3 illustrates the five subscales and the possible range of scores for each of these subscales.

Table 3
Measure of Processes of Care 20- Item Scale (MPOC- 20)-
Domains of Family-Centered Care

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item #’s</th>
<th>Scale Range</th>
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</thead>
<tbody>
<tr>
<td>Enabling and Partnership</td>
<td>4, 7, 8</td>
<td>3 – 21</td>
</tr>
<tr>
<td>Providing General Information</td>
<td>16, 17, 18, 19, 20</td>
<td>5 – 35</td>
</tr>
<tr>
<td>Providing Specific Information about the Child</td>
<td>2, 14, 15</td>
<td>3 – 21</td>
</tr>
<tr>
<td>Coordinated and Comprehensive Care</td>
<td>5, 6, 10, 12</td>
<td>4 – 28</td>
</tr>
<tr>
<td>Respectful and Supportive Care</td>
<td>1, 3, 9, 11, 13</td>
<td>5 – 35</td>
</tr>
</tbody>
</table>
The MPOC-20 Scale has been utilized widely to measure the domains of family centered care and has established reliability and validity across populations and, in particular, among populations of families of children with special health care needs. The tool also has been utilized across different professional groups including early education and health provider settings. For these reasons, this tool was utilized in this study to measure family centered care from the family perspective.

Initial development and testing of the MPOC-56 for reliability and validity involved four data sets: a pilot test study with parents of CSHCN (N=653), a field test study with parents of CSHCN (N=151) enrolled in a regional cleft palate program, a test-retest reliability study with parents of CSHCN (N=29) enrolled at a local treatment center, and a validation study with a convenience sample of parents of CSHCN (N=14) enrolled at the local treatment center to assess social desirability response bias (King, S., Rosenbaum, P., and King, G., 1995). Evidence from these initial studies supports the validity of the MPOC tool in respect to content, face, and construct validity. These studies were unable to support criterion validity at the time as there was no existing criterion or comparable measure.

Content validity was established during this development phase through the course of these four studies. Items retained were rated as highly important by parents with means ranging from 2.2 to 2.96 on a three point scale with greater than 75% receiving average scores of 2.7 or higher (King, Rosenbaum and King, 1995, p. 42). While face validity is not considered to be a sufficient measure of validity, it was examined during the development of this tool. Response rates were considered good
ranging from 74.8% for the pilot, 87.9% for test-retest reliability, 62.3% for the field test, and 93.3% for the validity study assessing social desirability bias. Parents who participated in these four studies commented that the issues addressed in the instrument were relevant and well-formulated.

During the initial development stage through the course of these four studies, construct validity was established. Exploratory factor analysis of the initial pilot data set resulted in five scales. The initial field test validation study findings indicated the MPOC scores were highly correlated with the Larsen Client Satisfaction Questionnaire scores with the Pearson correlations ranging from .40 to .64 (King, Rosenbaum, and King, 1997). Results also indicated that the MPOC scores were inversely correlated with the measures of stress as evidenced by Spearman correlation coefficients ranging from -0.23 to -0.55 (King, Rosenbaum, and King, 1997). These results for both the satisfaction and stress variables are consistent and statistically significant (ranging from \( p < .05 \) to \( p < .0001 \)) across the pilot, field testing and reliability studies (King, Rosenbaum, and King, 1995).

The initial test-retest reliability tests of the MPOC-56 within a one month period resulted in stability with intraclass correlation coefficients ranging from .78 to .88 (King, Rosenbaum, and King, 1997). The MPOC-20 has reported satisfactory to strong internal consistency with alpha coefficients ranging from .63 to .92 and test–retest reliability yielding interclass correlation coefficients of .81 to .86 (Trute & Hiebert-Murphy, 2007).

Further studies have continued to document the reliability and validity of the MPOC-56 and MPOC-20 as measures of family perceptions of family-centered care for
CSHCN in clinical and community settings (Dyke, Buttigieg, Blackmore, and Ghose, 2006; King, King, and Rosenbaum, 2004; McConachie and Logan, 2003; Siebes, Wijnroks, Ketelaar, van Schie, Vermeer, and Gorter, 2007; Trute and Hiebert-Murphy, 2007). The MPOC was developed focusing on families of CSHCN and has been utilized effectively in a variety of settings with consistent evidence of reliability and validity.

Family demographic form

The Family Demographic Form (Appendix D) collected information regarding the CSHCN age, diagnoses, race/ethnicity, insurance status including type, and CMS clinic visit history (type and number of specialty visits) for the previous year. Demographic data included age, sex, race, and ethnicity of CSHCN, and family income (Three groups: 100% or less of Federal Poverty Level (FPL); >100% <200% of FPL; >200% FPL). This demographic questionnaire also included a section noting the number of pediatric specialty visits over the last year by specialty type and by telemedicine as a mode of health care delivery. The Family Demographic Form also collected information on the parent/guardian including age, gender, race/ethnicity, employment, education, and marital status.

Data Collection

Data collection occurred over a six month period from August 19, 2009 through February 24, 2010 supervised by the principal investigator in coordination with the research assistant. Recruitment of families was done through mailings and onsite
following pediatric specialty clinic visits. Recruitment and survey materials were available in English. Families responding to the initial recruitment letters and posters were screened for eligibility; and if determined eligible for participation, were scheduled for an appointment at the local CMS office. Families also were invited to participate in the study during clinical visits.

A CITI certified research assistant was hired and trained in all aspects of the research study. The research assistant was a graduate student in Public Health. The research assistant reported directly to the principal investigator. A project manual was developed to guide the research project. The principal investigator trained the research assistant prior to participation in the study regarding overall project, study recruitment, consents/ethical considerations, data collection, and research project timelines.

All family participants completed the Family Demographic Data Form, Caring Professional Scale, Measure of Process of Care-20 Scale, and Family Cost Survey within ninety days following their pediatric specialty visit. It was estimated that completion of these tools averaged 15 to 30 minutes but no more than one hour. The family completed the surveys onsite. The principal investigator or research assistant was available to the family participant while they were completing the survey to answer any questions. The family participant completed the survey in a private room onsite at the CMS local office in their community. The research team member reviewed the survey for any questions and missing data with the participant following completion of the survey. The participant was provided with a $20 Publix gift card upon returning the completed survey to the research team member.
Data Analysis

Data were analyzed using the Predictive Analytic Software (PASW) Version 18.0 formerly known as Statistical Package for Social Sciences (SPSS). The analyses included univariate statistics including descriptive statistics and Analysis of Variance (ANOVA).

Descriptive statistics such as frequencies, means, and standard deviations; as well as t tests and chi squares ($\chi^2$) of the individual variables were calculated to compare the demographics of the two study groups as well as for the outcome variables of family cost, caring and family-centered care. The two study groups were comprised of parents whose CSHCN received pediatric specialty care face-to-face and parents whose CSHCN received pediatric specialty care via telemedicine. Analyses of Variance (ANOVA’s) were used to examine the individual dependent variables, caring and family-centered care, between these two groups. These outcomes were measured utilizing the scores on the Caring Professional Scale (CPS) and the Measure of Process of Care-20 Scale (MPOC-20). If imbalances had been found in one or more of the demographic variables, an Analysis of Covariance (ANCOVA) would have been conducted to determine whether there were differences among the groups when controlling for one or more of these variables or covariates.
CHAPTER IV

Results

The purpose of this research project is to examine cost, caring and family-centered care in relation to pediatric specialty services utilizing telemedicine technology compared to traditional face-to-face visits for Child with Special Health Care Needs (CSHCN) in rural, remote and medically underserved areas of Southeast Florida. Cost, caring, and family-centered care were examined from the perspectives of the parents/guardians of CSHCN. This chapter presents the study results. The first section will present the sample characteristics including the parent/guardian respondents as well as the CSHCN. The next section will discuss the reliability of the measurement tools utilized for caring and family-centered care. The following section will present the results from analyses for the three research questions. Predictive Analytic Software (PASW) Version 18.0 for Windows was used to evaluate the data and derive the findings.

Sample

The study sample included a convenience sample of 222 parents or legal guardians of CSHCN enrolled in Children’s Medical Services in the Florida Southeast Region receiving pediatric specialty care for one year or more prior to onset of the research project. The sample was divided into two subject groups: traditional group \( n = 110 \) which included families receiving traditional face-to-face pediatric specialty care; and the telemedicine group \( n = 112 \) which included families who have received telemedicine visits along with traditional face-to-face pediatric specialty care. The majority of the surveys were completed within 30 days of the most recent clinic visit for
both the traditional (83.6% ≤ 30 days; 8.2% ≤ 60 days; 8.2% ≤ 90 days) and telemedicine (90.2% ≤ 30 days; 4.5% ≤ 60 days; 5.4% ≤ 90 days) groups.

Characteristics of parents/ guardians.

The characteristics of the parents/ guardians for each group are presented in Table 4. The majority of the participants in each group were female (traditional: $n = 101$, 91.8%; telemedicine $n = 98$, 87.5%) with ages ranging from 20 to 73 years ($M = 40.3$, $SD = 10.9$) in the traditional group and 18 to 74 years ($M = 40.0$, $SD = 12.1$) in the telemedicine group.

