

EFFECTS OF MEDICAL HOME AMONG CHILDREN WITH SPECIAL HEALTH
CARE NEEDS

by

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ABSTRACT

KATHRYN ANN WILLITS. Effects of medical home among children with special health care needs (Under direction of DR. MARY NIES)

The purpose of this study was to examine the influence of having access to a medical home on the use of the emergency department, primary care office visits and the number of missed school days among children with special health care needs.

Analysis of 40,723 children, aged 0-18, from the 2005-2006 National Survey of Children with Special Health Care Needs (CSHCN) was conducted. Descriptive statistics characterize CSHCN and elements of medical home. Separate ordinal regression models were used to calculate the associations between presence of medical home, ED visits and missed school. Primary care office visits were examined using multivariate regression. The covariates were chosen using previous literature and Andersen's Behavioral Model of Health Services Use, and included, gender, age, race, ethnicity, education, functional limitation, poverty, metropolitan statistical area of residence, and insurance.

The association between medical home and emergency department (ED) visits was not statistically significant. Females, Non-Hispanic Black, CSHCN living in rural areas, and those with moderate or severe functional limitations made the greatest ED visits. Medical home was associated with more primary care office visits for CSHCN (AOR 1.60; 95% CI 1.47-1.75). Non-Hispanic Blacks and uninsured CSHCN had fewer office visits. The presence of a medical home among CSHCN was associated with eight or more missed school days (AOR 2.46; 95% CI 1.46-3.16).

The implications of this study may serve to point out that the services included in the current model of medical home are not serving those children with special needs who are most vulnerable in the areas of fragmented care.

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TABLE OF CONTENTS

LIST OF TABLES	viii
LIST OF FIGURES	ix
LIST OF ABBREVIATIONS	x
CHAPTER 1: INTRODUCTION	1
Statement of Purpose	6
Hypotheses	7
Definition of Terms	9
Importance of the Study	12
CHAPTER 2: LITERATURE REVIEW	14
Enabling Factor: Medical Home	15
Predisposing Factor: Race and Ethnicity	18
Predisposing Factor: Highest Level of Education in Household	19
Predisposing Factor: Poverty Level	20
Predisposing Factor: Functional Status of Child	21
Predisposing Factor: Metropolitan Statistical Area of Residence	22
Predisposing Factor: Age and Gender of Child	23
CHAPTER 3: METHODOLOGY	24
Data Collection	25
Dependent Variables	27
Independent Variables	28
Analysis	31
Emergency Department Visits	31

	vii
Pediatric Primary Care Office Visits	32
Missed School Days	34
CHAPTER 4: RESULTS	36
Emergency Department Visits	37
Pediatric Primary Care Office Visits	38
Stratified Analysis of Medical Home and Functional Status	39
Missed School Days	41
CHAPTER 5: DISCUSSION AND CONCLUSION	43
Emergency Department Utilization	43
Pediatric Primary Care Office Visits	45
Missed School Days	50
Limitations	52
Conclusion	53
REFERENCES	58
APPENDIX A: VARIABLE CODE FOR REGRESSION ANALYSIS: 2005-2006 NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS	72

LIST OF TABLES

TABLE 1: Characteristics for Children with Special Health Care Needs and Medical Home Components	66
TABLE 2: Weighted and Unweighted Frequencies and Percentages of Emergency Department Visits (N=40,723)	67
TABLE 3: Ordered Logistic Regression Analysis of Emergency Department Visit Outcome as a Function of Predictors of Medical Home (N=36,577)	67
TABLE 4: Weighted and Unweighted Frequencies and Percentages of Pediatric Primary Care Office Visits (N=40,723)	68
TABLE 5: Logistic Regression of Pediatric Primary Care Office Visits on Medical Home Independent Variable and Confounders (N = 32,897)	68
TABLE 6: Stratified Analysis of PPC Office Visits (6 or more) on Medical home and Functional Status of Children with Special Health Care Needs	69
TABLE 7: Stratified analysis of PPC office visits (6 or more) on Medical Home and Race/ Ethnicity of Children with Special Health Care Needs	69
TABLE 8: Bivariate Analysis of Variables with Missed School Days among Children with Special Health Care Needs	70
TABLE 9: Odds Ratios (95% CI) for Missed School Days among Children with Special Health Care Needs (N = 34,375)	71

LIST OF FIGURES

FIGURE 1: Adapted from Andersen's Behavioral Model of Health Services Use 26

LIST OF ABBREVIATIONS

AAP	American Academy of Pediatrics
AMA	American Medical Association
CAHMI	Child and Adolescent Health Initiative
CMS	Centers for Medicare and Medicaid
CSHCN	Children with Special Healthcare Needs
ED	Emergency Department
EPSDT	Early Periodic Screening Diagnosis and Treatment
FPG	Federal Poverty Guidelines
FPL	Federal Poverty Level
MCHB	Maternal and Child Health Bureau
MEPS	Medical Expenditure Panel Survey
MHI	Medical Home Initiative
MSA	Metropolitan Statistical Area
NIS	National Immunization Survey
NORC	National Organization Research Council
NSCH	National Survey of Child Health
NSCSHCN	National Survey of Children with Special Healthcare Needs

CHAPTER 1: INTRODUCTION

According to the World Health Organization (WHO), health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 2003). Proper and timely health care is essential for maintaining a state of physical, social, and psychological well being. Keeping this aspect in consideration, it is essential to provide appropriate health care, and ensure access to available health care facilities. Individuals affected with chronic illness and poor health need open access to community-based services for accurate monitoring of their health conditions. Children suffering with chronic conditions, especially children with special health care needs, benefit from assistance with coordination and communication within a complex array of health services. Often, low income or under educated families are affected with inappropriate or inadequate health services (Homer, 2008; Inkelas, 2007; Pittard, 2007). Therefore, access to health care plays a critical role in health outcomes and health behaviors for the chronically ill child. The development and growth of all children requires health care professionals, as well as stakeholders, to provide holistic support and community-based service systems.

The Maternal and Child Health Bureau (MCHB) established measurement outcomes to be used for implementation and evaluation of community-based services. One of the MCHB outcomes is for children to be screened early and continuously for special needs. Children are to receive age appropriate well child visits including: vision, hearing,

developmental, behavioral, mental, oral health, and early periodic screening (Schor, 2004). Federal regulations require state Medicaid programs to set their own schedules for periodic screening and to consult with medical organizations for best practice recommendations. State Medicaid programs frequently look to the American Academy of Pediatrics (AAP) for periodicity schedules (AAP, 2005). The AAP follows the well-child periodicity schedule developed by the Committee of Practice and Ambulatory Medicine which recommends 28 visits between birth and 16 years of age (Schor, 2004).

Preventive care is an essential part of the AAP's medical home policy statement (AAP, 2002). Houtrow (2007) set out to evaluate the preventive health care CSHCN were getting. The results provide valuable insight into the increased need of CSHCN for the basic child health care services. CSHCN made a significantly higher number of PPC office visits than children without special needs (6.1 vs. 1.9 per year; $p < .001$) (Houtrow, 2007).

Over the past few decades, for children with chronic conditions, the survival rates have increased due to pharmaceutical and medical advances (Mohler-Kuo, 2009). It is unknown why the risks of chronic medical, behavioral, developmental or emotional disorders are increasing in children. It is known that CSHCN require a large amount of attention to support and health services. They are prone to behavioral problems and developmental disabilities like autism, Down syndrome, difficulty in learning, understanding or attention deficit disorder, as well as cerebral palsy, and chronic illness such as asthma, and juvenile diabetes.

The definition of CSHCN, created by the Maternal Child Health Bureau (MCHB), was not created from medical diagnoses or from specific conditions for a reason

(McPherson et al., 1998). Identifying children who are in need of special health care services and focusing on the health care and support services to satisfy their needs are the two principal objectives of the current definition of CSHCN. As per the new definition, results of the National Survey of CSHCN (NSCSHCN) demonstrated that 13.85% of children have special needs (Bloom & Freeman, 2009; Newacheck & Kim, 2005; Blumberg, Foster, Fraiser, & Skalland, 2009; Kogan, Strickland, & Newacheck, 2009).

During the last two decades, different health services provided to children have become a contentious national issue. Unfortunately, this problem still exists and is an obstacle to lack of quality of health care and cost effective, efficient service. Thus it is being subjected to extensive study and controversy (Betz, Baer, Poulsen et al., 2004). This controversy has given rise to studies that identify factors associated with accessing these costly services as well as services underrepresented by new physicians joining pediatric practice.

Research specifically focused on the utilization of urgent and emergency services as a child's primary source of care, has shown children to have poorer health outcomes (Kuhlthau, 2004; Mayer, 2004). Children who rely on emergency departments (ED) as their primary care center have a higher number of hospital readmissions, symptom persistence, and poor care coordination of care after discharge (Brousseau, Gorelik, Hoffman, & Nattinger, 2007; Flores, Fuentes, Barbot, Carter, Claudio, Lara, & McLaurin, 2002). For children with specific chronic disorders, empirical research has established that access to comprehensive and quality primary care reduces ED utilization and subsequent hospital admissions (Knapp, Madden, & Marcu, 2010; Wang, Villar, Mulligan, & Hansen, 2005; Weiss & Lonnquist, 2006). While examining populations of

children with respiratory disorders, a strong relationship has been documented among access to primary care services and decreased ED visits (Wang & Watts, 2007; Liu, Zaslauskys, & Ganz, 2008).

The need for an ongoing, comprehensive source of health care, ideally a medical home, for all children has been identified as a priority for child health policy reform at the national level (Nageswaran, Roth, Klutz-Hile, & Farel, 2006). A medical home is defined by the American Academy of Pediatrics (AAP) as a partnership approach with families to provide primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (Blumberg, Welch, Chowdhury, Upchurch, Parker, & Skalland, 2007). Medical homes were first introduced by the AAP in 1967 as a central source for the child's pediatric records and emphasized the importance of centralized medical records to CSHCN (Sia, Tonniges, Osterhus, & Taba, 2004). In 1974, the council on pediatric practice held a meeting to develop a policy statement titled "Fragmentation of Health Care Services for Children." The council noted that the, "...delays, gaps, duplications, and diffused responsibilities which characterize fragmented care are expensive, inefficient, and sometimes hazardous to health..." and that, "...implicit in these standards is a commitment to the principle that each child deserves a 'medical home (AAP, 2002).'" Efforts to establish medical homes for all children have encountered many challenges, including the existence of multiple interpretations of the concept and the lack of adequate reimbursement for services provided by physicians caring for children in a medical home. Within the medical home model of care, the pediatric primary care (PPC) office is the central location for not only healthcare, but also serves as a resource for community information and services.

The AAP proposed a new policy statement in 2002 that contained an expanded and more comprehensive definition of the medical home concept. This definition referenced seven domains of health services supporting quality care: accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-effective (AAP, 2002).

Both the AAP and American Medical Association (AMA) have called for an accepted operational definition for measuring the value of the medical home model. The AMA called for public and private insurance plans to use a single standard for qualifying a practice to be a medical home. The president of the AAP indicated that when studied in a systematic way, data would show that the medical home approach in pediatrics improves the quality of care and controls costs (Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002).

