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The use of the patient-centered medical home for children with medical complexity

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BOSTON UNIVERSITY
SCHOOL OF MEDICINE

Thesis

**THE USE OF THE PATIENT-CENTERED MEDICAL HOME FOR CHILDREN
WITH MEDICAL COMPLEXITY**

by

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ABSTRACT

Children with medical complexity (CMC) comprise a small amount of total pediatric patients but contribute to a large portion of total pediatric spending and health care utilization. As a result, there is great interest in creating innovations in their health care delivery systems to improve their quality of care and contain costs. One unique aspect of the health care of CMC is its fragmented nature. Since CMC commonly have multiple co-morbidities, they often receive care from several different specialists at any given time. The patient-centered medical home (PCMH) was previously suggested as a possible tool to improve the fragmented care of CMC. Although definitions of the medical home vary, common themes are its function to better coordinate and integrate the care of patients. Current studies suggest that many CMC do not make regular primary care visits or receive care that fulfills a majority of the components of a medical home. In addition, according to the limited studies that exist which examine CMC and other children with special health care needs (CSHCN), primary care and medical home usage amongst these populations may reduce the occurrence of preventable medical events like hospital readmissions or emergency department visits. Therefore, further research and work should be conducted to examine the feasibility and actions that must be conducted in order to increase the prevalence of these medical home programs amongst CMC.

TABLE OF CONTENTS

TITLE.....	i
COPYRIGHT PAGE.....	ii
READER APPROVAL PAGE.....	iii
ABSTRACT.....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES.....	vii
LIST OF FIGURES.....	viii
LIST OF ABBREVIATIONS.....	ix
I. INTRODUCTION.....	1
<i>Specific Aims</i>	5
II. HEALTH CARE UTILIZATION TRENDS OF CHILDREN WITH MEDICAL COMPLEXITY.....	6
<i>Health care spending</i>	6
<i>Hospitalizations and readmissions</i>	7
<i>Emergency department visits</i>	10
<i>Other unmet needs</i>	10

III. HOSPITALIZATIONS, READMISSIONS, AND THEIR PREVENTABILITY.....	12
IV. DESCRIPTION OF THE PATIENT-CENTERED MEDICAL HOME AND ITS RECOMMENDATION FOR CHILDREN WITH MEDICAL COMPLEXITY.....	16
<i>Medical home models for children with medical complexity</i>	17
<i>Clinician attitudes towards the medical home</i>	23
V. DATA ON THE CURRENT USAGE OF THE PATIENT-CENTERED MEDICAL HOME AMONG CHILDREN WITH MEDICAL COMPLEXITY	25
VI. THE RELATIONSHIP BETWEEN THE USE OF THE PATIENT-CENTERED MEDICAL HOME AND THE HEALTH OUTCOMES OF CHILDREN WITH MEDICAL COMPLEXITY	27
<i>Medical home usage in general pediatric patients</i>	27
VII. CONCLUSION AND RECOMMENDATIONS	34
<i>CMC vs. CSHCN</i>	35
<i>Multiple Definitions of the Medical Home</i>	36
<i>Barriers to medical home implementation</i>	37
REFERENCES	38
VITA	46

LIST OF TABLES

Table	Title	Page
1	Health care costs for CMC with Medicaid	7
2	The Medical Home Index	20
3	Barriers to care coordination of CSHCN reported by outpatient pediatricians	24

LIST OF FIGURES

Figure	Title	Page
1	Operational definition of CMC	2
2	Hospitalization rates for children with complex chronic conditions	4
3	A rise in inpatient hospital use by children with CCC between 1997 and 2006	9
4	The preventability of 30-day readmissions over time	13
5	Other policies that could be funded by reduction in inpatient resource utilization by CMC	15
6	A model for the coordinative function of a medical home	19
7	The approach of Perrin et al. in modeling community-based services for CSHCN	21
8	Integration of health care delivery for CSHCN	22
9	Effect of a tertiary-care medical home program on the resource utilization of CMC	30

LIST OF ABBREVIATIONS

ACO	Accountable Care Organization
AHRQ	Agency for Healthcare Research and Quality
CMC	Children with medical complexity
CSHCN	Children with special health care needs
CCC	Chronic complex conditions
MHI	Medical Home Index
NS-CSHCN	The National Survey of Children with Special Health Care Needs
PCMH	Patient-centered medical home
PCP	Primary care physician