In terms of race, the traditional group was comprised of 25.5% White ($n = 28$), 25.5% Hispanic ($n = 28$), 41.8% Black ($n = 46$) including 11.8% Haitian ($n = 13$), 2.7% Multi-Racial ($n = 3$), 3.6% Asian/ Pacific Islander ($n = 4$), and 0.9% reported as other ($n = 1$). The telemedicine group was comprised of 28.6% White ($n = 32$), 22.3% Hispanic ($n = 25$), 43.8% Black ($n = 49$) including 6.3% Haitian ($n = 7$), 0.9% Native American ($n = 1$), 1.8% Multi-Racial ($n = 2$), 1.8% Asian/ Pacific Islander ($n = 2$), and 0.9% reported as other ($n = 1$). Slightly less than half of both groups were reported as married (traditional: $n = 52$, 47.7%; telemedicine: $n = 50$, 45.0%). In terms of employment, 40% of the traditional ($n = 44$) and 46.4% of the telemedicine ($n = 52$) groups reported employment (full or part time) with 30.9% (traditional, $n = 34$) and 19.6% (telemedicine, $n = 22$) reporting unemployment. In terms of education, 24.5% of the traditional ($n = 27$) and 24.3% of the telemedicine ($n = 27$) groups reported that they did not graduate from high school, while 37.3% (traditional, $n = 41$) and 37.8% (telemedicine, $n = 42$) reported
graduating from high school, and the remaining respondents (traditional: \( n = 38, 34.5\% \); telemedicine: \( n = 36, 32.4\% \)) reported two years or more of post secondary education.

The parent/ guardian characteristics of both groups were compared using \( t \) test for age as a continuous variable and chi square (\( \chi^2 \)) for the remaining categorical variables. There were no significant differences between the two groups.

Characteristics of Children with Special Health Care Needs (CSHCN).

The characteristics of the CSHCN for each group are presented in Table 5. The children ranged in ages from 1 to 20 years (\( M = 9.8, SD = 5.1 \)) in the traditional group and similarly from 1.5 to 20 years (\( M = 9.97, SD = 5.4 \)) in the telemedicine group. In terms of race, the traditional group was comprised of 21.8% White (\( n = 24 \)), 26.4% Hispanic (\( n = 29 \)), 41.8% Black (\( n = 46 \)) including 10.9% Haitian (\( n = 12 \)), 0.9% Native American (\( n = 1 \)), 7.3% Multi-Racial (\( n = 8 \)), and 1.8% Asian/ Pacific Islander (\( n = 2 \)). The telemedicine group was comprised of 20.5% White (\( n = 23 \)), 25.0% Hispanic (\( n = 28 \)), 48.2% Black (\( n = 54 \)) including 7.1% Haitian (\( n = 8 \)), 0.9% Native American (\( n = 1 \)), 4.5% Multi-Racial (\( n = 5 \)), and 0.9% reported as other (\( n = 1 \)).

Parents/ guardians reported that the majority of the CSHCN in both groups (traditional: \( n = 65, 59.5\% \); telemedicine: \( n = 76, 67.9\% \)) had two or more reported health conditions with 30.2% and 25.9% of parents in the traditional (\( n = 33 \)) and telemedicine (\( n = 29 \)) groups respectively reporting four or more reported health conditions. The specific reported health conditions most frequently reported as primary presenting were neurological/ seizure disorders (\( n = 29, 26.6\% \)), cerebral palsy (\( n = 14, 12.8\% \)), genetic conditions (\( n = 13, 11.9\% \)), and pulmonary/ respiratory conditions (\( n = 12, 11\% \)) for the
Table 4

Parent/ Guardian Characteristics

<table>
<thead>
<tr>
<th>Parent/ Guardian Characteristics</th>
<th>Group</th>
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<tbody>
<tr>
<td></td>
<td>Traditional Total (n = 110)</td>
</tr>
<tr>
<td></td>
<td>Traditional Neurology (n = 57)</td>
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<tr>
<td></td>
<td>Telemedicine Total (n = 112)</td>
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<td></td>
<td>Telemedicine Neurology (n = 54)</td>
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<tr>
<td></td>
<td>M (SD)</td>
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<td>Age (in years)</td>
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<th>No. (%)</th>
<th>No. (%)</th>
<th>No. (%)</th>
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<tbody>
<tr>
<td>White</td>
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<td>9 (17)</td>
<td>19 (33.3)</td>
<td>32 (28.6)</td>
<td>16 (27.6)</td>
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<td>28 (25.5)</td>
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<td>14 (24.6)</td>
<td>25 (22.3)</td>
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<td>16 (28.1)</td>
<td>42 (37.5)</td>
<td>25 (43.1)</td>
<td>17 (31.5)</td>
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<tr>
<td>Black (Haitian)</td>
<td>13 (11.8)</td>
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<td>5 (8.8)</td>
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<td>Multi-Racial</td>
<td>3 (2.7)</td>
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<td>3 (5.3)</td>
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<td>2 (3.4)</td>
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<tr>
<td>Asian/ PI</td>
<td>4 (3.6)</td>
<td>4 (7.5)</td>
<td>0 (0.0)</td>
<td>2 (1.8)</td>
<td>0 (0.0)</td>
<td>2 (3.7)</td>
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<tr>
<td>Other</td>
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<td>1 (1.9)</td>
<td>0 (0.0)</td>
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Table 4 (continued)

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<td>Traditional Total (n = 110)</td>
<td>Traditional Nutrition (n = 53)</td>
<td>Traditional Neurology (n = 57)</td>
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<tr>
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<td>No. (%)</td>
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<td>Gender</td>
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<td>45 (84.9)</td>
<td>56 (98.2)</td>
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<tr>
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<td>9 (8.2)</td>
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<td>Single</td>
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<td>32 (57.1)</td>
<td>50 (45.0)</td>
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<td>1 (1.8)</td>
<td>7 (6.3)</td>
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<td></td>
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<td>10 (9.2)</td>
<td>7 (13.2)</td>
<td>3 (5.4)</td>
<td>9 (8.1)</td>
<td>4 (7.0)</td>
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<tr>
<td></td>
<td>Other</td>
<td>8 (7.3)</td>
<td>2 (3.8)</td>
<td>6 (10.7)</td>
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(Table 4 continued)

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<td>Full Time</td>
<td>28 (25.5)</td>
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<td>15 (26.3)</td>
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<td>16 (14.5)</td>
<td>6 (11.3)</td>
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<td>10 (18.9)</td>
<td>11 (19.3)</td>
<td>25 (22.3)</td>
<td>12 (20.7)</td>
<td>13 (24.1)</td>
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<td>Unemployed</td>
<td>34 (30.9)</td>
<td>17 (32.1)</td>
<td>17 (29.8)</td>
<td>22 (19.6)</td>
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<td>Other</td>
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<td>7 (13.2)</td>
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</tbody>
</table>

ª Note: Of total participants, 18 parent/guardians did not report age with the n reporting noted for each group. Two parent/guardians did not report marital status (traditional neurology = 1; telemedicine nutrition = 1) and one parent (telemedicine neurology) did not report education.
traditional group; and neurological/ seizure disorders ($n = 22, 19.6\%$), genetic conditions ($n = 16, 14.3\%$), obesity ($n = 15, 13.4\%$), and endocrine/ metabolic conditions ($n = 11, 9.8\%$) for the telemedicine group. Length of time enrolled in Children’s Medical Services (CMS) was consistent for both groups with length of enrollment averaging 68.1 months ($SD = 51.1$) for traditional and 60.7 months ($SD = 50.9$) for the telemedicine groups. In terms of the number of visits to a specialist at the CMS clinical sites, the groups averaged 5.7 ($SD = 5.4$) and 6.0 ($SD = 4.5$) visits in the past year for the traditional and telemedicine groups respectively.

The preponderance of the families reported having health insurance at the time of the survey with 95.5\% of the traditional ($n = 105$) and 96.4\% of the telemedicine ($n = 108$) groups reporting that their CSHCN was insured. However, 16.4\% of the traditional ($n = 18$) and 13.5\% of the telemedicine ($n = 15$) groups reported that their CSHCN had been uninsured at some point during the past year. The mean length of time uninsured for this group was 5.7 months ($SD = 5.4$). Within this uninsured group, minorities were more likely to be uninsured with 77.7\% of minorities (44.4\% Hispanic, 33.3\% Black including 22.2\% Haitian) in the traditional group and 80\% of minorities (40\% Hispanic, 40\% Black including 20\% Haitian) in the telemedicine group reporting that they were uninsured at some point within the previous year. Of those reporting having insurance at the time of the survey, the majority were covered by Medicaid including 79.1\% of the traditional ($n = 87$) group and 83.8\% of the telemedicine ($n = 93$) group.