In response to research presented on adults and children, Congress stated that medical homes provide patient-centered care, leading to better health outcomes and greater patient satisfaction. The Medical Homes Act of 2007 was introduced in the Senate in the 1st session of the 110th Congress to establish a demonstration project to provide for patient-centered medical homes. The purpose was to improve the effectiveness and efficiency in providing medical assistance under the Medicaid program and child health assistance under the State Children's Health Insurance Program (Pan & Tayloe, 2009).

Statement of Purpose

The purpose of this study was to determine the associations between presence of medical home and emergency department, pediatric primary care office utilization, and number of missed school days among CSHCN. As access to health care services is affected by both internal (age, gender, race and ethnicity, functional limits of child), and external factors (lack of insurance, medical home), detailed examination of this phenomenon should be performed, and the causes must be identified for health care service use. This research also identified the limitations of present special health care services and provides the necessary suggestions that can help to improve the system, so that CSHCN can have better and easier access to receive adequate health care.

Hypotheses

Emergency Department (ED) visits were chosen as a dependent variable of interest for this study because of the trends toward inappropriate utilization, such as non-emergent use for illnesses among children. This type of ED utilization does not support the continuity of care that is the foundation of the comprehensive care the AAP envisions for medical homes. Increased ED utilization as a child's usual source of care would not be in alignment with the MCHB outcome for CSHCN to receive coordinated, ongoing, comprehensive care; therefore, this study examined the association between access to medical home and number of ED visits reported in the previous twelve months.

1. Among CSHCN, there is a direct negative relationship between presence of a medical home and frequency of emergency department visits.

Secondly, this study examined how Pediatric Primary Care (PPC) was affected by having a medical home. Well child visits, preventive care, immunizations, early periodic screening and diagnosis and treatment is essential for all children, but especially CSHCN. Further, a child's primary care provider is the source for referrals to specialists the child may need throughout her/his development. The investigator hypothesized that children with medical homes will have a greater number of office visits related to routine and preventive care requirements such as immunization schedules, lab testing and follow up requirements, and referrals necessary for specialist's visits; while those children without medical homes will have fewer office visits.

2. Among CSHCN, there is a direct positive relationship between presence of a medical home and frequency of pediatric primary care office visits.

The final main dependent variable, school attendance, examines the vital return to normalcy for the child and family, a connection to resources and socialization. The 2007 Medical Home Act states that programs increasing school attendance are one element of a medical home (S 2376 IS). Children with developmental and behavioral disorders, beginning at the age of 3 years, are served through the school system and Medicaid's Early and Periodic Screening Diagnostic and Treatment (EPSDT).

3. Among CSHCN, there is a direct negative relationship between having a medical home and the number of missed school days due to illness within the past 12 months.

Definition of Terms

Children with Special Health Care Needs: According to the Maternal Child Health Bureau, children with special health care needs are those “who have or are at increased risk of 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).

Community Based Services: The National Survey of CSHCN defined community based services such as early intervention programs, child care facilities, vocational education and rehabilitation programs, and other community programs. The MCHB has identified six core outcomes to be used for measuring progress in the implementation of community based systems of services for CSHCN.

These outcomes are also being used as performance measures for states’ Title V programs. These outcomes measure the extent to which:

1. Families of CSHCN are partners in decision-making at all levels and are satisfied with the services they receive;
2. CSHCN receives coordinated, ongoing, comprehensive care within a medical home;
3. Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
4. Children are screened early and continuously for special health care needs;
5. Community-based services are organized so families can use them easily; and

6. Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Medical Home: A medical home is defined by the AAP as having five essential elements: 1) having a usual source of care; 2) having a professional healthcare provider who knows the child; 3) receiving all referrals for specialty care; 4) receiving required help to coordinate care within the healthcare system; and 5) receiving family-centered care (AAP, 2005).

Andersen Behavioral Model: Andersen's model theorizes that health service utilization is associated with two primary factors: the societal environment, including the health services system and the general external environment factors, and the individual or population factors. Individual factors are further delineated as predisposing and enabling factors. Predisposing factors are found in the demographic and social structure aspects of a particular individual's population (Andersen, 1995).

Predisposing factors: In Andersen's Behavioral Model, predisposing factors influence a person or family to receive health care when they are in need. Predisposing factors are demographic factors such as age and gender, social structure such as education, race, ethnicity, and health benefits such as attitudes, values, and knowledge that can affect the perception of need and use of health services (Aday, Lee, & Spears et al., 1993).

Enabling factors: Enabling factors are resources for health care service use and are open to interventions. The Andersen Model suggests that enabling factors influence health care service use and are categorized into two classes. They are community enabling and health

resources such as knowledge of accessing these services and utilization of health care services (Aday et al., 1993).

Importance of the Study

This study is important because no other research using nationally representative data: the 2005-2006 National Survey of Children With Special Health Care Needs and all five criteria established for a medical home has analyzed the health care and child function outcomes of ED utilization, PPC visits and school attendance. Most previous research for CSHCN focused on access to selected components of the medical home. Over a decade ago, the Health Resources and Services Administration created a national strategy to increase the number of CSHCN with medical homes, and established the national survey to track progress in achieving that goal (HRSA, 1997). The lack of a clear definition for medical home, as well as no operational definition for clinical practice has hampered the development of medical homes for CSHCN. This research builds upon information from the 2001 NSCSHCN data and reports of health service needs. This work is important because it examines the emergency department services that are overburdened and costly. This work has the potential to provide policy makers and legislatures with the impetus to invest intellectual property and economic resources into the medical home model of care if it is proven to be cost effective and efficient. The importance of this study is that it demonstrates the significance of medical homes in the development and growth of the CSHCN holistically. This study will be beneficial to the field of public health, as this will help bring the necessary attention to current policies prevalent in providing effective insurance reimbursement for medical homes. Results of the study could help educate and inform policymakers of individual and social barriers to comprehensive care for CSHCN so that they can formulate and make new amendments in

policies to improve services. These are the significant mile stones that are planned through this research.

CHAPTER 2: LITERATURE REVIEW

This section provides a comprehensive review of the previous research done related to this particular research topic. Findings from previous research formed a platform for further research to identify factors which are associated with the barriers to using community based resources, such as a usual source of care from a primary care provider in a medical home.

For more than a decade, the objective of health professionals at both the national and state levels has been to provide a high quality system of health care services for women and children, especially for CSHCN (McPherson et al., 1998). Several studies have estimated the extent and quality of available care and unfulfilled needs for children during the past two decades. Lack of insurance, race and ethnicity, and income level are disparities in the access of health care services among CSHCN (Newacheck, Hung, & Wright, 2002; Newacheck, McManus, Fox, Hung, & Halfon, 2000). Financial burdens and employment difficulties affect access to health care for CSHCN (Mohler Kuo, 2009). One study showed that compared to other families, out-of-pocket expenditure for health care is on average two times higher among families of CSHCNs (Newacheck & Kim, 2005). Most of Latino families reported that barriers to health care access for children were lack of health insurance, cultural differences, and poverty (Mulvihill, Altarac, & Swaminathan, 2007).

Families with CSHCN face financial difficulties due to higher personal out of pocket costs, transportation expenses, and missed-work problems. The financial strain is especially common in low income families. Apart from the above mentioned factors, language barriers also affect access to health care. This can be illustrated by the example that when parental intake forms were completed in any other language than English, they had more difficulty in coordinating required health care (Yu, Nyman, Kogan, Huang, & Schwalberg, 2004).

Enabling Factor: Medical Home

Among the studies on CSHCN and medical home, most of them used different survey questions to construct the medical home variable. The 2005-2006 NSCSHCN utilized 14 different survey questions to analyze the 5 components of medical home for its national publications and reports. Many studies isolate five stem questions that are aligned with the five key domains of a medical home while not considering the results of the other nine that provide greater depth to the findings. Many studies examined only having a usual source of care, denoting this as the essential element of medical home. Many studies elected CSHCN to have a medical home if they had three out of five components of the medical home variable. Most recently published, Strickland (2009) utilized all 14 survey questions the 2005-2006 NSCSHCN introduced to explain medical home. As it has not been tested empirically that all 14 questions provide statistically stronger evidence than using fewer survey questions, further research is needed in this area to determine if greater definitional depth through all 14 questions would provide more accurate data. An algorithm developed in 2004 as part of the Child and Adolescent Health Measurement Initiative (CAHMI) has been used to determine the presence of

medical home as defined by the AAP for CSHCN. Their results indicate that medical home determination can be obtained by using a subset of questions from the NSCSHCN (Bethell, Read, & Brockwood, 2004). These five stem questions are used in this present study to compile the medical home variable.

Strickland (2009) measured the impact of having a medical home to 4 variables: delayed or forgone care, unmet needs for care and family services, and school absences. Strickland hypothesized that having a medical home would decrease unmet needs, delay of care and missed school days. Among her sample ($N=38,886$) as a whole, 47.1% had access to a medical home, defined as achieving a usual source of care, a personal doctor or nurse, had no problems obtaining referrals when needed, received effective care coordination when needed, and received family centered care. Overall, 14.3% of CSHCN had missed more than 10 days of school because of illness in the past 12 months. Having a medical home was associated with a modest but statistically significant decrease in the likelihood of missing more than 10 days of school (Strickland, 2009).

One element of medical home that is considered essential is that a child must have a usual source of care. Two studies found no statistically significant difference in ED utilization between CSHCN with a usual source of care and those without (Raphael, Zhang, Liu, Tapia, & Giardino, 2009; Homer, Klatka, Romm, Kuhlthau, Bloom, Newacheck, Van Cleave, & Perrin, 2008). Within research among the CSHCN population, some investigators have chosen to examine medical home on a continuum scale using a medical home index. In one study, the hypothesis was tested that an increased number of medical home elements in pediatric primary care settings was associated with a decrease in health care service use (outside the primary care setting).

Cooley (2009) hypothesized that having more aspects of a medical home within a practice site would be associated with lower utilization of specialty care, urgent care and emergency department services. The results were modest (-0.12 and -0.16, $p < .05$), but suggested that primary care practices with strong chronic condition management and care coordination had fewer CSHCN emergency utilization (Cooley, McAllister, Sherrieb, & Kuhlthau, 2009).

Families play a critical role in the development and nurturing of their children; and therefore, family-centered care has evolved as an essential element of medical home. Denboba (2006) examined the aspect of partnership and family centered care among families of children with special needs. They found that one aspect of parents not feeling involved as partners in the care of their child, increased absenteeism (AOR:1.56; (95% CI:1.33-1.83) (Denboba, 2006).