I. INTRODUCTION

Children with medical complexity (CMC) are children who have particularly complicated medical conditions and require extensive health care utilization. They comprise a subset of a broader category of pediatric patients, Children With Special Health Care Needs (CSHCN). CSHCN are defined as children, “who have or are at increased risk for a chronic physical developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998). Previous reports estimate that 18% of children in the US have special health care needs (Newacheck et al., 1998). It is important to identify children who fall under the category of CSHCN since they require specific health care programs to meet their unique medical needs. Failure to properly identify the special health care needs of these children could result in the provision of low quality care that leads to poor health outcomes or ineffective care that results in increased medical costs.

As compared to CSHCN, CMC typically have more serious medical conditions and utilize greater amounts of health care resources. Cohen et al. created a formal definition of CMC that includes four criteria: Needs, Chronic Condition(s), Functional Limitations, and Health care use (See Figure 1) (Cohen et al., 2011). CMC require extensive utilization of health care services to satisfy their needs, with the burden falling upon the child’s to ensure their child meets this increased demand. The utilization of health care can vary throughout a child’s lifetime. As defined by Cohen et al., chronic conditions can be either diagnosed or unknown, and are typically severe or associated

with medical fragility (e.g., high morbidity and mortality rates). Cohen et al. define functional limitations as those, “using key dimensions of body structure and function, performance of activities, and participation in communal life.” Lastly, Cohen et al. describe CMC as having, “high projected utilization of health resources that may include frequent or prolonged hospitalization, multiple surgeries, or the ongoing involvement of multiple subspecialty services and providers.”

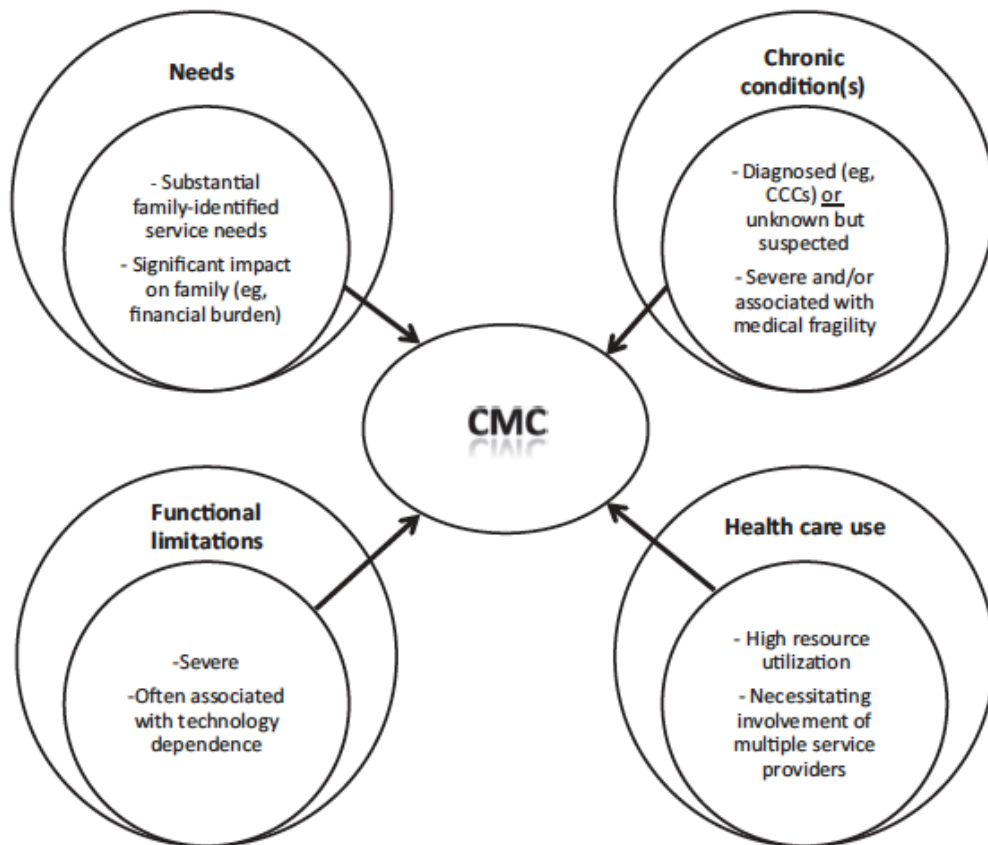


Figure 1. Operational definition of CMC(Cohen et al., 2011)