The characteristics relating to CSHCN for both groups were compared using $t$ test for the continuous variables and chi square ($\chi^2$) for the remaining categorical variables. There were no significant demographic differences between the two groups.
<table>
<thead>
<tr>
<th>Children Characteristics</th>
<th>Traditional Total (n = 110)</th>
<th>Traditional Nutrition (n = 53)</th>
<th>Traditional Neurology (n = 57)</th>
<th>Telemedicine Total (n = 112)</th>
<th>Telemedicine Nutrition (n = 58)</th>
<th>Telemedicine Neurology (n = 54)</th>
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<tr>
<td></td>
<td>( M ) (( SD ))</td>
<td>( M ) (( SD ))</td>
<td>( M ) (( SD ))</td>
<td>( M ) (( SD ))</td>
<td>( M ) (( SD ))</td>
<td>( M ) (( SD ))</td>
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<td>10.3 (5.1)</td>
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<td>2.5 (1.4)</td>
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<tr>
<td>Number of times seen by a specialist at CMS clinic in past year</td>
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<td>5.2 (4.2)</td>
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<td>NA</td>
<td>NA</td>
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(Table 5 continued)

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<th>Telemedicine Total (n = 112)</th>
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<td></td>
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<td>No. (%)</td>
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(Table 5 continued)

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<thead>
<tr>
<th>Group</th>
<th>Traditional Total (n = 110)</th>
<th>Traditional Nutrition (n = 53)</th>
<th>Traditional Neurology (n = 57)</th>
<th>Telemedicine Total (n = 112)</th>
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<tr>
<td>Children Characteristics</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
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<td>Uninsured past yr&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>No</td>
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<td>47 (82.5)</td>
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<td>52 (89.7)</td>
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<td>6 (10.3)</td>
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<tr>
<td>61 ≤ 90 days</td>
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<td>One</td>
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<td>21 (36.2)</td>
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<td>Two</td>
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<tr>
<td>Three</td>
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<td>7 (12.1)</td>
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<tr>
<td>≥ Four</td>
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<td>14 (24.6)</td>
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<td>14 (26.0)</td>
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<td>Children Characteristics</td>
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<td>Traditional Nutrition (n = 53)</td>
<td>Traditional Neurology (n = 57)</td>
<td>Telemedicine Total (n = 112)</td>
<td>Telemedicine Nutrition (n = 58)</td>
<td>Telemedicine Neurology (n = 54)</td>
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</tr>
<tr>
<td></td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
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<td>**Specific Health Conditions Reported (Primary Presenting)**ª</td>
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<td>3 (5.6)</td>
</tr>
</tbody>
</table>

ª Note: Of total participants, one parent/guardian in the telemedicine neurology group did not report information relating to insurance type and insurance/uninsured status. One parent/guardian in the traditional neurology group did not report health conditions of their CSHCN. One parent/guardian in the traditional nutrition group did not report the number of health conditions.
Validity and Reliability

Two standardized instruments were used to measure caring and family-centered care variables. The cost survey questions were developed specifically for this research project and were not tested prior to this research project. The cost survey questions were checked for reading level and were graded at the Flesch-Kincaid 5.0 grade level. During the initial data collection phase, the researcher attended to the first ten parent/guardian participants completing the survey questions and, determined based on user comments that the questions were clear and understandable.

Caring was measured using the Caring Professional Scale which includes two factor analytically derived subscales, the compassionate healer and the competent practitioner (Swanson, 2002). Cronbach’s alpha reliability for internal consistency (Appendix F) for the total scale were $r = .92$ and $r = .86$ for each of the subscales. These results were consistent with previous studies when this tool was utilized to measure caring for multiple providers with Cronbach’s alpha reliabilities ranging from $r = .74$ for advanced practice nurses, $r = .97$ for nurses, and $r = .96$ for physicians (Swanson, 1999).

Family-centered care was measured using the Measure of Processes of Care- 20 Item Scale which includes five subscales representing the fundamental components of family-centered care. Cronbach’s alpha reliability for internal consistency (Appendix F) for the subscales ranged from $r = .80$ to $r = .92$ and the total scale reliability was $r = .95$. These alphas indicate strong internal consistency. This is better than other studies’
reports of Cronbach’s alpha reliability coefficients ranging from $r = .63$ to $r = .92$ (King, King, and Rosenbaum, 2004; Trute and Hiebert-Murphy, 2007).

The correlation between the Caring Professional Scale and the MPOC-20 Item Scale was $r = .62$; and correlations between subscales ranged from $r = .40$ to $r = .68$ (all significant at $p < .001$). These correlations suggest that while the two measures share a similar underlying construct; there remain unique differences between caring and family-centeredness.

Research Questions’ Results

1. What are the differences in cost to parents/guardians when care is provided via telemedicine compared to traditional face-to-face care?

Traditional Compared to Telemedicine.

The Family Cost Survey was developed for this study about family out-of-pocket costs related to pediatric specialty clinic visits for their CSHCN. This survey included questions about travel, special transportation, loss of wages, child care, food, and lodging costs related to the CSHCN’s visit to the CMS clinical site for traditional and telemedicine visits. The survey also included questions regarding the anticipated cost to the parent/guardian for clinical visits with specialists if telemedicine was unavailable. Parents in the telemedicine group also were asked to identify where they would receive pediatric specialty care and project the out-of-pocket costs for a pediatric specialty visit if telemedicine was not available at their local CMS clinical site. Descriptive statistics, $t$
tests and chi squares were used to describe and analyze the differences in cost to the parent/guardians in respect to pediatric specialty visits.

Table 6 presents the results examining the differences in costs to parents/guardians when their CSHCN receive care at their local CMS clinical site through traditional face-to-face visits compared to telemedicine. The majority of parents in both groups (traditional = 94.5%, telemedicine = 97.3%) traveled using their personal cars with a significant difference noted in respect to families requiring special transportation such as wheelchair vans or ambulance (traditional = 19.1%, telemedicine = 8.0%). With respect to special transportation, only one parent/guardian in the traditional group reported an out-of-pocket cost ($50.) based on special transportation needs. Travel miles reported to and from the clinics were similar across both groups (traditional, $M = 33.14, SD = 26.81$; telemedicine, $M = 32.25, SD = 28.04$). Slightly less than half of each group (traditional = 40.9%, telemedicine = 40.2%) reported family members missing work with reported loss of work hours (traditional, $M = 2.24, SD = 3.3$; telemedicine, $M = 2.33, SD = 3.41$) and wages (traditional, $M = $27.78, $SD = 46.52$; telemedicine, $M = $28.06, $SD = 52.16$) being similar across both groups. Child care costs were reported as necessary by 13.6% of the traditional and 16.1% of the telemedicine group with no significant difference in terms of cost between the groups. Few parents reported lodging costs (traditional = 5.5%, telemedicine = 5.4%) across both groups with no significant cost difference. Other costs associated with the pediatric specialty clinic visit were reported by 16.4% and 14.3% of the parents/guardians in the traditional and telemedicine respectively with no significant difference in cost. Total family out-of-pocket costs
(traditional, $M = 53.10, SD = 58.62$; telemedicine, $M = 54.15, SD = 67.63$) were also similar across both groups.

The family cost variables of both groups were compared using $t$ test for the continuous variable and chi square ($\chi^2$) for the categorical variables. Other than the number of families reporting the need for special transportation, there were no significant differences in costs between the groups based on mode of care provision.
<table>
<thead>
<tr>
<th>Family Cost/ Impact</th>
<th>Traditional Total (n = 110)</th>
<th>Telemedicine Total (n = 112)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel Miles</td>
<td>33.14 (26.81)</td>
<td>32.25 (28.04)</td>
<td>0.238</td>
<td>.812</td>
</tr>
<tr>
<td>Travel Cost (dollars)</td>
<td>18.73 (17.19)</td>
<td>17.88 (15.56)</td>
<td>0.387</td>
<td>.699</td>
</tr>
<tr>
<td>Work Hours Loss</td>
<td>2.24 (3.30)</td>
<td>2.33 (3.41)</td>
<td>-0.189</td>
<td>.851</td>
</tr>
<tr>
<td>Wages Loss (dollars)</td>
<td>27.78 (46.52)</td>
<td>28.06 (52.16)</td>
<td>-0.042</td>
<td>.966</td>
</tr>
<tr>
<td>Child Care Cost (dollars)</td>
<td>3.47 (19.70)</td>
<td>3.92 (11.67)</td>
<td>-0.208</td>
<td>.835</td>
</tr>
<tr>
<td>Lodging Cost (dollars)</td>
<td>1.02 (4.77)</td>
<td>1.99 (14.56)</td>
<td>-0.666</td>
<td>.506</td>
</tr>
<tr>
<td>Other Costs (dollars)</td>
<td>2.16 (6.87)</td>
<td>2.15 (7.72)</td>
<td>0.005</td>
<td>.996</td>
</tr>
<tr>
<td>Total Family Out-of-Pocket Cost (dollars)</td>
<td>53.10 (58.62)</td>
<td>54.15 (67.63)</td>
<td>-0.123</td>
<td>.902</td>
</tr>
</tbody>
</table>
Table 6 (continued)

<table>
<thead>
<tr>
<th>Family Cost/ Impact</th>
<th>Traditional Total (n = 110)</th>
<th>Telemedicine Total (n = 112)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. (%)</td>
<td>No. (%)</td>
</tr>
<tr>
<td>Travel using Personal Car</td>
<td>104 (94.5)</td>
<td>109 (97.3)</td>
</tr>
<tr>
<td>Special Transport Necessary</td>
<td>21 (19.1)</td>
<td>9 (8.0)</td>
</tr>
<tr>
<td>Family Member(s) Missed Work</td>
<td>45 (40.9)</td>
<td>45 (40.2)</td>
</tr>
<tr>
<td>Number of Family Missed Work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>39 (35.5)</td>
<td>43 (38.4)</td>
</tr>
<tr>
<td>Two</td>
<td>6 (5.5)</td>
<td>3 (2.7)</td>
</tr>
<tr>
<td>Child Care Necessary</td>
<td>15 (13.6)</td>
<td>18 (16.1)</td>
</tr>
<tr>
<td>Lodging Required</td>
<td>6 (5.5)</td>
<td>6 (5.4)</td>
</tr>
<tr>
<td>Other Additional Costs = Yes</td>
<td>18 (16.4)</td>
<td>16 (14.3)</td>
</tr>
</tbody>
</table>

Telemedicine costs compared to projected costs were telemedicine not available.