Enabling Factor: Insurance

For children with special needs, health insurance plays a major role in access to care and use of services. Being uninsured or underinsured has been associated with inadequate use of health services, including ED and inpatient services, such as not taking a child for care when it is actually needed (Lieu et al., 2002; Montes, 2009). Health insurance becomes more essential for CSHCN to access health services. Health insurance coverage can diminish financial burdens that arise for families from health care expenses. Child health insurance coverage is an advantage that each family can receive to access health services and protect their families and children from illness (Newacheck, McManus et al., 2000). Newacheck et al. showed that 89% of the children had health insurance coverage. Most of the coverage provided was by private insurance companies. Insured children

were more likely (96.9% vs. 79.2%) to have a usual source of care when compared with uninsured children. Insured children also were more likely (87.6% vs. 80.7%) to have a regular health care provider compared with uninsured children. The uninsured were more likely to report being unable to reach needed medical care (10.5% vs. 2.2%), dental care (23.9% vs. 6.1%) and mental health care (3.4% vs. 0.9%) compared with insured children. Wood (2009) found that uninsured children, and those who had public insurance, were more likely to have unmet healthcare needs when compared to CSHCN covered by both public and private health plans (Wood, 2009).

Several studies have found that patients with public insurance, such as Medicaid, Medicare and the State Children's Health Insurance Program, are more likely to make multiple visits to emergency departments than uninsured or privately insured patients (DeVoe, 2008; Oswald, 2007; Haley, 2007; Wang, 2007; Chen, 2006). Yu (2006) also noted that people without insurance are less likely to have one consistent care provider, and are less likely to make appointments for care.

Predisposing Factor: Race and Ethnicity

Several studies examined racial and ethnic differences in access to health care and utilization of health care. One of the previous studies demonstrated that among CSHCN, minority children had greater odds of having no insurance coverage (10.3% vs. 13.2%), having no usual source of care (4.3 vs. 6.7%), and being unable to get needed medical care (2.8% vs. 3.9%) (Newacheck et al., 2002). Previous studies have demonstrated that among CSHCN families, racial and ethnic disparities exist in satisfaction with care in use of services (Ngui & Flores, 2006).

Research conducted by Strickland et al. (2004) revealed an association between race and ethnicity and receiving care in a medical home. Non-Hispanic Black, Hispanic, and Non-Hispanic other race CSHCN demonstrated a decreased odds of receiving care in a medical home as compared to Non-Hispanic White CSHCN (Strickland, 2004).

Analysis of type of care and its interactions with race and ethnicity showed that Non-Hispanic Black children with a medical home were more likely (AOR: 1.26; 95% CI: 1.03-1.54) to have 1 or more ED visits than Non-Hispanic White children with a medical home. Emergency care utilization for CSHCN differed significantly according to race and ethnicity (Raphael, Zhang & Giardino, 2009).

A study by Ryan et al (2004) showed that children with different sources of care for preventive services versus sick visits were almost twice as likely to have received care in an ED compared to those with a consistent source of care (Ryan, Riley, Kang, & Starfield, 2004) Brousseau et al (2009) demonstrated that family centeredness and realized access to primary care were associated with fewer ED visits for CSHCN (Brousseau, Gorelick, & Hoffman, 2009).

Predisposing Factor: Highest Level of Education in Household

Parent or guardian education can affect access to health care and use of needed services. Lack of education may reduce a parent's access to information about interventions for their child. Parents of CSHCN may not be aware of how to navigate or utilize the available programs for CSHCN due to lack of education. Additionally, education can also limit access to information regarding health insurance and its benefits (Newacheck, Inkelas, & Kim, 2004). Families with high school education or less (AOR: 0.70; 95% CI: 0.65-1.01, p-value: <0.05) were not as likely to receive the services they

needed (Warfield & Gulley, 2006). Similarly, Ngui et al (2006) found that parents with less than a high school degree were more likely to report difficulty in using health care services (37.1% vs. 22.7%) compared with parents with a college graduate degree (Ngui & Flores, 2006).

Parents who are less educated were found to utilize specialty care for their CSHCN less than parents with some college (Kuhlthau, Nyman, Ferris, Beal, & Perrin, 2004; Mayer, Skinner, & Shilkin, 2004). Porterfield et al (2007) found that CSHCN of less educated parents had decreased access to health services in general. This study is especially important because it points out that even though a family may be supplied insurance to cover the special needs of the child, service will not occur if the parent does not seek care because of lack of knowledge.

Predisposing Factor: Poverty Level

Poverty also may contribute to diminished health care access for CSHCN. Families with lower incomes reported dissatisfaction with care for any unmet need for specific care services (26.8% vs. 8.6%), family support services (6.8% vs. 2.8%) and no usual source of care (8.0% vs. 6.4%) compared with higher incomes (van Dyck et al., 2004). Families with <100% FPL (36.8%) were more likely to have issues in accessing health care services compared with families >200% FPL (21.5%), after adjustment. Families of CSHCN living at >200% FPL had 20% more difficulty using health and community based services than families at <200%FPL (AOR: 1.20; 95% CI: 0.75-1.92) (Ngui & Flores, 2006).

Predisposing Factor: Functional Status of Child

Nageswaran, Johnson et al (2008), categorized functional limitations into three parts. When compared to CSHCN without limitations, those with severe limits got early interventions 7.5 times more often. CSHCN with minor limits received early interventions only 2.2 times more often than those without functional limitations. (Nageswaran, Silver, & Stein, 2008). From these studies, it was concluded that access to health care was not increased adequately to meet the increased demands of health care services due to the rapid increase in the number of functional limitations in the population of children with special needs and functional limitations.

CSHCN in the severe functional limitations subgroup, compared to minor limits (13.1% vs. 4.1%, $P < 0.05$) more often needed to see a specialist or to go to the emergency department, and were the most likely to have unmet needs (Bramlett, Read, Bethell, & Blumberg, 2009; Foster, Fraiser, & Skalland, 2009).

In 2009, Bramlett et al. addressed the heterogeneous group of CSHCN by differentiating subgroups according to functional limitations, and need for specific services. The purpose of the study was to understand the health needs of CSHCN by population. They found that CSHCN whose health consequences include functional limitations generally exhibited the poorest health status and most complex needs among all the subgroups. Almost one quarter (23.7%) of CSHCN with moderate to severe functional limitations missed 11 or more school days compared to 3% of non-CSHCN. CSHCN in the functional limitation group more often needed to go to the emergency room (22.8%) compared to 4.1% non-CSHCN (Bramlett, 2009).

Predisposing Factor: Metropolitan Statistical Area of Residence

Living in a rural location may compound the problems with access to quality care faced by families of CSHCN. There are shortages of pediatricians and specialized services in rural areas that put CSHCN at particular risk for fragmented care. These shortages in the community require families to travel long distances at great personal and financial cost. With a medical home demonstration project, Farmer et al. (2005) examined the impact of a program to enhance comprehensive and coordinated care in a rural area. They examined program outcomes in 3 broad areas: access to and satisfaction with health care and related services, family functioning, and child functioning. Study hypotheses included: the medical home would help access to needed services, and improve family functioning. Post intervention, no changes were seen for the number of CSHCN who received specialty, inpatient, or emergency services (McNemar $S [1, N = 51] = 4.0; P = .11-1.0$). However, school attendance significantly improved after the one year intervention. Fewer children missed 13 or more days of school after the intervention (28% at time 1 vs. 14% at time 2; McNemar $S [1, N = 36] = 5.0; P = .025$) (Farmer, 2005).

Predisposing Factor: Age and Gender of Child

The most recent descriptive research on CSHCN using the 2005 NSCSHCN revealed substantial differences for achieving a medical home. Younger children were more likely to achieve the medical home outcome, whereas there were no significant differences among gender (Strickland, Singh, Kogan, Mann, van Dyck, & Newacheck, 2009).

CHAPTER 3: METHODOLOGY

This chapter summarizes the methods describing how the data were obtained and used in this research. It explains the variables such as dependent variables and independent variables used in the analysis. It also explains how the data were analyzed using different statistical methods.

The National Survey of Children with Special Health Care Needs (NSCSHCN) was sponsored by the MCHB and conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics. The survey was first conducted in 2001. The NSCSHCN was designed to produce national and state-specific prevalence estimates of CSHCN, describe the types of services that they need and use, and assess aspects of the system of care for CSHCN. A random-digit-dial sample of households with children less than 18 years of age was constructed for each of the 50 states and the District of Columbia. A parent or guardian who knew about the child's health and health care provided the information. Eligible children who were younger than 18 years were identified using the CSHCN Screener developed in collaboration with the Foundation for Accountability and based on the definition of special needs adopted by the MCHB. A representative sample from all 50 states and the District of Columbia was screened until a minimum of 750 children who met the definition per state were identified. The national overall response rate for the survey was 56.1% (Blumberg, Foster, Fraiser, & Skalland, 2009).

Data Collection

For this research, no primary data were collected. The National Survey of CSHCN is a publicly available source (<http://www.cdc.gov/nchs/slait/cshcn.htm>). The NSCSHCN was conducted as part of the State and Local Area Integrated Telephone Survey program. This is a broad-based, ongoing survey system at the national, state, and local levels to track and monitor the health and well-being of children and adults. This survey used the same sampling frame as the Centers for Disease Control National Immunization Study (NIS) and immediately follows the NIS household sample. The NIS screens over 1 million households per year to identify a residence with at least one child aged 19 months to 35 months. These children are targeted for immunizations. Because less than 5% of households contain children within this age range, a large number of households are screened to identify households with eligible children. The NSCSHCN was programmed as a module of the NIS, integrating the two surveys into a single interview. The sampling frame of telephone numbers is updated quarterly to reflect new telephone exchanges and area codes. The NIS sampling frame excludes cellular telephone numbers. Data collection for the 2005-2006 NSCSHCN started on April 5, 2005, and ended on February 5, 2007. The computer assisted telephone interview was translated into five languages: Spanish, Mandarin, Cantonese, Vietnamese, and Korean. CSHCN screening was completed for 192,083 households with children in the main sample. These households included a total of 364,841 children. Of these children, 56,014 had special health care needs. These children lived within 44,923 screened households. From each household one child with special needs was randomly selected to be the target of the special-needs interview. Interviews were completed for 40,723 children.

The Andersen Behavioral Model was used to identify factors that affect presence of the medical home and the utilization of healthcare and education services (Andersen, 1995). Even though this model was developed four decades ago, it is still useful in health administration and health care services research. This model includes predisposing factors such as demographics, and functional limitations of the child; and enabling factors such as insurance and medical home (Aday et al., 1993; Andersen, 1995).