The National Survey of Children with Special Health Care Needs (NS-CSHCN) was a survey that took place between 2001 and 2010 with the purpose of gathering more

information about CSHCN (“National Survey of Children with Special Health Care Needs--Data Resource Center,” n.d.). According to data from this survey, 13% of children could be classified as CSHCN in 2001 (Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). When examining CSHCN, 3% of the children within this category also met the definition for classification as CMC (Kuo, Cohen, Agrawal, Berry, & Casey, 2011). Further analysis of NS-CSHCN found that 59% of families of CMC faced hardships financially and more than half of families of CMC reported one family member forgoing employment in order to care for their child (Kuo et al., 2011). Roughly half of families of CMC also reported having one or more unmet medical needs and one-third reported facing difficulty accessing non-medical services(Kuo et al., 2011).

The prevalence and hospitalization rates of CMC have also been demonstrated to be on the rise (See Figure 2) (Burns et al., 2010). However, evidence demonstrates that the actual incidence of disease commonly associated with CMC, such as cerebral palsy, has been fairly consistent over past years (Burns et al., 2010). The increased incidence could be due to a number of factors involving the improvement of medical care for children born with complicated medical disorders. For example, there has been vast improvement in the survival rates of children born with very low birth weights (Kaiser, Tilford, Simpson, Salhab, & Rosenfeld, 2004). Improvements in medical technology, such as the use of gastrostomy tubes in children with cerebral palsy, also contribute to the increased incidence of CMC (Sullivan et al., 2005). With improvements and innovations in the treatment options for CMC, they are surviving adverse medical events at greater rates and living longer.

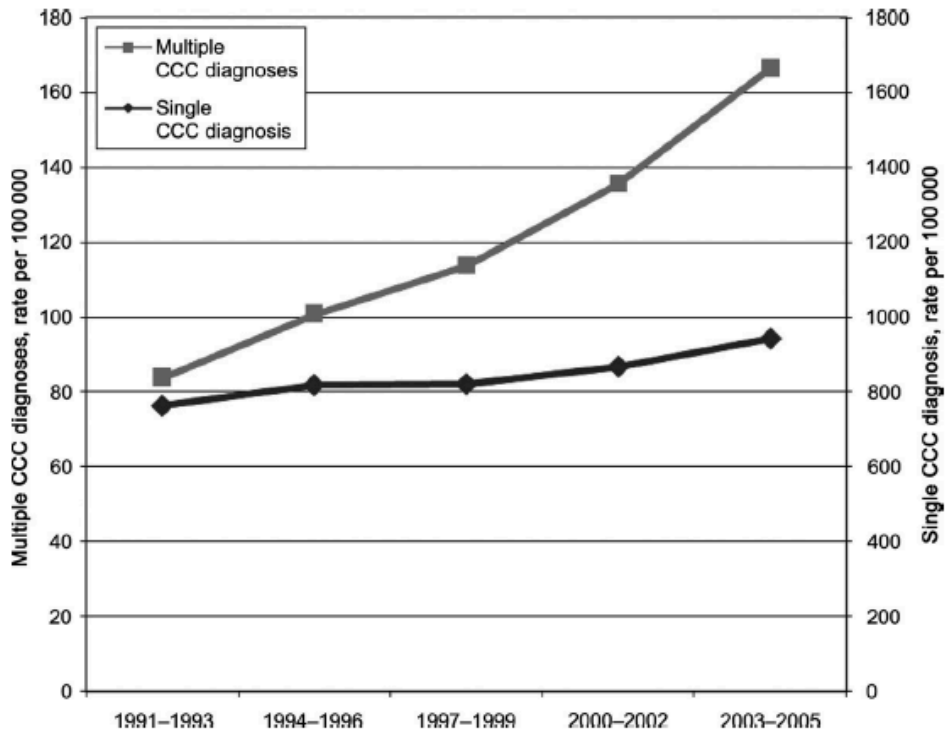


Figure 2. Hospitalization rates for children with complex chronic conditions (Burns et al., 2010)