Table 7 illustrates the results examining the differences in costs to parents/guardians in the telemedicine group when their CSHCN receives pediatric specialty care at their local CMS clinical site through telemedicine compared to the projected costs were telemedicine not available locally. The comparison is identified as ‘telemedicine’ and ‘telemedicine not available’. The only similarities between the responses were that both reported using their personal car for travel (telemedicine = 97.3%, telemedicine not available = 98.2%) and requiring special transportation (telemedicine = 8.0%,...
telemedicine not available = 6.3%) to and from the clinical visit. There were significant differences found across all other family cost variables. Travel miles reported to and from the clinics were significantly different (telemedicine, $M = 32.25, SD = 28.04$; telemedicine not available, $M = 155.45, SD = 76.72$) as was the cost of travel (telemedicine, $M = $17.88, $SD = 15.56$; telemedicine not available, $M = $90.28, $SD = 47.96$) Family members were reported to have missed work 40.2% of the time for a telemedicine visit compared to 58.9% had telemedicine not been available. The reported loss of work hours was greater had telemedicine not been available (telemedicine, $M = 2.33, SD = 3.41$; telemedicine not available, $M = 5.3, SD = 5.45$) and also, wages lost per family were greater (telemedicine, $M = $28.06, $SD = 52.16$; telemedicine not available, $M = $69.48, $SD = 110.20$). Child care was reported as necessary by 16.1% for telemedicine and 28.6% for telemedicine not available with significant differences in child care costs (telemedicine, $M = $3.92, $SD = 11.67$; telemedicine not available, $M = $8.73, $SD = 18.23$). Parents/ guardians reported lodging needs 5.4% of the time for telemedicine, but 24.1% of the time if telemedicine was not available. The associated cost of lodging was $M = $1.99 ($SD = 14.56$) and $M = $19.51 ($SD = 48.35$) when telemedicine was not available. Parent/ guardians more frequently reported other out-of-pocket costs if the telemedicine was not available at their local clinic site with significant increases reported in these other costs (telemedicine, $M = $2.15, $SD = 7.72$; telemedicine not available, $M = $10.01, $SD = 22.03$). Total family out-of-pocket costs reported were significantly higher when telemedicine was not available at the local CMS clinical site with significant differences noted (telemedicine, $M = $54.15, $SD = 67.63$; telemedicine not available, $M = $197.24, $SD = 159.42$). In summary, family costs in every area
examined were reported by parents/guardians more frequently and reported to be significantly higher for their families if telemedicine were not available within their communities.

Table 7

<table>
<thead>
<tr>
<th>Family Cost/Impact</th>
<th>Telemedicine Total (n = 112)</th>
<th>Telemedicine Not Available Total (n = 112)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel Miles</td>
<td>32.25 (28.04)</td>
<td>155.45 (76.72)</td>
<td>16.33</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Travel Cost (dollars)</td>
<td>17.88 (15.56)</td>
<td>90.28 (47.96)</td>
<td>15.12</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Work Hours Loss</td>
<td>2.33 (3.41)</td>
<td>5.30 (5.45)</td>
<td>7.11</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Wages Loss (dollars)</td>
<td>28.06 (52.16)</td>
<td>69.48 (110.20)</td>
<td>5.61</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Child Care Cost (dollars)</td>
<td>3.92 (11.67)</td>
<td>8.73 (18.23)</td>
<td>3.30</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Lodging Cost (dollars)</td>
<td>1.99 (14.56)</td>
<td>19.51 (48.35)</td>
<td>3.93</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Other Costs (dollars)</td>
<td>2.15 (7.72)</td>
<td>10.01 (22.03)</td>
<td>3.98</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Total Family Cost (dollars)</td>
<td>54.15 (67.63)</td>
<td>197.24 (159.42)</td>
<td>10.71</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Table 7- (continued)

<table>
<thead>
<tr>
<th>Family Cost/ Impact</th>
<th>Telemedicine Total (n = 112)</th>
<th>Telemedicine Not Available Total (n = 112)</th>
<th>$\chi^2$</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. (%)</td>
<td>No. (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel using Personal Car</td>
<td>109 (97.3)</td>
<td>110 (98.2)</td>
<td>0.025</td>
<td>.651</td>
</tr>
<tr>
<td>Special Transport Necessary</td>
<td>9 (8.0)</td>
<td>7 (6.3)</td>
<td>0.269</td>
<td>.604</td>
</tr>
<tr>
<td>Family Missed Work</td>
<td>45 (40.2)</td>
<td>66 (58.9)</td>
<td>7.876</td>
<td>.005</td>
</tr>
<tr>
<td>Number of Family Missed Work</td>
<td>46 (41.1)</td>
<td>66 (58.9)</td>
<td>9.612</td>
<td>.008</td>
</tr>
<tr>
<td>One</td>
<td>43 (38.4)</td>
<td>55 (49.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>3 (2.7)</td>
<td>11 (9.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Care Necessary</td>
<td>18 (16.1)</td>
<td>32 (28.6)</td>
<td>5.046</td>
<td>.025</td>
</tr>
<tr>
<td>Lodging Required</td>
<td>6 (5.4)</td>
<td>27 (24.1)</td>
<td>16.469</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Other Additional Costs = Yes</td>
<td>16 (14.3)</td>
<td>34 (30.4)</td>
<td>8.342</td>
<td>.004</td>
</tr>
</tbody>
</table>

2. What are the differences in parents/guardians perceptions of the system of care as caring when care is delivered utilizing telemedicine compared to traditional face-to-face care?

The Caring Professional Scale was used to determine parents/guardian’s perception of the care their CSHCN received as caring. Descriptive statistics as well as Analysis of Variance (ANOVA) were used to analyze this question. Table 8 presents
these results. Items in the Caring Professional Scale are scored on a 5-point Likert scale. The mean score for the compassionate healer subscale was 36.44 ($SD = 5.2$) and 37.12 ($SD = 4.43$) respectively for the traditional and telemedicine groups. The mean score for the competent practitioner subscale was 32.86 ($SD = 3.38$) for the traditional group, and 33.39 ($SD = 3.15$) for the telemedicine group. The mean score for caring (total) was 69.33 ($SD = 8.08$) and 70.51 ($SD = 7.21$) respectively for the traditional and telemedicine groups.

The traditional and telemedicine groups were compared using Analysis of Variance (ANOVA) to determine if there were significant differences between the two groups. Results from a two-way ANOVA (delivery mode by clinic type), $F (1, 218) = 0.099, p = .753$, determined that clinic type (nutrition or neurology) had no interaction effect on perception of caring between the traditional and telemedicine groups. Results from the ANOVA, $F (1, 220) = 1.31, p = .253$, indicated that there were no significant differences in perception of system of care and specifically the health care providers as caring. This result also was consistent in respect to the competent practitioner and compassionate healer subscales.
Table 8

Comparisons of Traditional versus Telemedicine on Parental Perceptions of Provider Caring

<table>
<thead>
<tr>
<th>Measure</th>
<th>M (SD)</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring (CPS Total)</td>
<td>1.313</td>
<td>.253</td>
<td></td>
</tr>
<tr>
<td>Possible Range (15 - 225)</td>
<td>1.313</td>
<td>.253</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>69.33 (8.08)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>70.51 (7.21)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compassionate Healer</td>
<td>1.086</td>
<td>.298</td>
<td></td>
</tr>
<tr>
<td>Possible Range (8 - 40)</td>
<td>1.086</td>
<td>.298</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>36.44 (5.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>37.12 (4.43)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competent Practitioner</td>
<td>1.457</td>
<td>.229</td>
<td></td>
</tr>
<tr>
<td>Possible Range (7 – 35)</td>
<td>1.457</td>
<td>.229</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>32.86 (3.38)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>33.39 (3.15)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. What are the differences in parents/guardians perceptions of the system of care as family-centered care when care is delivered utilizing telemedicine compared to traditional face-to-face care?