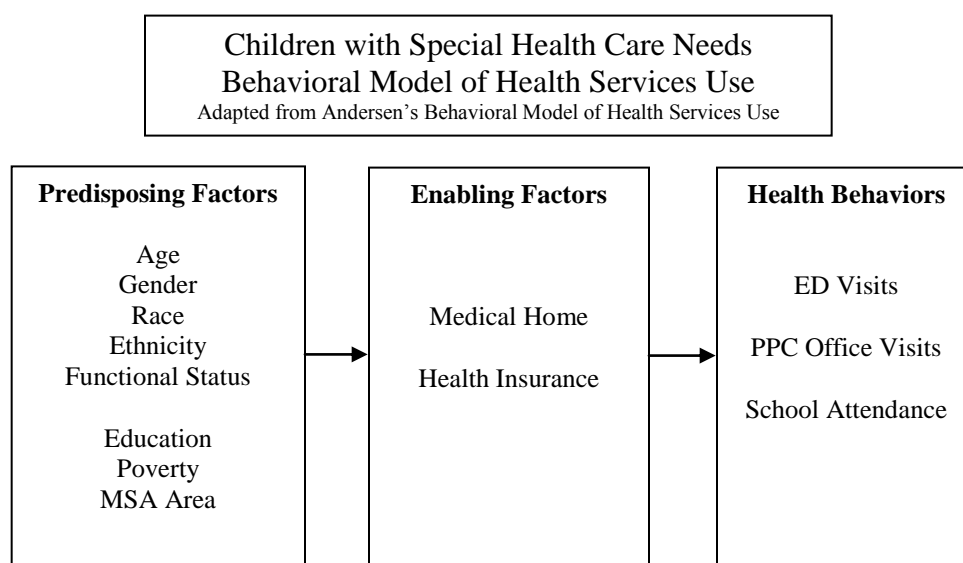


FIGURE 1: Adapted from Andersen's Behavioral Model of Health Services Use

Dependent Variables

The dependent variable, ED visits, was measured from one survey question. In the NSCSHCN the respondent was asked: “In the past twelve months, how many times has your child been to the Emergency Department?” The question was ordinal, with emergency room visit counts from 0 to 14-14+ (the data counts were right censored after the count of 14). In the 2005-2006 NSCSHCN only 0.54% (221 observations) answered 14-14+ visits. For this study, the variable of ED visits was divided into three categories coded as: (0) 0-3 visits, (1) 4-10 visits, and (2) 11 or more visits. The responses “Don’t Know” or “Refused” were counted as missing. There were 105 (0.26%) records with missing ED visit data.

The dependent variable, PPC visits, was measured from one survey question. In the NSCSHCN the respondent was asked: “In the past twelve months, how many times has your child been for a doctor’s office visit?” The number of physician visits in the 12 months before the survey was categorized as < 5 or > 5 visits, because 5 was the median number of physician visits for the sample. The sample size of CSHCN with PPC office visits was $n = 40,266$. There were 457 missing data deleted for this variable ($< 1\%$ of total sample).

The dependent variable of missed school days was obtained from one survey question. Participant responses were coded as 0-3 days, 4-7 days, and 8-14 missed days. The respondent was asked: “In the past 12 months, how many days of school has your child missed due to illness or injury”. There were 5,493 respondents who answered with the responses, did not go to school, home schooled, don’t know or refused to answer. Further, the 2005-2006 NSCSHCN edited the publically available data files to protect

confidentiality of CSHCN and families. Therefore, these children were not included in the analysis. The sample analyzed for association between medical home and missed school was 35,230 CSHCN.

Independent Variables

Predisposing factors: Demographic characteristics were commonly considered predisposing factors, and this study included the following variables in the model:

- Child's age: For the analysis of ED visits and PPC office visits, the categories were classified as birth to five (≤ 5 years old), elementary school (6-12 years old), and high school 13-18 years old). For analysis of school attendance the age categories were birth to 3 years, 4 to 12 years, and 13 to 18 years of age.
- Gender: The categories were male and female.
- Race/Ethnicity: Parents were asked if the child was Hispanic or Non-Hispanic. For race, the parent was asked to select from the following categories: White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander or Other. For the purposes of this study, children's race and ethnicity were combined into one categorical variable and grouped into five groups of (a) Non-Hispanic White, (b) Non-Hispanic Black, (c) Non-Hispanic multi-racial, (d) Non-Hispanic other race, and (e) Hispanic.
- Metropolitan Statistical Area of Residence: The demographic variable, residence was defined as households located inside or outside a MSA. If within a MSA with a population of 500,000 persons or more, the CSHCN was considered to live in an urban area. If the household was located outside an MSA, it was considered a rural residence. The analysis was limited by missing data, and a more thorough

analysis of the association between rurality and the dependent variables, would have been preferable, this was not possible with the available data. Due to survey design, MSA status was withheld for states where either the MSA or non-MSA population was less than 500,000. There were 12,572 (30.9%) missing values that were included in a missing category for the MSA variable, such that the MSA variable included three groups of (a) urban, (b) rural, and (c) missing.

- **Parent/Guardian's level of Education:** The educational level of the respondent or potential caregiver was assessed by the highest level of education of anyone living within the household. This variable was categorical with two groups of (a) less than high school diploma, and (b) high school graduate or more.
- **Functional Status of the CSHCN:** The covariate functional status was categorized as CSHCN with minor, moderate or severe limitations. There were 6,690 (16.0 %) records missing information for the functional status variable. This is explained in the original operation manual for the 2005 NSCSHCN; and identified these missing values were due to legitimate skip patterns implemented in the survey questionnaire. This variable specified the reported restriction on the child's life functioning because of her or his disease or disorder. The functional status variable included 4 groups of (a) minor, (b) moderate, (c) severe limits, and (d) missing.
- **Poverty Level of Household:** The Federal Poverty Guideline (FPG) was used to adjust for a child's socio-demographic status for standard of living as denoted by household income. This poverty level variable was categorized into two dichotomous groups of (a) less than 200%, and (b) 200% up to 400% FPG.

Enabling Factors: The resources for health care service use.

Insurance: Insurance coverage was included as a dichotomous variable and coded as (a) insured, and (b) not-insured.

- Medical Home: The medical home variable was compiled from five survey questions that represent key conceptual domains. The survey questions used for medical home include: (a) whether the child has a personal doctor or nurse, (b) if the child has a usual health care source, (c) how satisfied the family is with communication among doctors who provide care for the CSHCN, (d) whether the family feels like a partner in care of the CSHCN, and (e) if providers are sensitive to the family's values and customs. The first two questions regarding a personal doctor or nurse and whether the child had a usual source of care were "Yes" or "No" questions. The remaining three questions targeting inter-physician communication, family-as-partner and care coordination required Likert-type responses of "Never," "Sometimes," "Usually" and "Always." The Likert-type responses were collapsed into binary form with the answers "Never" and "Sometimes" measured as "No" and "Usually" and "Always" as "Yes." If a CSHCN met all five inclusion criteria then the child was coded for the medical home variable as yes = 1. If a CSHCN did not meet all five medical home criteria, then he or she was considered to have not met the inclusion criteria for having a medical home, and was coded for the medical home variable as no = 0.

Analysis

The data files were transferred from SAS version 9.1.3 to Stata version 10, and a data set was created. The variables chosen for this study were recoded. The variables and coding are provided in appendix one. The dataset of 363,183 was limited to represent CSHCN only. There were three elemental steps in the analysis for each hypothesis:

1. Descriptive analysis
2. Simple logistic regression analysis and
3. Survey ordinal logistic regression analysis.

All statistical results were analyzed at 5% level of significance. These data were collected using random sampling techniques. Statistical analysis accounted for survey weighting and the complex sampling design. Multicollinearity was tested in logistic regression between the independent variables. No correlation was found between the variables.

Emergency Department Visits

Because of the ordinal nature of the ED outcome variable, the Proportional Odds Model (POM) was used to estimate a relationship between medical home and ED visits. The design-based approach was implemented to estimate parameters, and the model-based approach for diagnostics. Goodness of fit tests was run using Pearson residuals and standardized Pearson residuals. Two way scatter plots were analyzed, and the Mantel-Haenszel test for homogeneity was performed. Coefficients (betas) and the cut points were estimated from the model using Maximum Likelihood methodology. The chi-square

test of proportional odds (omodel) and Brant test (brant) were not significant in the final model, suggesting that the proportional odds assumptions hold true.

Data was missing for some records across the variables used in the analysis; two variables, functional status and MSA, contained more than 10% missing data (15.44% and 10.1% missing data respectively). A category for the missing data was made for these variables, in order to retain as much data as possible for analysis and therefore retain power of the statistical tests.

Outliers in a dataset have the potential to distort results of an inferential analysis. The data was mostly categorical and a check was done using frequency analysis to investigate for erroneous or missing entries of categorically coded variables. The outlier assumption was not violated.

Pediatric Primary Care Office Visits

The multivariate ordered logistic model did not pass the proportional odds assumption test. Therefore, the PPC office visit variable was dichotomized into 0-5 visits (low PPC visit outcome) and >5 visits (high PPC visit category). A binary logistic regression model was run using the variables. The dichotomous variable of medical home (0 = no, 1 = yes) was used as the independent variable. Two variables were chosen as stratification variables, functional status, and ethnicity. The variable of functional status was tested for interaction with the presence of medical home on the PPC visit outcome. Ethnicity was also tested for possible interaction with the presence of medical home on the PPC visit outcome. Classification groupings were the same for these two stratification variables as for the ordinal logistic regression. A statistical method utilized by Lee and Forthofer (2007) was used for the stratified analyses in this study. The process includes

four steps. First, a standard logistic regression analysis, without the survey weights and design features, is modeled with the independent variables of medical home and the stratification variable and the dichotomous PPC visit outcome variable. This first step returns a likelihood ratio chi-square to investigate the interaction effect of the two independent variables on the PPC visit outcome. The first step also computes a pseudo R-square value derived from the raw sample data. The second step obtains a goodness of fit statistic for the model and associated degrees of freedom which can suggest an interaction effect between the two independent variables. These first two steps are utilized on the sample data, without the survey weights, but the information returned is useful in interpretation of results. The third step makes use of the survey weights to derive pseudo likelihood for model fit using an F-statistic, and adjusted odds ratios for the independent variables. Finally, the fourth step involves summing the linear combinations of model parameters to test the hypothesis that the sum of parameters for medical home and the levels of the associated stratification variable equal zero. Odds ratios are used in this determination to determine statistical significance in the odds of a given combination on the PPC visit outcome in relation to the reference combination of the independent variables.

The PPC visit outcome was categorized into two groups, 0 = 0-5 visits, and 1 = 6 or more visits. Although not a true dichotomy, the outcome variable of PPC visits can be considered for this study as 0 = not a large number of annual PPC visits, and 1 = a large number of annual PPC visits. Linear combinations of the medical home and functional status variable pairs were performed to analyze the relationship between these pairs and

the reference category pair of children not having a medical home with minor functional limitations.

A standard logistic regression with the dichotomous outcome of PPC visits and independent variables of medical home and ethnicity was performed to investigate a possible interaction effect. The pseudo R-square value was .0039, indicating that only 3.9% of the total variance in the outcome of PPC visits was accounted for by the two independent variables. Much of the variance in the PPC visit outcome is not explained by medical home status and ethnicity. The likelihood ratio chi-square value of 204.10 ($df = 5, p < .0005$) indicated that medical home status and ethnicity status together have a significant effect on more than 5 PPC office visits. A goodness of fit test on the raw sample data returned a significant result [$\chi^2 (4) = 40.27, p < .0005$] indicating that the model was not a good fit with the sample data. The degrees of freedom associated with the goodness of fit model suggest no interaction effect between medical home and ethnicity in relation to the proportion of CSHCN with more than 5 PPC visits. The survey logistic regression, which takes the survey design of the study into account, indicated that the model was a good fit for the data as relates to a null model in which all outcomes are set to the PPC visit coding of 0 (0-5 PPC office visits) [$F(5, 39924) = 23.86, p < .0005$].