Clearly, CMC and their families face tremendous long-term challenges as a result of the child’s illness. Much effort has been made to improve the quality of care of CMC in order to improve their health outcomes and health care experience, as well as to reduce preventable medical events and spending. One particularly popular idea has been that of the medical home (Sia, Tonniges, Osterhus, & Taba, 2004). Since CMC commonly have multiple co-morbidities, they sometimes receive care from several different health care providers and specialists. Thus, one cause of the potentially low-quality care received by CMC could be the fragmented nature of their health care, in the absence of a central care provider acting as an overseer and coordinator. The implementation of a medical home for all CMC has been suggested as a potential remedy for this fragmented care and a

solution to help improve the medical outcomes of this patient population (American Academy of Pediatrics, 2002).

Specific Aims

This thesis aims to elucidate and evaluate the recommendation for medical home implementation for CMC. In the second section of thesis, there will be a description of the health care utilization trends of CMC in order to target specific areas in which the health care of CMC is lacking. Next, there will be an analysis of current literature on some of the possible disagreements over whether medical events such as readmissions are actually preventable for CMC and pediatric patients in general. The fourth section of the thesis will serve to set the foundation of the patient-centered medical home and the theories behind its recommendation for CMC. After doing so, current literature will be reviewed to determine whether an accurate measurement for current PCMH usage amongst CMC exists. Current literature regarding the possible effects of PCMH usage amongst CMC on health outcomes will also be reviewed. Finally, there will be a discussion of the merits and limitations of PCMH implementation to improve the health outcomes of CMC, as well as recommendations for future research surrounding these topics.

II. HEALTH CARE UTILIZATION TRENDS OF CHILDREN WITH MEDICAL COMPLEXITY

A growing trend in health policy work has been to target patient groups who contribute to a disproportionate amount of health care spending in order to contain costs; CMC are a model example of such a population. As previously suggested, CMC utilize a disproportionately high amount of health care resources as a result of their unique medical characteristics. Utilization of health care services can be measured through several metrics, including spending, hospitalizations, readmissions, and ER visits.

Health care spending

Cohen et al. examined the health care spending patterns of a pediatric patient population in Ontario, Canada (Cohen et al., 2012). While CMC made up 0.67% of the total number of pediatric patients, they contributed to 33% of pediatric health care costs in this region. The top three costs were attributed to rehospitalizations, home care, and physician services. This same trend was found in the US. CMC were responsible for one-third of Medicaid spending while only comprising 6% of pediatric Medicaid patients; 50% of these health care costs could be attributed to a smaller group of 5% of CMC (Berry et al., 2014). The top costs for CMC on Medicaid within this study were out-of-hospital care, outpatient specialty and other care, and prescription drugs (See Table 1). In both of these studies, outpatient spending contributed to a significant amount of total spending.

Health Service	Children Using the Health Service (%)	Annual spending per child (\$)	Health care spending for children with medical complexity (%)
Hospital care	13.0	5,903	47.2
Outpatient specialty and other care	66.0	3,136	25.1
Medications	89.9	1,677	13.4
Outpatient therapy	22.4	593	4.7
Emergency care	32.3	383	3.1
Primary care	59.6	275	2.2
Laboratory and radiographic testing	54.9	230	1.8
Home health care	3.2	204	1.6
Medical equipment and supplies	16.7	98	0.8

Table 1. Health care costs for CMC with Medicaid. Table copied from (Berry et al., 2014)

Hospitalizations and readmissions

CMC require a large amount of inpatient resources as well. When examining rates of readmission in children’s hospitals around the nation, Berry et al. found that as rates of readmission increased, so did the proportion of patients with complex chronic conditions (CCC) (Berry et al., 2011). In a total sample of 69,294 pediatric patients, 3% of individuals had 4 or more readmissions within a 1-year period of initial admission. 19% of total hospital admissions and 23% of spending can be attributed to individuals who had

4 or more readmissions. Pediatric patients within this group are likely to be those who qualify as CMC. Patients within this group were more likely to suffer from a complex chronic condition and require technological medical assistance. The authors determined that 29% of children with 4 or more readmissions were readmitted for issues related to the organ system they were initially hospitalized for. Other characteristics of individuals within this subset of high frequency hospital readmissions were an increased likelihood of utilizing public insurance and identifying as non-Hispanic black.