The Measure of Processes of Care- 20 Item Scale (MPOC-20) was used to determine parents/ guardian’s perception of the system of care as family-centered. Items in the MPOC- 20 Scale are scored on a 7-point Likert scale. Descriptive statistics as well as Analysis of Variance (ANOVA) were used to analyze this question. Table 8 presents
these results. The mean scores for the subscales ranged from the lowest for both groups on the Providing General Information Subscale with a mean of 4.65 (SD = 1.91) and mean of 5.36 (SD = 1.89) to the highest mean scores on the Respectful and Supportive Care Subscale with a mean of 6.05 (SD = 1.05) and mean of 6.33 (SD = 0.94) scores respectively for the traditional and telemedicine groups. The mean score for family-centered care (total) was 5.47 (SD = 1.29) and 5.96 (SD = 1.16) respectively for the traditional and telemedicine groups. The mean scores were higher across all subscales and the total scale for the telemedicine group as compared to the traditional group.

The traditional and telemedicine groups were further compared using Analysis of Variance (ANOVA) to determine if there were significant differences between the two groups. Results from a two-way ANOVA (delivery mode by clinic type), $F(1, 217) = .036, p = .85$, determined that clinic type (nutrition or neurology) had no interaction effect on the group perception of the system of care as family-centered. Results from the ANOVA, $F(1, 219) = 8.96, p = .003$, indicated that there were significant differences in parent/guardian’s perception of the system of care as family-centered between the traditional and telemedicine groups. This result also was consistent in respect to the subscales for each domain of family-centered care. The most significant difference between the groups was for the Coordinated and Comprehensive Care Subscale, $F(1, 220) = 11.61, p = .001$. In terms of perceptions of family-centered care, there were significant differences between the groups with parents/guardians in the telemedicine group reporting more positive perceptions of the system of care as family-centered compared to families receiving traditional face-to-face pediatric specialty care.
### Table 9

Family-Centered Care: Measure of Processes of Care – 20 Item Scale (MPOC-20) Results

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD)</th>
<th>F Value</th>
<th>p Value</th>
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</thead>
<tbody>
<tr>
<td><strong>Family Centered Care Total</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPOC-20 Total Scale</td>
<td>8.96</td>
<td>.003</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>5.47 (1.29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>5.96 (1.16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Domains of Family-Centered Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enabling and Partnership</td>
<td>3.76</td>
<td>.054</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>5.77 (1.52)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>6.13 (1.20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing General Information</td>
<td>7.91</td>
<td>.005</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>4.65 (1.91)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>5.36 (1.89)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing Specific Information about Child</td>
<td>6.05</td>
<td>.015</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>5.22 (1.83)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>5.79 (1.56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coordinated and Comprehensive Care</td>
<td>11.61</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>5.73 (1.31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>6.27 (1.03)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respectful and Supportive Care</td>
<td>4.37</td>
<td>.003</td>
<td></td>
</tr>
<tr>
<td>Traditional</td>
<td>6.05 ± 1.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telemedicine</td>
<td>6.33 ± 0.94</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER V

Discussion

This research project was designed to further our understanding of costs, caring, and family-centered care from the perspective of parents/guardians of Children with Special Health Care Needs (CSHCN) when pediatric specialty care was provided via telemedicine technology compared to traditional face-to-face care. Three different conceptual frameworks were utilized to examine the constructs of cost, caring and family-centered care. A cost-minimization framework was used to guide the cost analysis focusing on identifying and determining differences in costs for families (Gold, et al, 1996; Muennig, 2008) using a Cost Survey Tool developed for this research project. The theoretical framework for caring guiding this research was the Swanson Caring Theory (Swanson, 1991) using the Caring Professional Scale (Swanson, 1998, 2000) to measure the therapeutic processes of caring for the purpose of exploring the differences in the family’s perceptions of the system of care as caring at the respective pediatric specialty clinic visits. The framework for family-centered care was based on the Maternal Child Health Bureau definition and guiding principles utilizing the Measure of Processes of Care – 20 Item Scale (MPOC-20) to measure the domains of family-centered care examining differences between the groups.

Review of the literature substantiated the challenges faced by families of CSHCN in terms of financial burdens and access to pediatric specialty care which were compounded when faced with issues such as poverty and residing in rural, medically underserved areas. The literature findings reinforce the importance of building systems
of care for CSHCN and their families which are construed by the recipients as caring and family-centered. This includes building family-provider partnerships and optimizing both satisfaction and health outcomes for CSHCN and their families. Telemedicine is increasingly being utilized as a mode of health care delivery to promote access to care for CSHCN and their families in these communities. Yet, there is a lack of research about telemedicine compared to traditional face-to-face care in terms of family financial burden/cost, caring, and family-centered care for CSHCN and their families.

This chapter presents a discussion and interpretation of the research findings in respect to the specific questions organized around the three major constructs: cost, caring, and family-centered care. The next section will discuss study limitations as well as implications for nursing practice, program planning, and policy. The following section will discuss recommendations for further research as well as a summary.

Cost

1. What are the differences in cost to parents/guardians when care is provided via telemedicine compared to traditional face-to-face care?

Cost was examined from a cost-minimization analysis framework focusing on the cost difference from the perspective of the family of the CSHCN measuring both direct and indirect costs recognized by the family but not evident to those outside the family or community health providers. Results indicated no differences in costs reported by parents when pediatric specialty care was provided by telemedicine compared to traditional face-to-face care at the local CMS clinical sites in their community.
However, families within the telemedicine group reported significantly greater anticipated costs for pediatric specialty care visits if telemedicine had not been available locally. If telemedicine had not been available, parents anticipated significant increases in both costs and burdens to the family including increased mileage/travel, number of family members missing work, loss of wages impacting family weekly incomes, child care needs, lodging, and additional other costs associated with the specialty visit.

The most significant increases in costs were noted in travel costs with mean costs increasing from $17.88 (SD = 15.56) per visit to $90.28 (SD = 47.96) per visit and the total family out of pocket costs increased from a mean of $54.15 (SD = 67.63) to $197.24 (SD = 159.42). Travel miles increased from a mean of 32.25 to 155.45 (SD = 76.72) miles per visit with significantly more families reporting loss of work hours from 45% to 66% and loss of wages increasing from a mean of $28.06 (SD = 52.16) to $69.48 (SD = 110.20). These additional anticipated costs and travel result in additional burdens and hardship as well as significantly impacting weekly incomes for these families with incomes < 200% of the Federal Poverty Level by virtue of their financial eligibility for this Title V program in Florida.

Results indicate a significantly reduced financial burden for families of CSHCN when pediatric specialty care is available through telemedicine in their local communities. Previous studies were sparse and limited in scope in regards to family costs related to pediatric specialty visits for CSHCN through traditional compared to telemedicine visits. These included a single case cost study for a family of a CSHCN in Georgia reporting a cost savings of $72.19 for a single visit (Karp et al., 2000). The Indian Health Service reported a telepsychiatry case experience which compared a single case study and
reported a $200. cost savings based on reduced cost for specialist travel (Savin et al., 2006). The Queensland pediatric experience suggested that telemedicine reduced family burdens with decreased travel time, out of pocket costs, and lost time from work (Williams and Smith, 2004; Smith et al, 2003). Results from an Iowa study with a school-based telemedicine program examined cost data for 83 families and reported family out-of-pocket cost savings (mileage and meals only) of $125 per visit (Harper, 2006). The results of this study further substantiate and strengthen these previous findings indicating that telemedicine can significantly reduce family costs and burdens in providing much needed access to health care, particularly for vulnerable populations such as families of CSHCN.

Caring

2. What are the differences in parents/guardians perceptions of the system of care as caring when care is delivered utilizing telemedicine compared to traditional face-to-face care?

Caring was examined from the framework of the Swanson Caring Theory which postulates that caring involves both compassion and competence in the delivery of health care (Swanson, 2000). Results of this study indicated that there were no significant differences in parents’/ guardians’ perceptions of the system of care, and specifically of the health care providers, as caring when care was delivered utilizing telemedicine compared to traditional face-to-face care. This was true for the total caring scores as well as for the subscales compassionate healer and competent practitioners. The mean scores
for all scale items, subscales, and total CPS scale were all above four indicating that families in both traditional and telemedicine groups perceived the care as ‘mostly’ caring.

Previous research regarding telemedicine and perceptions of personal and human connections or caring in respect to families of CSHCN or other populations is sparse. These earlier studies focused on patient/caregiver and provider satisfaction with telemedicine and indicated that patients, families and caregivers are positive about and satisfied with telemedicine (Harrison et al., 2006; Karp et al., 2000; Marcin et al., 2004; McConnochie et al., 2005; Nesbitt et al., 2005; Thurmond et al., 2002; Williams et al., 2001). While satisfaction is proven important to health outcomes, this current study examined the human connection of caring. Caring is a concept central to the delivery of health care with caring interventions recognized as impacting health outcomes for the recipients of care (Swanson, 1999, 2000; Swanson and Wojnar, 2004).

The Caring Professional Scale scores overall were positive in terms of parent/guardian perceptions of care as caring. These results were consistent with results in other studies done with maternal-child health populations using this scale (Swanson, 1999, 2000). The results of this study determined that there are no significant differences in terms of parent/guardian’s perception of care as caring when pediatric specialty care is delivered utilizing telemedicine.