Missed School Days

Multivariate ordinal logistic regression was used to estimate a relationship between number of missed school days and the main independent variable presence of medical home. The rationale for this age group categorization is that at the age of 3 years, CSHCN are placed in preschool programs and receive services through the school system. The outcome variable was an ordinal variable: 0-3 (referent), 4-7 missed days,

and 8-14 missed days. Building upon prior research reviewed during the literature review, all covariates that appeared to be confounders in the bivariate analysis were tested one by one, to find the most parsimonious model. Only the variable insurance was non-significant and later dropped from the model. Functional status was tested for effect modification and none was present. It is well documented in the literature that the poverty level of a household influences school attendance; poverty was tested for confounding and effect modification, and included in the final model. Effect modification was assessed using stratified analysis. None of the interaction terms tested significant according to the Wald tests. Statistical evaluation included a Test for homogeneity. The design-based approach was implemented to estimate parameters, and the model-based approach for diagnostics. Once the final model was achieved, the Hosmer-Lemeshow Goodness of Fit test was performed to test the significance of the model. Two-way scatter plots were analyzed, and the Mantel-Haenszel test for homogeneity was performed. Coefficients (betas) and the cut points were estimated from the model using Maximum Likelihood methodology.

Reported results are survey weighted using the Interview File weight (weight i) as recommended in the Design and Operation of the National Survey of Children with Special Needs, 2005-06. STATA statistical software version 10 (Stata Corporation, College Station, Texas, 2009) was implemented in the analyses. This study was approved by the University of North Carolina at Charlotte institutional review board.

CHAPTER 4: RESULTS

The demographic and prevalence characteristics for children with special health care needs and the individual components of medical home are provided in table 1. The total sample of 40,723 CSHCN are considered in this study. The majority of CSHCN in the sample are Non-Hispanic White (72%), males (59%) with insurance (96%). Similarly, a majority of CSHCN were between 6 and 11 years of age (44%) when interviewed for the survey. Sixty-four percent of the children live in households with incomes above or equal to 200% of the poverty level as established by the Federal Poverty Guidelines (FPG). Eighty-two percent of CSHCN were reported to have some or little functional limitations.

Overall, 34% of children did not have a medical home. Families reporting they felt like partners in the care of the CSHCN (88%) and receiving family centered care (90%) were the two medical home components with the least access.

Non-Hispanic Black and Hispanic children had similar access rates to medical home (57% and 56%). The majority of CSHCN have public insurance coverage through Medicaid because of the broad service coverage it provides. Insured children made up a significantly higher percentage of CSHCN with a medical home compared to uninsured CSHCN (70% vs. 43%). Not surprisingly, CSHCN living in households where the highest education level was more than a high school diploma had greater access to medical home than children from homes with less education (72% vs. 48%).

Emergency Department Visits

The majority of CSHCN had less than four ED visits in the past twelve months, while about 1% had eleven or more ED visits (table 2). The unadjusted and adjusted odds ratio and their associated 95% confidence intervals are presented in Table 3. When examined singularly, medical home was associated with fewer ED visits among CSHCN by 36% (OR 0.64; 95% CI: 0.55-0.74). However, the odds diminished to 18% and became statistically non-significant after adjustment for potential confounders (AOR 0.82; 95% CI: 0.71-1.01).

Female gender was positively associated with ED utilization. Although the association was not statistically significant at the univariate level (OR 1.14; 95% CI: 0.92-1.32), after adjusting for potential confounders, a significantly elevated 29% increased odds of ED visits was observed among CSHCN (AOR 1.29; 95% CI: 1.09-1.51). Unadjusted odds ratios for ethnicity/race indicated that Non-Hispanic Blacks, Non-Hispanic multiracial children, and Hispanics were more likely to visit the ED compared to Non-Hispanic Whites. However, when adjusted for other covariates in the model, a significant association was only observed for Non-Hispanic Blacks who were 1.87 times more likely to visit ED (AOR 1.87; 95% CI: 1.51-2.30).

The odds of ED visits were elevated more than two-fold for CSHCN with moderate (AOR 2.08; 95% CI: 1.71-2.51) and severe (AOR 3.69; 95% CI: 2.90-4.70) functional limitations. CSHCN living in households with income levels greater than 200% FPG were 70% less likely and 46% less likely to visit ED in the univariate and multivariate analysis, respectively.

Although, the odds ratios were statistically significant at the univariate level for children with at least one person in the household who had more than a high school education when compared to children who lived within households of less than high school education (OR 0.87; 95% CI: 0.67-1.12), the results became statistically non-significant when adjusted for other covariates (AOR 1.14; 95% CI: 0.85-1.52).

Rurality was positively associated with ED utilization. The unadjusted odds ratio for the MSA status of rural was 1.74 (95% CI: 1.47-2.07) indicating that CSHCN living in rural settings are 1.74 times more likely to frequently visit ED than CSHCN living in an urban setting. The odds ratio were slightly reduced in the multivariate model, but remained statistically significant (AOR 1.65; 95% CI: 1.37-1.98).

Pediatric Primary Care Office Visits

Table 4 presents the weighted and unweighted frequencies and percentages of PPC office visits at the significance level $p < .0005$. The majority of CSHCN had 5 or fewer visits in the previous year, while 36% had 6 or more visits. The logistic regression results revealed that medical home was positively associated with the number of PPC visits (table 5). The unadjusted odds ratio for the medical home variable (OR:1.50; 95% CI: 1.40-1.61) indicated that CSHCN with a medical home have 1.5 times the odds of having more PPC visits as CSHCN without a medical home. With adjustment the odds increased (AOR 1.60; 95% CI: 1.47-1.75), a child with a medical home was 1.60 times more likely to have more PPC visits than a child without a medical home. Female children had 1.27 times the odds more PPC visits (AOR 1.27; 95% CI: 1.17-1.36) than male CSHCN. The adjusted odds ratios for the three ethnic groups of Non-Hispanic Black (AOR 0.95; 95% CI: 0.79-0.1.13), Non-Hispanic Other (AOR 0.74; 95% CI: 0.61-0.90), and Hispanic

(AOR 0.77; 95% CI: 0.67-0.88) also indicated statistically significant negative association with increased numbers of PPC visits when compared to Non-Hispanic Whites ($p < .005$). The ethnic group of Non-Hispanic Multi-race was not statistically significant. Adjusted odds ratios for children with moderate limitations (AOR 2.35; 95% CI: 2.15- 2.57) and children with severe limitations (AOR 4.66; 95% CI: 3.95- 5.49) also indicated increases in the number of PPC visits associated with increases in functional limitations. As education level in the household increased, the PPC visits also increased. The adjusted odds ratio for CSHCN living in a household where the highest level of education of a household member was greater than a high school diploma was (AOR 1.53; 95% CI: 1.27-1.86). CSHCN living in rural areas were more likely to have more PPC visits than children living in urban areas (OR 1.23; 95% CI: 1.14-1.34). When the other independent variables were included in the model, the odds decreased, but remained statistically significant for having more PPC office visits than urban (AOR 1.15; 95% CI: 1.05-1.26). Being uninsured was associated with fewer PPC office visits. (AOR 0.56; 95% CI: 0.46- 0.68).

Stratified Analysis of Medical Home and Functional Status

A standard logistic regression with the dichotomous outcome of PPC visits and independent variables of (a) medical home (reference category = no), and (b) functional status (reference category = minor limitations) was performed on the sample data of the study to derive a pseudo R-square value and to investigate a possible interaction effect of the two independent variables. The pseudo R-square value was .0533. Only 5.3% of the total variance in the outcome of PPC visits was accounted for by the two independent variables. The likelihood ratio chi-square value of 2801.59 ($df = 4, p < .0005$) indicated

that medical home status and functional status together have a significant effect on more than 6 PPC visits. A goodness of fit test on the raw sample data returned a non significant result [$\chi^2(3) = 7.31, p = .063$] indicating a good model fit. The degrees of freedom associated with the goodness of fit model suggest that an interaction does not exist between medical home and functional status in relation to the proportion of children with more than 6 PPC visits in the previous 12 months.

The survey logistic regression, which takes the survey design of the study into account, indicates that the model is a good fit for the data as relates to a null model in which all outcomes are set to the PPC visit coding of 0 (not a large number of annual PPC visits) [$F(4, 40212) = 180.4, p < .0005$]. Table 6 presents the adjusted odds ratios and 95% confidence intervals for the independent variables. All variables in the model were statistically significant for the outcome of more PPC visits. CSHCN with a medical home had 1.59 times the odds of having more PPC visits than children without a medical home (AOR 1.59; 95% CI: 1.46-1.72). When compared to children with minor functional limitations, children with moderate limitations were 2.14 times more likely to have had more visits (AOR 2.14; 95% CI: 1.97-2.32), children with severe limitations had 3.49 times the odds more visits (AOR 3.49; 95% CI: 3.03-4.01).

Children with a medical home and with moderate limitations had 3.39 times the odds of children in the reference category of more PPC visits. Children with a medical home with severe functional limitations were 5.53 times more likely to have more PPC visits than CSHCN without a medical home and with minor limitations.

Table 7 presents the adjusted odds ratios and 95% confidence intervals for medical home and race/ethnicity. Children with medical homes had 1.22 times the odds of having

more PPC visits than children without a medical home (AOR 1.22; 95% CI: 1.17-1.28). When compared to Non-Hispanic White children, Non-Hispanic Black children were less likely to have more PPC visits (AOR 0.70; 95% CI: 0.65-0.75). This finding suggests that Non-Hispanic Black CSHCN's are 30% less likely than Non-Hispanic White CSHCN to have 6 or more PCC office visits. In this stratified analysis, results were not significant for the other ethnicity categories.

Missed School Days

The total sample available for the outcome variable missed school days was 35,230. Data missing was due in part to the fact that some CSHCN did not attend school, some were home schooled and some were in alternative programs that did not meet 5 days per week. The age category for missed school was birth to 3 years, 4 to 12 years and 13 to 18 years. Among CSHCN with medical homes, only 23% fell within the category of missing the most school (8-14 days). Older CSHCN missed slightly more school than younger children. Among rural children, 27% missed 8-14 days compared to 23% of urban CSHCN who missed 8-14 days ($p < 0.001$). Those children without health insurance coverage missed more school when compared to their insured peers. A child's limitations were associated with school attendance. Those with severe limitations missed more school days than peers with some or little limitations (Table 8).

The presence of medical home among CSHCN was associated with being in the highest category of missed school days. The odds of missing more school increased when all other factors were included into the regression model (Table 9). After adjustment for poverty, MSA status, education in the household, age, race and ethnicity, the adjusted odds ratios (AOR) for the number of missed school days, illustrates that access to a

medical home does not decrease school absences (AOR 2.46, 95% CI: 1.46-3.10). The odds were lower for those living in households with greater than 200 percent poverty level to miss 8-14 school days (AOR 0.67; 95% CI: 0.59-0.74). As severity of functional limitation increased, the odds of increased missed school days increased. Those children with severe functional limitations had greater odds of missing 8-14 school days in the past year (AOR 2.90; 95% CI: 2.36-3.54).