Another study examining readmissions at a children's hospital found 44% of all 15-day readmissions were due to a small group of pediatric patients with 3 or more readmissions, with most of these patients suffering from some sort of chronic condition (Gay, Hain, Grantham, & Saville, 2011). Jurgens et al. report that among a sample of children with complex chronic conditions, 19% had one or more 30-day readmissions (Jurgens, Spaeder, Pavuluri, & Waldman, 2014). In another retrospective cohort study of children with cerebral palsy, slightly more than half of patients within the cohort had one or more same-day admissions within a four-year period (Meehan et al., 2015).

Increased rates of hospitalizations and inpatient readmissions are a common trait for CMC. As mentioned before, the prevalence of CMC has been reported to be increasing; this same trend has also been seen in the use of inpatient resources by CMC. Simon et al. report a rise in the proportion of hospital admissions, hospital days, and hospital charges attributed to US children with one or more CCC (See Figure 3) (Simon et al., 2010).

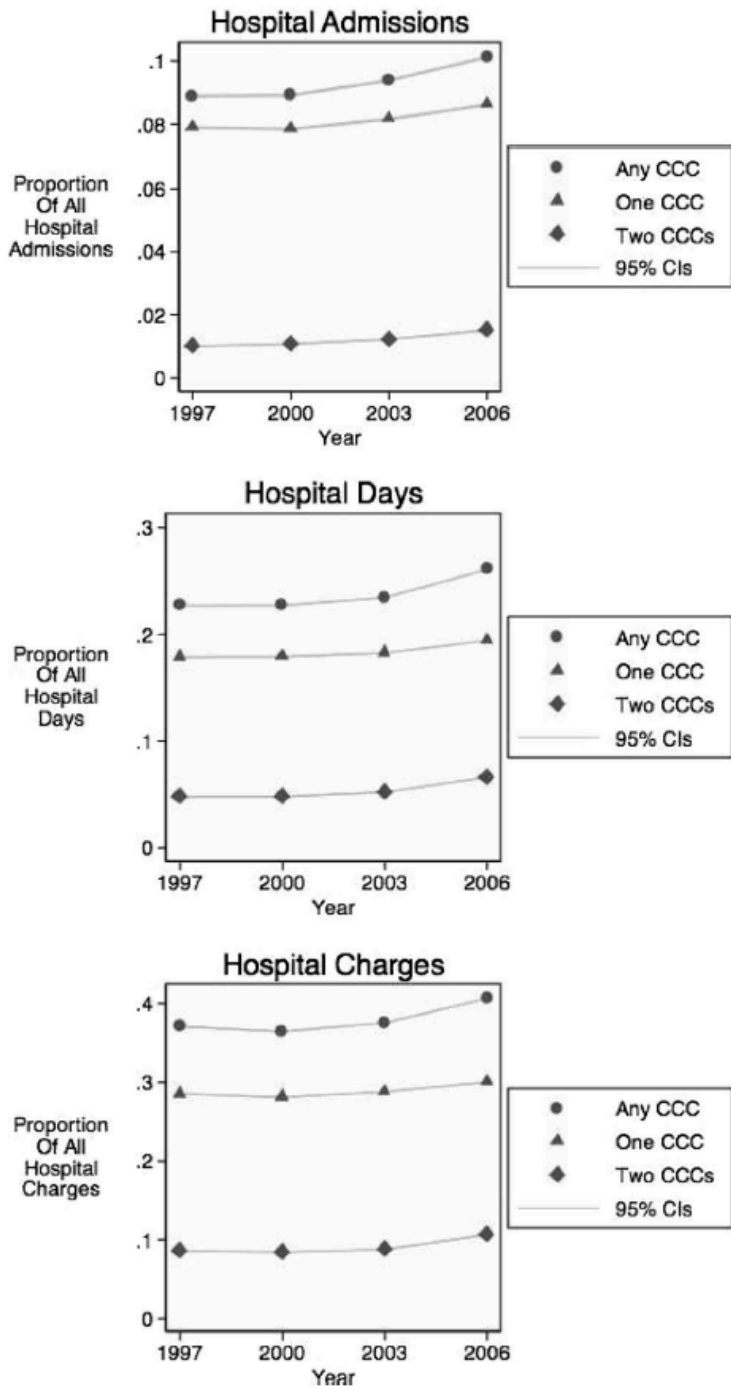


Figure 3. A rise in inpatient hospital use by children with CCC between 1997 and 2006 (Simon et al., 2010)

Emergency department visits

In addition to inpatient services, CMC also account for a disproportionate amount of emergency department visits (Hudson, 2013). Most pediatric patients with repeated emergency visits have some sort of chronic disease, with neurologic conditions, commonly found in CMC being the most common type of condition among repeat emergency department visitors (Yamamoto et al., 1995). The use of medical technology, which is also commonly found in CMC, has been shown to increase the utilization of emergency department services among pediatric patients, as well as readmission rates within 30 days of hospital discharge (Goldin et al., 2016). Almost one-third of all CMC on Medicaid had at least one emergency department visit (Berry et al., 2014).

Other unmet needs

CMC and their families are more likely to have a greater number of unmet needs as well. For example, it has been demonstrated that over time, the amount of unmet dental, therapy, and other health service needs have grown for CMC (Sannicandro, Parish, Son, & Powell, 2016). Due to the logistical aspects of caring for CMC, much stress is placed on the families of CMC. Familial caregivers of CMC are more likely to report both financial and psychological stress (Goudie, Narcisse, Hall, & Kuo, 2014). Caretaking for CSHCN has also been implicated to have an effect on the employment status of the parents of CSHCN; roughly a quarter of the parents of CSHCN have reported to have lost employment due to the burden of caring for their child (Okumura, Van Cleave, Gnanasekaran, & Houtrow, 2009). It has also been demonstrated that insurance coverage does not decrease the likelihood that a CMC's family will face