The instructions for the completion of the Caring Professional scale ask the participant to refer to their family’s experience and their perception of care during their most recent clinical visit. The majority of the respondents in each group (traditional 83.6%, telemedicine 90.2%) completed the survey within 30 days of the clinical visit and perceived the care as ‘mostly’ caring. This raises questions about whether it is the
tendency of responders to rate their current providers as caring, particularly when asked soon after clinical visits which also may explain why there are no differences between the groups in respect to perceptions of care as caring. It is possible that caring behaviors may be rated higher by respondents by virtue of the fact that they are simply present so that any indications of caring are rated high. Furthermore, it is possible that caring as a variable ought to be measured as ‘present versus absent’ or ‘criterion versus norm’ referenced. The providers were aware that research was being conducted including surveys which may have impacted provider care and interaction with families during these visits prompting more caring behaviors during the period of data collection. Combined with a possible tendency to rate providers as caring, the presence of a research team may have impacted results prompting ‘mostly’ caring behaviors among both groups as a potential explanation for no differences in caring behaviors. Together, this suggests the need to further examine the use of this scale related to perceptions of care as caring over time versus at a specific point in time.

Family-Centered Care

3. What are the differences in parents/guardians perceptions of the system of care as family-centered care when care is delivered utilizing telemedicine compared to traditional face-to-face care?

Family-centered care was examined from the framework of the Maternal Child Health Bureau definition inclusive of the guiding principles of family centered care: families and professionals working together in the best interest of the child, with the child
assuming a role in this partnership as they grow; respect of skills and expertise brought to
the relationship from both families and professionals; trust, communication and sharing
of information, decision making together, and a willingness to negotiate (Dendoba et al.,
2006). The Measure of Processes of Care- 20 Item Scale was used to measure the five
domains of family-centered care: enabling and partnership, providing general
information, providing specific information about the child, coordinated and
comprehensive care, and respectful and supportive care.

The results of this study indicated that parents/ guardians perceive the system of care
as significantly more family-centered when care is delivered utilizing telemedicine
compared to traditional face-to-face care across all domains of family-centered care. As
noted before when discussing the construct of caring, there is a documented paucity of
research related to telemedicine and human connections including family-centered care.
The majority of the research articles relative to telemedicine and particularly to families
of CSHCN relate to patient/ family satisfaction noting consistently that families, patients,
and caregivers are satisfied with telemedicine (Harrison et al., 2006; Karp et al., 2000;
Marcin et al., 2004; McConnochie et al., 2005; Nesbitt et al., 2005; Thurmond et al.,
2002; Williams et al., 2001). Literature reviews have reinforced the lack of research in
regards to telemedicine particular to the human connections and connecting with families
(Siden et al., 2001; Thurmond and Boyle, 2002).

The results of this study are significant because they indicate that families do perceive
systems of care inclusive of telemedicine as family-centered. In fact, while parent/
guardians in both groups reported that they perceived the system of care as family-
centered, the scores were significantly higher among the parent/ guardians in the
telemedicine group compared to traditional face-to-face care across all domains of family-centered care. The most significant differences in scores were identified in the Coordinated and Comprehensive Care, Respectful and Supportive Care, and Providing General Information domains of family-centered care. The lowest scores consistently for both groups were identified in the Providing General Information and Providing Specific Information about the Child domains of family-centered care.

These results with significantly higher scores for family-centered care under the telemedicine condition render further investigation. The provider groups were consistent across traditional and telemedicine clinics within the same overall system of care for CSHCN in the Southeast region of Florida. One primary difference observed is that, within the telemedicine clinics, there is consistently a Registered Nurse (or Advanced Registered Nurse Practitioner) with the family during the telemedicine sessions. While traditional clinics may have a Registered Nurse present, they are not consistently with the family throughout the clinical sessions. In contrast, there may be a Licensed Practical Nurse or Medical Assistant with the family and pediatric specialty provider in traditional face-to-face clinics. This warrants further study not only in respect to telemedicine but the possible impact of the Registered Nurse role in terms of effect on family-centered care across the system of care including the pediatric specialty clinics for CSHCN.

There are general telemedicine protocols as well as specific telemedicine protocols for each pediatric specialty clinic. The Registered Nurse in the telemedicine clinic is responsible for assuring compliance with the protocol. These protocols delineate responsibilities for the Registered Nurse presenter as well as for the specialty provider offsite. Because the specialty provider is not physically present in the telemedicine
clinics, there is an enhanced focus on assuring the family receives and understands the information being provided from the specialty provider at the tertiary site. There is a sense of ‘intentional presence’ as providers are more apt to concentrate and focus on the CSHCN and family during the ‘live on camera’ telemedicine sessions. The Registered Nurse onsite with the family reinforces the information and is responsible for assuring that this information also is provided to the primary care provider and medical home for each CSHCN. These protocols focus on many of the areas that guide family-centered care including providing general information and specific information about their CSHCN as well as assuring coordinated and comprehensive care. The additional clinical protocols combined with the enhanced role of the Registered Nurse in this clinic may be contributing factors to the more positive perceptions of the system of care as family-centered reported by families in the telemedicine group.

The instructions for the MPOC-20 Item Scale refer to the family’s experience and their perception of care over the past year in contrast to the Caring Professional Scale which refers families to their most recent clinical visit. This may be a factor in explaining why there were no differences in family’s perceptions of the care and the provider as caring compared to the significant differences between the groups related to their perceptions of family-centered care. Perceptions of care as caring or family-centered may be considerably different on one specific occasion compared to perceptions of multiple experiences over time which may elicit more variance in family perceptions of the care as caring or family-centered. This warrants further research with both tools examining the relationship between time and perceptions of care.
Previous research studies do not address the impact of telemedicine on systems of care in terms of the impact on family’s perception of the care as family-centered. These results go beyond the previously reported findings about satisfaction with telemedicine. The evidence from this study provides support that pediatric specialty care can be delivered by telemedicine to vulnerable populations of CSHCN and their families, and is perceived as family-centered care. In fact, the findings in this study indicate a need to look further at the systems of care to determine why parent/guardians in the telemedicine group perceived the care as more family-centered than parent/guardians of CSHCN receiving pediatric specialty care in a traditional face-to-face clinic visit.

Study Limitations

This study was conducted with a convenience sample drawn from parents’/guardians’ of CSHCN in Southeast Florida, all of whom were enrolled in the area office Children’s Medical Services Program. Financial eligibility for this program is limited to those families who meet income requirements less than 200% of the Federal Poverty Level which did limit this sample to families from these socioeconomic strata. In addition, the overall sample was comprised of 79% minorities including 25.7% Hispanic, 45% Black, and 9% Haitian Black. Inclusion criteria were that the participant had to be able to read and speak English. This limited the sample of Hispanics and Haitians by excluding those who spoke and read Spanish and Creole respectively. Both the Caring Professional Scale and the Measure of Processes of Care- 20 Item Scale had been tested with and utilized primarily in samples with non-minority and middle-class economic
backgrounds. However, the psychometrics for the scales proved satisfactory for this study sample.

The cost survey questions developed for this study were not pilot tested prior to the study. It would have been best to have pilot tested the survey booklet with 3 - 4 parents of CSHCN to check for clarity and understandability before beginning data collection.

An additional limitation is that, as the Principal Investigator, I am also an employee of Children’s Medical Services in an administrative nursing position within the Southeast Region primarily based in Ft. Lauderdale. Primary responsibilities of this position are administrative with no clinical duties at any of the three sites. As the principal investigator, I did collect data and there is the possibility that this could have biased the responses in a positive or even possibly a negative way. In an effort to reduce this possibility, a research assistant was hired and assisted in data collection particularly at the Ft. Lauderdale clinic site.

Implications of the Study

The results of this study indicate that telemedicine is a viable and amenable option for families of CSHCN providing access to much needed pediatric specialty care in a caring and family-centered manner while reducing financial burdens and costs for the family. These findings present significant implications for education and practice.

Educational programs for health care professionals need to incorporate telemedicine into their curriculums preparing our current and future work force to embrace the technology. Protocols and standards need to be further developed for more
rapid expansion of telemedicine programs incorporating models of excellence that can be replicated. In an effort to further strengthen family-centered care and caring, families and providers need to partner in the development of educational programs and materials.

As telemedicine programs are implemented for vulnerable populations such as CSHCN and their families, leaders and practitioners need to consider the domains of family-centered care and caring as well as the cost burdens to families of CSHCN into the clinical planning process. For example, virtual specialty clinics could be coordinated across several different localities with core groups of specialty providers at ‘base’ sites and families in their local communities at rural health centers, a local CMS clinic, nurse managed health centers, or potentially their own homes. Appointments could be scheduled with multiple specialty providers at different sites for a CSHCN and family at the remote site during one virtual clinic exam session. This could reduce costs and burdens for the family by consolidating several specialty appointments into one session. In addition, program planners and administrators need to further examine and consider the role and impact of the Registered Nurse within systems of care, particularly for vulnerable populations such as CSHCN and their families.

The findings of this study indicate that the use of technology, specifically telemedicine, did not diminish the human connection, caring, and this has implications for all kinds of health care technologies. For example, potential technologies could range from video teleconferencing ‘home visits’ through computer technology connecting families to a community health nurse, medical home, pediatric specialist, or even back to the Neonatal or Pediatric Intensive Care Unit for a follow-up; telemedicine based in pediatrician offices connecting to schools and day cares perhaps conducting
‘sick’ visits; to the use of twitter or other social networking tools to provide health information or health reminders to a child with Juvenile Diabetes. The possibilities for the use of technology in health care are vast and have not been tapped to their full potential.