CHAPTER 5: DISCUSSION AND CONCLUSION

This study focused on factors associated with medical home and emergency department, PPC office visits and school attendance among CSHCN.

Emergency Department Utilization

Among 9 factors examined for association with ED utilization, being of Non-Hispanic Black race, having moderate or severe functional limitations, and living in a rural area, were significantly associated with having 11 or more ED visits. According to Andersen's Behavioral Model of Health Services Use, race and rurality are predisposing factors that affect use of health services. Functional limitation is a need factor, indicating the severity of the child's health or illness. Factors that were expected to be protective or enabling, such as presence of a medical home, education level of individuals in the household and insurance status of the child were found to have a statistically insignificant association to ED visits. The presence of a medical home for those CSHCN living at FPG >200%, was not associated with having fewer ED visits.

Previous literature suggests demographic variables (race and ethnicity, education, age and poverty level), type of health insurance, and the functional limitation of child significantly affect accessing any kind of services among CSHCN (Mayer et al., 2004; Newacheck, & McManus et al., 2000; van Dyck et al., 2004; Yu et al., 2004). Care organized according to the principles of a primary care medical home is expected to reduce barriers to and ensure adequate use of services for CSHCN (AAP & Medical

Home Initiatives for Children with Special Needs Project Advisory Committee, 2004; Cooley & McAllister, 2004, NAPNP, 2007). This research reveals gaps where medical home would be expected to serve the most vulnerable child. Interestingly, a child classified as having a medical home does not differ significantly from children without medical homes in the occurrence of being in the highest category of ED visits.

The results of this study were consistent with recent research by Raphael et al. (2009). In that study, Non-Hispanic Black CSHCN with medical home had greater odds of ED utilization compared with Non-Hispanic White CHSCN with a medical home (Raphael, 2009). Like Raphael, in the current study, ED utilization differed significantly (in unadjusted analysis) according to race and ethnicity. Newacheck (2002) found similar results for minority CSHCN. In that study, Non-Hispanic Black children were less likely to have a usual source of care and more likely to utilize emergency care compared to Non-Hispanic White children (Newacheck, 2002).

The association of a child classified with functional limitations and the number of ED visits is stronger when the other factors were not included in the analysis. However, when adjusted for medical home and other variables, children with severe functional limits were less likely to have 11 or more ED visits. Still, as expected, CSHCN with severe limitations had the greatest likelihood of more ED visits. The important point is that with adjustment, including presence of medical home the odds decreased slightly. These distributions mirrored a dose-response pattern between the severity of the child's condition, the likelihood of securing a medical home, and the number of ED visits; as the severity of the child's condition increased, the likelihood of meeting all the criteria for a medical home decreased, and the number of ED visits increased. This inverse relationship

has been reported by Strickland et al. (2009) and Fulda et al. (2009) and raised concerns about the capacity of the current fragmented health care system to meet the needs of CSHCN. Presence of a medical home for a severely limited CSHCN had very small odds of that child being in the highest category of ED visits.

Economic resources play an essential role in a family's ability to access and utilize health services. In 2008, approximately 2 million children in the United States did not receive care because their families were unable to afford it, and care for 3.5 million children were delayed because of concerns about cost (Bloom et al., 2009). Studies examining the association between poverty level and asthma confirm that children in poor families are more likely to rely on the ED as their usual source of care than those in higher income families (MCHB, 2008). Consistent with previous study results, the present research study revealed less ED utilization for those CSHCN for those families living with higher income levels. It is difficult to compare studies when one examines the area of poverty. Income is self reported in this survey. Differences in study results may be due to the complexities in accessing even ED services at this level of poverty. A further explanation for this difference points to a limitation in the study. The NSCSHCN edited data for poverty level creating 34,809 missing data from the entire sample. Possible bias exists in the variable poverty level.

Pediatric Primary Care Office Visits

Primary care is the medical source that provides preventive medical services, such as immunizations and well-child examinations. According to the 2008 National Survey of Children's Health (NSCH), children with special needs had more well child visits than other children (AOR=1.45; 95% CI 0.99-1.59) (Cooley, McAllister, Sherrieb, &

Kuhlthau, 2009). CSHCN age 6-17 were not more likely to have more PPC office visits than younger children. This result may be due to inconsistent insurance coverage or lack of coverage. Services for special needs children are one of the original purposes of Title V (covers children ages 0-6 years). Eight-five percent of the Title V appropriation is allocated to the state grants according to a formula based on the number of low-income children. Coordination between Title V and Medicaid is required as a condition for funding under their statutes; and State Children's Health Insurance Program (SCHIP) has broad requirements to coordinate with other child health programs. Together, these programs provide many CSHCN with comprehensive insurance and specialty care services. CSHCN at poverty levels greater than 200 percent FPG, insured children, and children ages birth to 5 years of age were found to have eight or more doctors' office visits in the past twelve months (Aday, 2004).

The pediatric primary care practice is central to the medical home model of care for CSHCN. In this study, the presence of insurance is an enabling factor for PPC office visits. The NSCSHCN provides detailed data on the type of insurance coverage the CSHCN has been covered under in the past 12 months. Further analysis using this revealed that children with both public and private coverage had greater odds of increased visits. The combination increase coverage allows families to avoid out of pocket cost and enables them to see the specialist needed. Further research using the type of insurance coverage and access to medical home might provide valuable insight into financial implications for families and states that pick up much of the slack in caring for CSHCN.

Previous research has suggested that inadequacies in the rural health delivery system are due to persistent shortages of pediatricians and other primary care providers in these areas (Farmer, Clark, Sherman, Marien, & Selva, 2005). In this study, CSHCN in rural areas had greater odds of more PPC office visits than children in urban areas. It is important to note that when examined in bivariate analysis the presence of a medical home was not associated with an increase in PPC office visits. In rural areas, one might suspect that the benefits of the medical home would be of most value, considering the possibility of isolation and scarcity of resources. Future research of the barriers for rurally located CSHCN is necessary to reach a disenfranchised population of children. This need for further research in this area is demonstrated by conflicting results found in the literature. For example, Mayer (2004) demonstrated that rural children had more unmet needs for routine care (AOR 4.20 vs. AOR 2.99) (Mayer, 2004). Again, 'unmet need' is a broad term that is inclusive of PPC visits, but also other outpatient services. Mayer's results (adjusted for gender, race, ethnicity, education, insurance and poverty status) showed that compared with children who reported receipt of needed routine and preventive care, the ratio of general pediatrician to the CSHCN population was significantly lower among children having an unmet need for routine services. Mayer also found greater unmet need for routine care (vs. specialty care) among minority CSHCN Non-Hispanic White: (AOR 2.32; 95% CI 1.97-2.67), Non-Hispanic Black: (AOR 5.40; 95% CI 4.59-6.00) and children from homes with less than a high school education (AOR 8.05; 95% CI 7.02-8.10) versus more than a high school education (AOR: 2.46; 95% CI 2.00-3.46). By adjusting for MSA status, and the selected survey question in the present study, it is reasonable to compare results of studies using the

unmet need variable to consider health services utilization behavior of CSHCN. In a study of CSHCN in Texas, living in a rural area was not associated with obtaining the referrals needed for specialty care (Young, Drayton, Menon, Walker, Parker, Cooper, & Bultman, 2005). Skinner (2007) found that rural parents reported more difficulties accessing a provider at all, due to geographic difficulties, where urban parents are more likely to report provider specific problems (Skinner & Slifkin, 2007). Skinner also controlled for poverty, education and insurance in her study, and found these factors did not influence provider availability. It is possible that providers located in rural areas are increasingly motivated to implement medical home components to offset the lack of primary and specialty providers in their communities. Further, caregivers of CSHCN living in rural areas may develop a better rapport with the primary provider and therefore feel more confident in taking a child to PPC office instead of emergent or urgent care centers. Rural primary care providers may have fewer CSHCN in their case loads and therefore may provide more 24 hour telephone availability which could provide much needed reassurance and communication leading to ability to wait until the office opened for a PPC visit.

Routine visits to the pediatrician provide the opportunity for preventive care through well child examinations and family centered care. The AAP recommends 28 well child visits between birth and 21 years of age. The elements of a well child visit change depending on age, generally recognized as early infancy (0-6 months), late infancy (7 months- 2 years), preschool (3-5 years), and elementary school (6-12 years) (Houtrow, 2007). Strickland et al. (2009) conducted a parent interview, medical record review, and insurance status verification on 2,767 children in North Carolina. The authors found that

late initiation or no prenatal care (OR: 0.6; 95% CI: 0.50-0.86), being uninsured (OR: 0.5; 95% CI: 0.35-0.86), decreased a CSHCNs odds of receiving an adequate number of well child visits. A very important aspect of the PPC office visit for CSHCN is the inclusion of well child visits, sick visits, medication management visits. This study did not develop this analysis and further research is necessary in order to determine the number of PPC office visits a child with special needs requires at varying ages and functional limitations. The implications are numerous, but access to care as restricted by insurance coverage would be of immediate importance.

Among CSHCN, the severity of limitations affects many aspects of access; to a medical home, access to care, satisfaction, employment status of family members, and financial strain on family members. Analysis of data from the NSCSHCN demonstrates that severity of limitation is negatively associated with access to a medical home. Tippy et al. (2005) found that among respondents in Maine, CSHCN with severe limitation demonstrated decreased odds of having comprehensive care in a medical home (AOR: 0.3; 95% CI: 0.2-0.6). CSHCN in Rhode Island with severity of condition categorized as “some” (AOR:1.87; 95% CI: 1.15-3.02) and “moderate” (AOR: 2.21; 95% CI; 1.18-4.14) are more likely to not have coordinated, ongoing, comprehensive care within a medical home as compared to CSHCN whose condition “never” limits activities (Viner-Brown & Kim, 2005). Nageswaran (2008) examined the association of child severity and physician office visits. The study revealed that 43% of CSHCN without functional limitations had more than 5 PPC office visits in the previous 12 months, compared to 64% of CSHCN with severe functional limitations. The results of this study were consistent with

Nageswaran, and demonstrated that as child functional limitation increased the number of PPC visits also increased.

Fewer minority children with special needs have medical homes (Non-Hispanic Black 57%), and report receiving significantly less family centered care (Non-Hispanic Black, Family-centered care 82%), than their Non-Hispanic White peers. Therefore, this research reveals areas where the standard of care in medical homes is not consistent for all children and disparities exist. The presence of a medical home with the emphasis on patient-centered, family involvement must be an overarching theme that trumps racial and cultural barriers. Future research to identify if there are different barriers among races and ethnicities of CSHCN and how the medical home is associated will be a valuable addition to the body of knowledge.