employment loss or financial hardships (Chen & Newacheck, 2006). As a result of these various challenges, there is an increased demand for social services among families of CMC. When compared to children without medical complexity, CMC were more likely to utilize social services and also utilized these social services to a greater degree (Coquillette, Cox, Cheek, & Webster, 2015).

III. HOSPITALIZATIONS, READMISSIONS, AND THEIR PREVENTABILITY

While it is clear that CMC have higher rates of health care utilization for medical events such as readmissions and hospitalizations, there is some debate as to whether these medical events are preventable. For example, Hain et al. conducted a retrospective chart review of patients admitted to a children's hospital in order to determine the degree to which 15-day readmissions could have been prevented by the hospital that discharged the patient initially (Hain et al., 2013). According to the pediatricians who assessed the preventability of readmissions, they concluded only 20% of the 15-day readmissions could have been prevented. The authors point out that this value is "4 times lower than that of adults" (Hain et al., 2013). The authors concluded that "[pediatric] readmissions are unlikely to serve as a highly productive focus for cost savings or quality measurement" (Hain et al., 2013). Gay et al. reached similar conclusions after analyzing preventable readmissions for 1,531,828 patients who were hospitalized at 58 different children's hospitals (Gay et al., 2015). The authors argued that only 4% of 15-day readmissions and 6% of 30-day readmissions could have been prevented. They also calculated that preventable readmissions accounted for 27% of total readmission costs. The parents of CMC themselves were found to believe hospitalizations of their children were unavoidable due to the nature of their medical conditions (Nelson et al., 2016).

However, possibly due to the subjectivity of the judgment by which Hain et al. and Gay et al. determined whether or not readmissions were preventable, there have been other studies that portray a slightly more optimistic picture. For example, Toomey et al.

employed a similar analytical method as Hain et al. and Gay et al. when evaluating preventable readmissions at a single children’s hospital (Toomey et al., 2016). Their evaluation of medical records determined 30% of the 30-day readmissions were preventable. According to their evaluation, the probability that a readmission could be prevented was related to the number of days that passed from discharge, and the relationship of the precipitating event for readmission to a chronic disease, causal factor, or contributing factor (See Figure 4).