While telemedicine is available in pilot and demonstration programs particularly in rural areas, program planning needs to consider the implementation of telemedicine in major metropolitan and other areas. There are access issues for families of CSHCN in urban and other areas including lack of special transportation modalities available through public transit and urban congestion issues which can cause travel to be particularly burdensome and costly for families of CSHCN. Another option for program planners to consider is connecting specialists from tertiary centers to medical home providers utilizing telemedicine particularly for vulnerable populations such as CSHCN. Telemedicine has potential to bring the much needed care to the CSHCN in their home community by breaking down some of the known barriers to care such as access, cost, and reducing hardship for these families while promoting coordination of care between the specialists at the tertiary center and primary care/ medical home providers in the community.

Currently, insurance companies do not cover telemedicine consistently across programs or states in the United States. Florida currently has a Medicaid waiver for CSHCN enrolled in CMS in specific counties allowing for Medicaid reimbursement for telemedicine visits. Further work needs to be done at the policy level to support insurance reimbursement for telemedicine visits in order to assure sustainability of programs.
Recommendations for Future Research

The results of this study indicate that parents/guardians in the telemedicine groups perceived care as significantly more family-centered than parents/guardians receiving traditional face-to-face care from the same provider groups. This warrants further study to examine how the dynamics and specifics of the telemedicine visits impacted family perceptions in a positive direction. The role of the Registered Nurse in telemedicine, as liaison for family and community providers at remote sites, needs to be further examined relative to both family-centered care and caring. This could lead to development of further interventions for these pediatric specialty clinics to promote a more consistent, positive caring and family-centered environment and system of care for CSHCN and their families.

Future research also needs to use the Caring Professional Scale and MPOC-20 Scale for diverse populations including translation and testing of both instruments in Spanish, Creole, and other languages depending on the specific communities. It would also be important to replicate or conduct future research in this area with a different population of families from other backgrounds/regions of the country or internationally to provide us with more knowledge on family perceptions of care using telemedicine compared to traditional face-to-face care. The question could be raised about whether the introduction and presence of telemedicine technology influences perceptions of care. These issues need to be further explored in future research.

Summary

In summary, this research study expands our knowledge and understanding of family costs/burdens and family perceptions of pediatric specialty care provided to their
CSHCN related to caring and family-centered care with telemedicine compared to traditional face-to-face care. Findings indicated that costs and financial burdens for families are anticipated to significantly increase if telemedicine for pediatric specialty care was not available in their local communities. If telemedicine was not available, there was a four-fold anticipated increase in total family costs averaging $197.24 per visit or $1,183.44 for an average of six pediatric specialty visits per year. This is a burden for economically disadvantaged families with incomes of less than 200% of the Federal Poverty Level.

Findings also indicate that there are no significant differences in parent/guardian perceptions of the care their CSHCN received as caring between the traditional face-to-face and telemedicine groups. In contrast, parents/guardians in the telemedicine group perceived the care as significantly more family-centered compared to parents/guardians in the traditional face-to-face group across all domains of family-centered care. These results together underscore the importance of assuring and facilitating access to pediatric specialty care for CSHCN and their families. The results suggest that telemedicine can reduce family cost burden, maintain caring behaviors on the part of health care professionals, and promote caring, family-centered systems of care in local communities.

We make the assumption that technology lessens the interpersonal relationship in the health care setting. This study debunks that mindset and provides evidence that the human connection is not lost through the use of technology. In this era of health care reform, this study provides powerful evidence to support expansion of technology in the health care arena.
REFERENCES


Trute, B., & Hiebert-Murphy, D. (2007). The implications of “working alliance” for the measurement and evaluation of family-centered practice in childhood disability services. *Infants & Young Children*, 20, (2), 109 – 119. doi: 0.1097/01.IYC.0000264479.50817.4b


Appendix A

Recruitment Letter

Florida Department of Health, Children’s Medical Services
Letter to Families of Children with Special Health Care Needs

Study Title: “Systems of Care for Children with Special Health Care Needs:
Cost, Caring and Family-Centered Care”

Principal Investigator: Mary Hooshmand, M.S., R.N., Ph.D. Candidate

Date: August 10, 2009

To: Potential Research Study Participants

The Florida Department of Health, Children’s Medical Services (CMS) Program supports
research programs that focus on improving the lives of Children with Special Health Care
needs and their families. As part of this effort, we may contact families of children receiving
care from Children’s Medical Services (CMS) to participate in these types of studies.

At this time, the Florida Department of Health is supporting researchers at the University of
Miami’s School of Nursing and Health Studies in Miami, Florida. These researchers are
currently requesting volunteers to participate in a study to understand what it is like to receive
pediatric specialty services at the CMS clinic in your local community. They will be comparing
how families feel about the different types of clinics in respect to costs, caring, and family-
centered care. The parent/ legal guardian will be asked to participate in this study. The
Institutional Review Board has approved this study.

To be eligible to participate in this study, you must be the parent or legal guardian of a CMS
child enrolled in CMS for one year or more. Your child must have received more than two CMS
clinic visits, and their most recent clinic visit must be within 90 days of participation in the
study. The participating parent/ guardian must be the parent who attended the most recent
CMS clinic visit. The parent/ guardian must be able to read and/ or speak English in order to
participate in the study. The parent/ guardian participating in the study will receive a Publix gift
certificate ($20.) if they complete the interview.

If you are interested in participating in this study, please complete the enclosed participation
form and mail in the enclosed self-addressed and stamped envelope. The researcher will
contact you in the future.

4052 Bald Cypress Way
Bin A06
Tallahassee, FL 32399-1707
Phone: (850) 245-4200
Fax: (850) 488-3513
Potential Research Study Participants
Page Two
August 10, 2009

In order to assure your confidentiality, CMS is mailing this request directly to you which provides you the opportunity to volunteer to participate. If you have any questions, please contact Mary Hooshmand, Principal Investigator, at 954-801-5017.

Sincerely,

[Signature]
Phyllis J. Sloyer, R.N., Ph.D., PAHM, FAAP
Division Director
CMS Network & Related Programs

PJS/jm
Florida Department of Health, Children’s Medical Services  
Letter to Families of Children with Special Health Care Needs  

Systems of Care for Children with Special Health Care Needs:  
Cost, Caring and Family-Centered Care  

Permission to Contact  

I have received the letter from Children’s Medical Services telling us about the research study examining clinical services for Children with Special Health Care Needs. I would like to hear more about the study. I understand that this does not obligate me to participate in the study but will allow me to make an informed decision.  

Name: ____________________________  

I am the (circle one): Parent  Guardian  Other: ____________  

You may reach me at the following phone numbers:  

Home: ____________________________ Best days and times to reach me are: ____________  
Work: ____________________________ Best days and times to reach me are: ____________  
Cellular: _________________________ Best days and times to reach me are: ____________  
Other Contact Information______________________  

This information will be kept confidential by the researcher, Mary Hooshmand, and will be destroyed if you decide not to participate in the study. Please mail in the self-addressed, stamped envelope that we have provided to you. Thank you!
Appendix B

Recruitment Flyer

Systems of Care for Children with Special Health Care Needs: Cost, Caring and Family-Centered Care

VOLUNTEERS WANTED FOR A RESEARCH STUDY

Researchers from the University of Miami School of Nursing and Health Studies are currently recruiting volunteers to participate in a research study to understand what it is like to receive pediatric specialty services at the Children’s Medical Services (CMS) clinic in your local community. They will be comparing how families feel about the different types of clinics in respect to costs, caring, and family-centered care. Study participants will be asked to complete a booklet of questions and it will take approximately 30-45 minutes to complete.

To be eligible to participate in this study, you must be the parent or legal guardian of a CMS child enrolled in CMS for one year or more. Your child must have received more than two CMS clinic visits, and their most recent clinic visit must be within 90 days of participation in the study. The participating parent/guardian must be the parent that attended the most recent CMS clinic visit. The parent/guardian must be able to read and/or speak English in order to participate in the study.

There are no direct benefits for participating in the study. The knowledge gained from this study may help families in the future. The parent/guardian participating in the study will receive a Publix gift certificate ($20.) if they complete the booklet of questions.

This research study will take place at the CMS clinic sites in Ft. Lauderdale, West Palm Beach and Ft. Pierce area offices. For more information, you may contact Mary Hooshmand, Principal Investigator, at 954-801-5017.
Appendix C

Informed Consent

University of Miami
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Research Study: Systems of Care for Children with Special Health Care Needs: Cost, Caring, and Family-Centered Care

You are being asked to participate in a research study about your experiences regarding the health care services provided to your Child with Special Health Care Needs. The purpose of this research is to learn what families think about getting health care in a clinic, or getting care using telemedicine equipment.

What we are asking you to do: You will be asked to complete a booklet of questions and it will take approximately 30-45 minutes to complete. The questions ask how you feel about your child’s health care services and your family costs.

Risks and Benefits: We don’t anticipate any risk to you in this study. Questions about your child’s care and the costs may raise feelings that may make you feel uncomfortable. You may choose not to answer any questions that you do not wish to answer. The knowledge gained from this study may help families in the future. There are no direct benefits for participating in this study.