Missed School Days

At any given time, ten million children with special healthcare needs (CSHCN) may be in the educational system (Bloom & Freeman, 2009). Underlying aims of The Individuals with Disabilities Act (1975) and the Medical Home Act (2007) is to enhance school attendance among children with special needs. Research has shown that when compared to children without special needs, CSHCN miss more school days due to illness (Bramlett, 2007). In the 2009 study by Strickland, 14.3% of CSHCN missed more than 10 days of school because of illness. Strickland does not report if this is weighted or unweighted. In the present study 23% (weighted n) CSHCN missed 8-13 days of school in the previous 12 months. Having a medical home was associated with a modest but statistically significant decrease in the likelihood of missing more than 10 days of school. The difference remained significant after adjustment for age, gender, race/ethnicity,

insurance, poverty, and functional status (Strickland, 2009). In the present study the analysis produced very different results. Strickland did not rank the missed school days in ordinal categories, but used a binary logistic regression. But, notably, the results in this study were different. It is possible the results are different due to the variance in the medical home definition between the two studies, as well as the variation in categorization of missed school days. The survey question focused on missed school days due to illness or injury. The NSCSHCN did not supply data on the number of school days missed due to health care or other service based appointments. This is an area where future research would provide valuable information.

Nageswaran (2008) reported similar results for CSHCN with severe functional limitations and school attendance. When considering the impact on the child, 7% of CSHCN without functional limitations missed more than 10 school days because of health conditions, compared to 28% of severely limited CSHCN who missed the same amount of days (Nageswaran, 2008). In this study, CSHCN in the severe functional limitations category had the greatest number of absences. It is documented in the literature that these children have up to two times the odds of missing more school days (Bethell, 2002; AAP, 2005; Bramlett, 2007). Bramlett (2007) found the subgroup of children with functional limitations to miss 11 or more school days in the past year. It is likely that CSHCN with more severe functional limitations may require more referrals for specialists and services, and simply more time away from school at health care facilities. For these children and families, communication among doctors may increase in significance. Therefore this aspect of medical home may be a particularly important link when coordinating such things as office visits so that the child misses fewer school days.

Young (2005) discovered that families and children, who experienced difficulties with referrals for specialist care, had over three times the odds of missing more than 11 days of school.

In a study to calculate and compare prevalence rates across child health surveys, Bethell (2008) reported the proportion of CSHCN who missed 11 or more days of school in the past 12 months due to illness. The 2001 NSCSHCN survey estimated 15.8% (15.0-16.6; $p=.05$) and the 2003 NSCH survey estimated 13.5% (12.6-14.5; $p=.05$) CSHCN missed 11 or more school days (Bethell, 2008).

Instead of differentiating from other children, families and communities need to accept CSHCN as part of the family and community like any other individuals. They should have the opportunity to share everyday family and community experiences and participate in normal day to day activities. The primary challenge in making this happen is to provide accessibility to needed health care. Resources such as early intervention programs, special education, nutrition, and rehabilitation services should be made available in the child's home community (Montes, Halterman, & Magyar, 2009; Homer, Klatka, Romm, Kuhlthau, Bloom, Newacheck, Van Cleave, & Perrin, 2008). These points highlight the importance of community based care and services for children.

Limitations

This study had several limitations. Foremost, no validated measure of medical home exists. Secondly, the population of CSHCN is broad and the use of one severity index question may have been inadequate to separately assess disparities in utilization of services. The categories of race and ethnicity included the subgroup "other." This category is heterogeneous, and the results may represent different Hispanic subgroups or

Non-Hispanic Black subgroups; but must be interpreted with caution. Some information that would provide greater detail and further information was not available from the survey questions, therefore this somewhat limits the direction of future research.

These data were collected using a cross-sectional study design, collected in 2005-2006. Therefore, causality cannot be inferred from this analysis. Since it is a snap shot of one point in time, the results may be different from one time point to another time point. There is also a possibility of recall bias since data collected for the National Survey of CSHCN were collected from parents or guardians via telephone interviews without any verification from medical records. Another limitation could be that all families with CSHCN might not have telephone access and therefore were not able to participate in the National Survey of CSHCN. Future surveys designed with the purpose of eliminating these limitations will prove beneficial.

Conclusion

The study reveals that, although over half of the children have access to medical homes, there is disparity in access to medical home that is a key to the success for this partnership approach for primary care to be successful. For example, only 55% of Hispanic CSHCN have medical homes and 57% Non-Hispanic Black CSHCN have medical homes compared to 73% of Non-Hispanic White children. This study suggests that the AAP definition of medical home is not being met for everyone when it comes to family centered care. Only 77% of uninsured CSHCN and those living in homes with less educated parents or guardians received family centered care. This study adds to the literature by revealing disparities in key components of medical home. A medical home is defined by the AAP as a partnership approach with families to provide primary care. The

implication from these findings may be that medical home presence will not be associated with decreased ED visits until family centered care, and family partnership is achieved for minority groups. This partnership is essential for the success of medical home for CSHCN in poverty, the uninsured children, the under educated families, and those families with CSHCN with moderate and severe functional limitations.

Based on this study, the evidence for access to medical home improving racial and ethnic health disparities is not good. In the research the expectation is that with family-centered care and the inclusion of family as partners in care there would be a reduction in cultural disparities. The implications from this study and the inclusion of this definition of medical home imply that the partnership approach of health care delivery may not improve upon the outcome of emergency care utilization; which for a CSHCN does not promote continuous, comprehensive or coordinated care that is the AAP goal. These study results may influence policy by providing evidence for economic incentive programs for medical and nursing students of minority races and ethnicities to join designated medical homes. This might improve the ratio of cultural matching within minority populations of CSHCN, and in this way promote partnership and compassion among minority populations.

CSHCN with a medical home had more PPC office visits than children without medical homes. No studies were discovered that directly examined the association of medical home to pediatric primary care office visits. Studies examined issues such as time allotted for CSHCN office visits, preventive visits, sick visits and specific elements of child's health such as genetic counseling that are included in PPC office visits. Areas for future study would include longitudinal analysis of CSHCN's office visit utilization at

different ages categorized by type of visit (well child, sick visit, medication only visit). The policy implication from these study results may be that CSHCN require more than the recommended PPC office visits. These visits need to be examined to determine adequate time for the visits and appropriate personnel necessary, and to be adequately covered by public or private insurers. The data also revealed that policy may need to identify children with moderate to severe functional limitations so that they can qualify for an increased number of PPC office visits. Future research needs to focus on parental satisfaction with communication and what factors are associated with access to medical homes for families of children with moderate and severe functional limitations.

The data did not support the hypothesis that CSHCN with a medical home would have fewer missed school days due to illness. Future research is necessary to analyze the association between parental perceptions of their child's health status with number of missed school days. Further, parental health perception may be associated with medical home. A thorough examination of adequacy of communication between family and healthcare provider in the medical home may reveal a negative association with number of missed school days. The policy implications from the study data that medical home is not associated with a decrease in missed school days could be to make medical home for CSHCN a school based clinic model. This idea might best be viewed from the 1967 perspective of medical home the AAP put forth, that it was a central source for the child's pediatric record. The school based medical home is an ideal setting to improve upon accessibility, to be continuous, family-centered, compassionate and culturally effective. Legislation must make allowance for care coordinators for CSHCN with moderate and severe functional limitations. Future research to determine the value of cost savings from

paying salaries of care coordinators compared to paying for ED visits for CSHCN would add tremendously to the body of knowledge.

Understanding disparities in health care experiences among CSHCN is essential to develop community-based service systems that are effective in meeting the needs of the most fragile. This research carries importance because of the evidence that the poorest, most vulnerable children are not receiving services on an equal level with other children. If policy makers, gatekeepers, and state legislators aim to meet the needs of the most vulnerable children, then it seems more likely all CSHCN will receive services. This data identifies that functional limitation of CSHCN is an important factor for disparities in their health care. Functional limitation, cultural sensitivity, and education should be considered in program planning for CSHCN. This definitely requires detailed investigation in future studies so that policies focused on overcoming barriers by taking into consideration these factors should be made. These factors should be considered for national and state policies when planning for health care services for CSHCN to optimize the utilization of cost effective, continuous, and comprehensive care.

Another important aspect regarding CSHCN and medical homes is that for those with some chronic conditions there may be more than one 'usual source of care', or more commonly known as a model of shared management for the child. An example of this might be the CSHCN with cerebral palsy who has involvement of multiple organ systems. Future research would be strengthened with in depth examination into the models of primary care management used to define 'usual source of care' for different strata of functional limitations of CSHCN. Some CSHCN with relatively common, uncomplicated conditions, such as those with moderate asthma, would be best served

with the primary care pediatrician (PCP) as the primary manager. In the opposite situation, in which the child's condition or problem is more severe, or limited to one specialty, the specialist may best serve as primary manager. Whereas when a CSHCN has a complex condition, shared management requiring the greatest of medical home resources may be required. Further research in practice management areas of the medical home models may reveal new methods for physicians and mid-level providers to provide cost efficient and comprehensive care for a greater number of CSHCN. For example, a 2007 study found that having at least the recommended number of EPSDT visits may shift some health provision from the ED to pediatrician's offices (Pittard, Laditka, & Laditka, 2007). Nurse practitioners and physicians assistants are adequately trained and often more available to travel to rural areas to perform such preventive care measures such as EPSDT visits. The federal government is supplementing professional staff at federally qualified community health centers by nurse loan repayments and by providing grant monies to establish electronic health records to supplement continuity of care. These efforts may support coordination and continuity of care for all children with special needs. Future research is needed to determine if these variations in funding and staffing of medical homes are associated with increased access to partnership based comprehensive primary care and health behavior changes among families that enhance comprehensive and coordinated care of children with special needs.

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TABLE 1: Characteristics for Children with Special Health Care Needs and Medical Home Components

	Unweighted (n)	Weighted (%)	Usual source of care	Personal MD or RN	Family centered care	Satisfied with communication	Partner centered care	Medical Home
Total Population	40,723		95.7	94.3	90.1	92.7	88.5	
Medical Home								
Yes	28,111							66.4
No	12,612							33.6
Age								
0-5 y	7,416	18	96.8	95.9	91.3	93.1	90.7	72.0
6-11 y	17,988	44	95.7	94.3	90.3	93.0	89.0	69.7
12-17 y	15,319	38	95.1	94.1	89.3	92.4	87.0	66.8
Gender								
Male	24,150	59	95.6	94.1	90.1	92.6	88.4	68.6
Female	16,498	41	96.7	94.5	90.1	92.9	88.8	69.7
Race/Ethnicity								
NH White	29,052	72	96.3	95.5	92.7	93.5	90.5	73.2
NH Black	4,189	10	94.3	90.8	82.8	92.4	83.4	57.3
NH Multi racial	1,642	4	95.7	93.5	89.2	91.9	86.7	67.11
NH Other race	1,532	4	93.9	91.7	85.1	90.6	84.7	60.8
Hispanic	4,016	10	96.7	90.6	81.1	89.2	81.3	55.6
MSA								
Urban	22,012	78	95.8	94.0	89.8	92.5	88.2	68.6
Rural	6,139	22	95.8	94.3	90.3	93.5	89.1	69.3
Poverty level								
< 200 % FPL	13,348	36	94.2	91.6	84.3	90.6	84.1	59.9
> = 200 % FPL	23,684	64	96.7	96.1	93.4	93.9	91.1	74.8
Functional status								
some/little limitations	20,260	82	95.6	94.1	88.5	92.1	87.1	67.5
severe limitations	4,526	18	94.6	93.4	82.8	81.7	79.5	57.0
Insurance								
Uninsured	1,437	4	87.1	82.7	77.8	85.6	77.1	43.1
Insured	39,197	96	96.0	94.8	90.6	93.0	88.9	70.0
Education								
<HS graduate	1,908	5	90.9	87.9	76.9	91.1	79.3	47.7
=HS graduate	6,449	16	94.1	91.1	85.8	93.5	85.9	61.2
>HS graduate	32,284	79	96.3	95.4	91.7	93.7	89.6	71.9