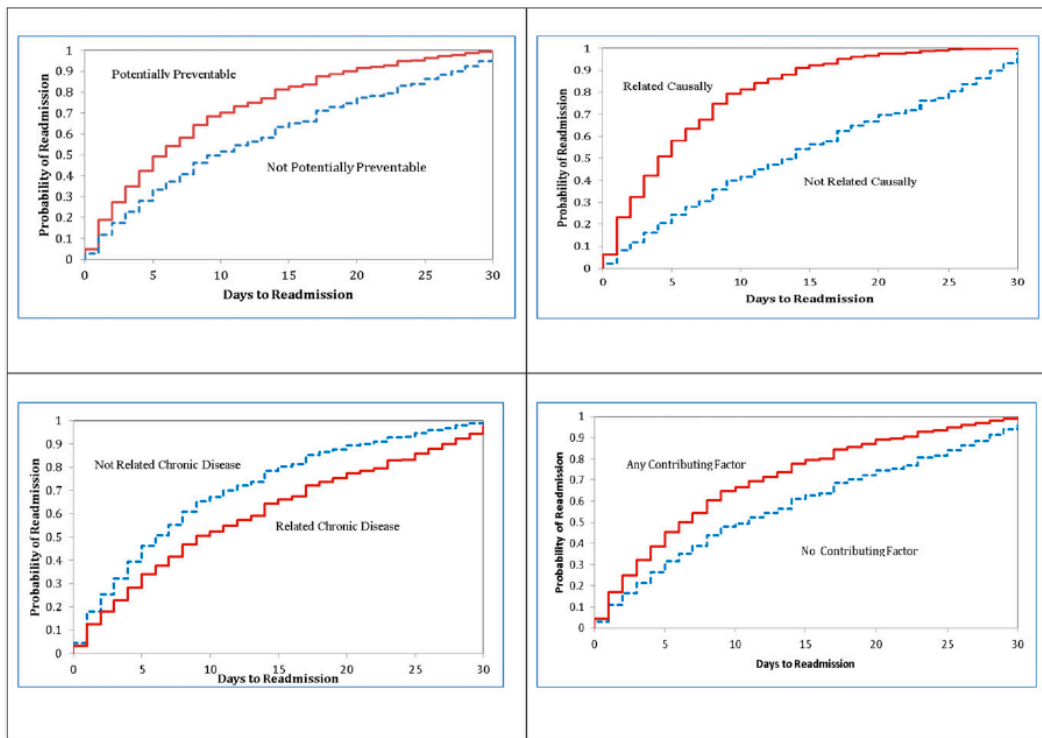


Figure 4. The preventability of 30-day readmissions over time (Toomey et al., 2016)

Hain et al. and Gay et al. examined the preventability of readmissions from the perspective of the discharging facility. In other words, they sought to determine whether there were steps or modifications the hospital could have taken in order to decrease the

likelihood of readmission of the patient being discharged. As a result, the possibility of reducing readmissions by modifying external factors, like primary care accessibility or increasing outpatient coordination, was not addressed.

In addition, these studies examined the pediatric population in general and not CMC specifically. Since CMC have markedly lower quality and more fragmented care than the average pediatric patient, interventions targeted specifically towards them and modifications in their health care delivery could provide substantially more noticeable improvements in readmission and hospitalization rates. Their standard of care is lower than the average pediatric patient's standard of care, so there is more room for improvement.

Therefore, it may still be a rewarding goal to reduce the hospitalization and readmission rates of CMC. Not only would reducing the rates of these preventable medical events decrease some of the burdens faced by CMC and their families, but various other policies targeted towards improving the health care of CMC could be funded with the savings. Indeed, Berry et al. outlined several policies that could be funded from a modest reduction in hospital use by CMC (See Figure 5). The rest of this paper will serve to examine the ability to reduce these preventable medical events through the modification of one of these external factors, namely increased primary care and medical home use for CMC.