Voluntary Participation: This study is voluntary. Taking part is up to you. You can refuse to take part. You can join now and quit later. Either way it won’t affect how we treat you or your child with special health care needs.

Gift Certificate: Participants completing the booklet of questions will receive a Publix gift certificate in the amount of $20.

Privacy: You will not put your name on the booklet. Each booklet will be assigned a number. Your name will be kept confidential, and will be kept separate from your answers to questions in the booklet. A summary of findings from this study may be used in publications or presentations. Names of participants will be kept confidential by the Principal Investigator.

Who to contact for more information: If you have any questions about the study, you can contact the Principal Investigator, Mary Hooshmand, University of Miami, at 954-801-5017. If you have any questions or concerns about your rights as a research participant, you can contact the Florida Department of Health IRB at (866) 433-2775 (toll free in Florida) or (850) 245-4585 or the Human Subjects Research Office, University of Miami, at (305) 243-3195.

PARTICIPANT AGREEMENT:

This study has been explained to me. I have read and understand this consent form, all of my questions have been answered, and I agree to participate. I understand that I will be given a copy of this signed consent form.

____________________________     __________________
Signature of Participant

Date

____________________________     __________________
Signature of Researcher obtaining Consent

Date
Appendix D

Family Questionnaire Booklet
EXAVLPE

Indicate how much this event or situation happened to you.

In the past year, how well you answer the following questions will be asked. This example also shows you what your answer could mean.

The question 'How well you answer the following questions will be asked. This example also shows you what your answer could mean.' appears incorrectly 20-25 times.

The purpose of this research study is to learn what families of children with special health care needs think about getting health care.

Dear Participant,

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Approved Date 1 0

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**Directions:** Please circle the number that best describes the way you experienced your health care providers during your child’s most recent doctor visit. Then you answer these questions, we want you to think about the providers taking care of you.
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1. To obtain information, do you contact other parents, special education? 
2. To obtain information, do you contact other parents, special education?

11. Have information available to you in English? 
12. Provide opportunities for the entire family...

13. To obtain information, do you contact other parents, special education?

14. Have information available to you in English?
PART 3: COST SURVEY

Directions: We would like to know about your out-of-pocket costs related to your child's special education needs. When you answer these questions, we want you to think about your child's special education needs.

We are interested in learning about the costs for you and your family for your child's special education and about your child with special health care needs. We are interested in learning about the costs for you and your family for your child's special education needs.
6. Are there any other costs you would have if you had to take your child to this other provider? Please list them with the amount you think you might have to pay.

__________________________________________________________________________
LIFE: How much do you think you would have to pay?

Yes __________ No __________

3. Would you have had to pay for over-the-counter costs including good meals?

See page 134 for more information.
PART 4: Family Demographic Form

1. How old is your child with special health care needs?

2. Does your child have Medicaid?
   - Yes
   - No

3. Has your child been enrolled in Medicaid since birth?
   - Yes
   - No

4. What type of Medicaid coverage does your child have?
   - Standard
   - Waiver
   - Other (please specify)

5. How do you identify your child's race or ethnic background? (circle one below)
   - African American
   - Asian
   - Native American
   - Black/Unknown
   - Hispanic/Latino
   - White

6. List the health conditions for your child with special health care needs:
   - Cerebral Palsy
   - Speech Delay
   - Autism
   - Bladder/or Urinary Problems
   - Digestive Problems
   - Other (please specify)
12. Is there anything else you would like to tell us today?

11. How would you describe your educational background? Circle one below:
   a. Not enrolled
   b. Enrolled
   c. Enrolled (Current student)
   d. Graduated
   e. Graduated (Not in field)

10. How would you describe your employment status? Circle one below:
   a. Work to support family
   b. Worked full time
   c. Worked part time
   d. Self-employed
   e. Employer

9. How do you identify your race or ethnic background? Circle one below:
   a. Other
   b. Asian
   c. Black/African American
   d. Hispanic/Latino
   e. White

8. How old are you in years?

7. Which grade do you expect to have completed?

6. Which grade do you expect to be enrolled in this year?

5. Which grade do you expect to graduate from this year?

4. Which grade do you expect to graduate from this year?

3. Which grade do you expect to graduate from this year?

2. Which grade do you expect to graduate from this year?

1. Which grade do you expect to graduate from this year?
Research Study.

Thank you for your time and participation in this study. With a $20 Publix Gift Card as a thank you for your time and participation in this study, you may have all this time. If the form is complete, they will provide you with the member of the research team. They will check the form and answer any questions you may have at this time. Please return the packet to:

Dear Family Participant,

Sincerely,
### Appendix E

#### Instrument Reliability Results

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<tr>
<th>Variable</th>
<th>Cronbach alpha</th>
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<tr>
<td>Caring Professional Scale</td>
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<td>Measure of Processes of Care – 20 Item Scale</td>
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<tr>
<td>Coordinated and Comprehensive Care Subscale</td>
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<td>Respectful and Supportive Care Subscale</td>
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</table>
Appendix F

NOTIFICATION OF INSTITUTIONAL REVIEW BOARD APPROVAL

August 3, 2009

To: Mary A. Hooshmand

Protocol Title: Comparison of Telemedicine to Traditional Face-to-Face Care for Children with Special Health Care Needs: Analysis of Cost, Caring, and Family-Centered Care

DOH IRB Number: H09042

Funding Agency: Robert Wood Johnson Executive Nurse Fellow Program

Submission Type: Protocol H09042

Review Type: Expedited Review

Approval Date: August 2, 2009

Expiration Date: August 1, 2010

The Department of Health Institutional Review Board, or representative, determined your study involves no more than minimal risk and meets the criteria for expedited review. It has been granted expedited approval. The study is approved for implementation.

As a reminder, the IRB must review and approve all human subjects research protocols at intervals appropriate to the degree of risk, but not less than once per year. You are responsible for completing a continuing review application for this project at least 60 days prior to the expiration date of August 1, 2010. Action is required even if your study is closing. Failure to complete an application for continuing review at least 60 days in advance of expiration is considered non-compliance by the Department of Health, and may result in closure of the study, reporting to institutional officials, and reporting to federal regulatory authorities, and suspension of funding, if funded by DOH.

Under federal regulations, if the IRB does not approve an application to continue research prior to expiration, then authorization to continue research expires automatically and all research must stop. Federal regulations do not allow any "grace" period or allow research to continue once authorization expires (except in limited circumstances).

Investigators are required to notify the IRB in writing as soon as possible, but within 10 working days, of the occurrence of any adverse events, unanticipated problems, injuries, side effects, deaths, or problems involving risks to subjects, or deviations from federal or state regulations, or DOH policies.

The IRB has approved exactly what was submitted. Any revisions to this protocol or consent form, matter how minor, must be presented to the IRB for review and approval before implementation. Changes, except where necessary to eliminate hazard to human subjects. If a change is require
eliminate an immediate hazard, the IRB should be notified as soon as possible but no later than 10 working days.

Research records must be maintained for three years after completion of the research; if the study involves medical treatment, it is recommended that records be maintained for eight years.

If you have any questions, or if we can be of any assistance, please contact the Department of Health IRB at (850) 245-4585 or toll-free in Florida (866)-433-2775.

You may also visit our website at: http://flpublichealthethics.net/

Thank you for your cooperation with the IRB.

Sincerely,

Robert Hood, Ph.D.
Ethics and Human Research Protection Program
Assistant Director, Office of Public Health Research

Federal Wide Assurance#: 00004682
Appendix G

Expedited Approval – University of Miami Human Subject Research Office

EXPEDITED – APPROVAL
July 7, 2009

Gail McCain, Ph.D.
University of Miami
Department of Nursing

HSRO STUDY NUMBER: 20090500
STUDY TITLE: Comparison of Telemedicine to Traditional Face-to-Face Care for Children with Special Health Care Needs: Analysis of Cost, Caring, and Family-Centered Care

IRB ACTION DATE: 7/2/2009
STUDY APPROVAL EXPIRES: 7/1/2010
SPONSOR NAME: Robert Wood Johnson Executive Nurse Fellows Program
FWA: FWA00002247

On July 2, 2009, an IRB Chair approved the following items under the expedited review process.

APPROVAL INCLUDES:

New Research Protocol
Research Materials (English Versions Only)

- Informed Consent Form
- Family Questionnaire Booklet
- Recruitment Letter
- Recruitment Flyer
- Recruitment Script

NOTE: Translations of IRB approved study documents, including informed consent documents, into languages other than English must be submitted to HSRO for approval prior to use.

Note to PI: Please submit a copy of the IRB approval from the Florida Department
of Health once it is obtained via a Notification Form. Study activities with Florida Department of Health cannot be initiated until approval is granted.

A request to continue this study must be submitted to the HSRO at least 45 days before IRB approval expires. If this study does not receive continuing IRB approval prior to expiration, all research activities must cease, and it may be officially suspended or terminated.

Sincerely,

[This is a representation of an electronic record that was signed electronically and this page is the manifestation of the electronic signature]

Amanda Coltes-Rojas, MPH, CIP
Director
Regulatory Affairs & Educational Initiatives

/vc

cc: IRB File

Gail McCain
Mary Hooshmand