TABLE 2: Weighted and Unweighted Frequencies and Percentages of Emergency Department Visits (N=40,723)

Variable Description	Unweighted n (%)	Weighted %
ED Visits		
0-3 visits	38,451 (94.4)	93.9
4-10 visits	1,844 (4.5)	5.2
11 or more visits	323 (0.8)	0.9
Missing	105 (0.3)	0.3

TABLE 3: Ordered Logistic Regression Analysis of Emergency Department Visit Outcome as a Function of Predictors of Medical Home (N=36,577)

Variable Description	Unadjusted Analysis		Adjusted Analysis	
	OR	95% CI	OR	95% CI
Medical Home				
No	1.00			
Yes	0.64	0.55-0.74	0.82	0.71-1.01±
Age				
0-5 y	1.00		1.00	
6-11 y	0.42	0.35-0.50	0.38	0.31-0.46
12-17 y	0.46	0.37-0.56	0.40	0.32-0.49
Gender				
Male	1.00		1.00	
Female	1.14	0.98-1.32±	1.29	1.09-1.51±
Ethnicity/Race				
NH White	1.00		1.00	
NH Black	2.64	2.21-3.16	1.87	1.51-2.30
NH Multiracial	1.49	1.09-2.04	1.28	0.92-1.76±
NH Other	0.96	0.68-1.35	0.94	0.64-1.36±
Hispanic	1.70	1.34-2.15	1.15	0.88-1.52±
Functional Status				
Minor	1.00		1.00	
Moderate	2.12	1.77-2.52	2.08	1.71-2.51
Severe	4.54	3.68-5.61	3.69	2.90-4.70
Missing	0.31	0.23-0.43	0.35	0.24-0.48
Poverty Level of Household				
< 200% FPG	1.00		1.00	
>= 200% FPG	0.30	0.26-0.30	0.54	0.44-0.66
Education level in House Hold				
< High school diploma	1.00		1.00	
> High school graduate	0.87	0.67-1.12	1.14	0.85-1.52±
Insurance Status				
Insured	1.00		1.00	
Uninsured	1.39	1.33-1.46	0.78	0.53-1.17
Metropolitan Statistical Area				
Urban	1.00		1.00	
Rural	1.74	1.47-2.07	1.65	1.37-1.98
Missing	1.01	0.85-1.19	1.15	0.95-1.39

± Not statistically significant $p > 0.05$

TABLE 4: Weighted and Unweighted Frequencies and Percentages of Pediatric Primary Care Office Visits (N=40,723)

Variable description	unweighted n (%)	weighted (%)
Office Visits		
0-5	25,852 (63.48)	63.56
6 or more	14,414 (35.40)	36.44
Missing	457 (1.12)	---

TABLE 5: Logistic Regression of Pediatric Primary Care Office Visits on Medical Home Independent Variable and Confounders (N = 32,897)

Variable	Unadjusted Analysis		Adjusted Analysis±	
	OR	95% CI	AOR	95% CI
Medical Home				
No	1.00			
Yes	1.50	1.40-1.61	1.60	1.47-1.75
Age				
0-5 y	1.00			
6-11 y	0.69	0.63-0.75	0.64	0.58-0.70
12-17 y	0.65	0.59-0.71	0.58	0.52-0.64
Gender				
Male	1.00			
Female	1.15	1.08-1.23	1.27	1.17-1.36
Race/Ethnicity				
NH White	1.00			
NH Black	0.62	0.56-0.68	0.51	0.45-0.57
NH Multi-race	0.98	0.81-1.18	0.95	0.79-1.13±
NH Other	0.71	0.60-0.84	0.74	0.61-0.90
Hispanic	0.77	0.69-0.86	0.77	0.67-0.88
Functional Status				
Minor	1.00			
Moderate	2.06	1.90-2.22	2.35	2.15-2.57
Severe	3.74	3.26-4.29	4.66	3.95-5.49
Missing	0.79	0.72-0.86	0.71	0.65-0.78
Poverty				
< 200% FPL	1.00			
>= 200% FPL	0.88	0.82-0.94	0.98	0.88-1.09
Education				
< High school diploma	1.00			
> High school diploma	1.41	1.21-1.63	1.53	1.27-1.86
MSA				
Urban	1.00			
Rural	1.23	1.14-1.34	1.15	1.05-1.26
Missing	1.02	0.95-1.09	0.97	0.89-1.05
Insurance Status				
Insured	1.00			
Uninsured	0.54	0.46-0.64	0.56	0.46-0.68

± Not statistically significant $p > 0.05$

TABLE 6: Analysis of PPC Office Visits (6 or more) on Medical Home and Functional Status of Children with Special Health Care Needs

Variable	Adjusted Odds Ratio	95% CI
Medical Home		
No	1.00	
Yes	1.59	1.46-1.72
Functional Status		
Minor limitations	1.00	
Moderate limitations	2.14	1.97-2.32
Severe limitations	3.49	3.03-4.01
Missing	0.73	0.65-0.81

Model: $F(4, 40,212) = 180.40, p < .0005$

TABLE 7: Analysis of PPC office visits (6 or more) on Medical Home and Race/Ethnicity of Children with Special Health Care Needs

Variable	Adjusted Odds Ratio	95% CI
Medical Home		
No	1.00	
Yes	1.22	1.17-1.28
Race and Ethnicity		
NH White	1.00	
NH Black	0.70	0.65-0.75
NH Multiracial	1.09±	0.99-1.21
NH Other race	0.91±	0.81-1.01
Hispanic	0.95±	0.89-1.02

Model: $F(5, 39,924) = 23.86, p < .0005$
± Not statistically significant, $p > 0.05$

TABLE 8: Bivariate Analysis of Variables with Missed School Days among Children with Special Health Care Needs

Independent Variables	Missed School Days						p-value
	0 – 3		4 – 7		8 - 14		
	Weighted %	Unweighted n	Weighted %	Unweighted n	Weighted %	Unweighted n	
Medical Home							0.256
Yes	52	12,386	25	5,990	23	5,368	
No	36	9,007	8	1,211	6	1262	
Age							
0-5 y	51	1,013	26	454	22	380	0.0002
6–11 y	52	7,833	26	3,840	22	4,174	
12–17 y	51	380	23	3,222	25	4,504	
Gender							0.0000
Female	49	6,834	24	3,505	22	3,601	
Male	54	11,041	25	4,946	26	4,487	
Race /Ethnicity							0.0007
NH White	51	12,949	25	6,245	24	5,736	
NH Black	56	1,967	22	768	22	772	
NH Multiracial	48	627	25	309	27	386	
NH Other	57	644	21	301	22	313	
Hispanic	48	1,586	26	791	25	842	
MSA							0.0000
Urban	52	9,855	24	4,571	23	4,184	
Rural	48	2,485	25	1,242	27	1,406	
Insurance							0.0481
Uninsured	51	602	21	286	28	355	
Insured	52	17,254	25	8,172	24	7,731	
Poverty							0.0000
< 200 % FPL	44	4,914	24	2,633	31	3,523	
>=200 % FPL	55	11,209	25	5,134	19	3,978	
Education							
< high school	52	926	24	440	24	426	0.9407
> High school	52	16,796	25	7964	24	7600	
Functional							0.0000
minor limits	55	8,610	26	4,730	18	851	
moderate limits	44	3,972	24	2,837	31	515	
severe limits	32	2,707	22	3,676	45	1,218	

Weighted % : Survey weighted percentages

Unweighted n: Frequency of sample observations

TABLE 9: Odds Ratios (95% CI) for Missed School Days among Children with Special Health Care Needs (N 34,375)

Variable Description	Adjusted Odds Ratio (95% CI)	Unadjusted Odds Ratio (95% CI)
Medical Home		
No	1.00	1.00
Yes	2.46 (1.46-3.16)	1.67 (0.70-2.87)
Age		
0-3y	1.00	1.00
4-12 y	.89 (0.72-1.00)±	1.06 (0.99-1.26)±
13-18y	.90 (0.84-1.11)±	1.18 (1.08-1.42)
Gender		
Male	1.00	1.00
Female	1.27 (1.18-1.37)	1.17 (1.11-1.25)
Race/Ethnicity		
NH White	1.00	1.00
NH Black	0.77 (0.71-0.87)	0.90 (0.81-1.10)
NH Multiracial	1.16 (0.95-1.42)±	1.26 (1.13-1.40)
NH Other	0.76 (0.54-1.07)±	1.05 (0.95-1.17)±
Hispanic	1.02 (0.86-1.21)±	1.13 (1.06-1.22)
MSA Status		
Urban	1.00	1.00
Rural	1.03 (0.92-1.16)±	1.05 (1.01-1.10)±
Poverty		
<200 % FPL	1.00	1.00
>= 200 % FPL	0.67 (0.59-0.74)	0.59 (0.55-0.66)
Education		
<High school	1.00	1.00
>High school	1.20 (0.92-1.56)	0.83 (0.78-0.88)
Functional Status of child		
Minor limitations	1.00	1.00
Moderate limitations	1.79 (1.61-1.99)	1.92 (1.83-2.01)
Severe Limitations	2.90 (2.36-3.54)	3.30 (3.05-3.58)

±Not statistically significant $p = >0.05$

All results survey weighted

APPENDIX A: VARIABLE CODE FOR REGRESSION ANALYSIS: 2005-2006
NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE
NEEDS

Variable Name	Variable Description	Variable Code
edvisits	Emergency Department Visits	0 = 0-3 1 = 4-10 2 = 11+
ppevisits	Pediatric Primary Care Visits	0=0-5 1=6+
misschool	Missed School Days	0 = 0-3 1 = 4-7 2 = 8-13
medhome	Classification as medical home	0 = no 1 = yes
age	Age group of child	0 = 0-5 years 1 = 6-11 years 2 = 12-17 years
sex	Gender of child	0 = male 1 = female
ethn	Ethnicity of Child	0 = Non-Hispanic White 1 = Non-Hispanic Black 2 = Non-Hispanic Multi-race 3 = Non-Hispanic Other Race 4 = Hispanic
functsta	Functional status of child	0 = minor limits 1 = moderate limits 2 = severe limits
povlevel	Poverty level of household	0 = <200% FPL 1 = >200% FPL
educr	Highest level of education of anyone living in the household	0 = Less than high school diploma 1 = High school graduate
unins	Insurance status	0 = insured 1 = uninsured
msastatr	Metropolitan statistical area (MSA) of residence	0 = urban 1 = rural