Percentage Of Children With Medical Complexity Who Could Receive Four Care Management Approaches With Funds Available From A 10 Percent Reduction In Hospital Lengths-Of-Stay

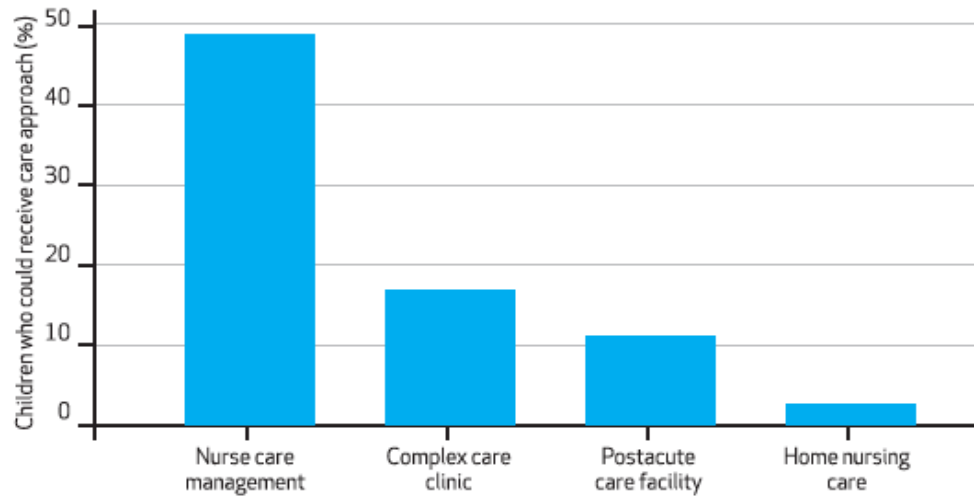


Figure 5. Other policies that could be funded by reduction in inpatient resource utilization by CMC (Berry et al., 2014)

IV. DESCRIPTION OF THE PATIENT-CENTERED MEDICAL HOME AND ITS RECOMMENDATION FOR CHILDREN WITH MEDICAL COMPLEXITY

The patient-centered medical home framework was developed to improve the quality of primary care provided by clinicians. While the first usage of the phrase medical home referred to an actual physical location that served as, “a single source of all medical information about a patient,” current usage refers to the medical home as, “a partnership approach with families to provide primary health care”(Sia et al., 2004). The Agency for Healthcare Research and Quality (AHRQ) defines the PCMH as the “model of the organization of primary care that delivers the core functions of primary health care,” which the AHRQ lists as Comprehensive Care, Patient-Centered, Coordinated Care, Accessible Services, and Quality and Safety (“Defining the PCMH | PCMH Resource Center,” n.d.). Stange et al. list the PCMH as consisting of:

1. The fundamental tenets of primary care: access, comprehensiveness, integration and relationship
2. New ways of organizing practice
3. Development of practices’ internal capabilities
4. Health care system and reimbursement changes (Stange et al., 2010)

Ideally, as a medical practice adopts more features of a PCMH, they will deliver more effective and efficient primary care while also improving patient outcomes and patient satisfaction. Therefore, the PCMH can be viewed as a tool that simultaneously improves the quality of person-centered care, reduces health care costs through increased prevention of unnecessary medical costs, and provides greater access to primary care.

Medical home models for children with medical complexity

The PCMH has long been recommended for CMC as a way to improve their health care experience. In 2002, the American Academy of Pediatrics issued an operational definition for a medical home and recommended that the care of all children contain the characteristics of a medical home, which the institution defined as being “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective” (American Academy of Pediatrics, 2002). The medical home would be overseen by, “well-trained physicians who provide primary care and help to manage and facilitate all aspects of pediatric care” (American Academy of Pediatrics, 2002). The American Academy of Pediatrics emphasized the particular importance of medical home use for children with special health care needs (CSHCN), since the, “lack of a complete record and a ‘medical home’ is a major deterrent to adequate health supervision” (Sia et al., 2004). Since the care of CSHCN is often fragmented and provided by multiple caregivers, a medical home would serve as a method to coordinate these different providers and create clearer communication between the different parties involved. In 1974, the American Academy of Pediatrics Council on Pediatric Practice stated the, “delays, gaps, duplications, and diffused responsibilities which characterize fragmented care are expensive, inefficient, and sometimes hazardous to health” (Sia et al., 2004). The medical home would serve as a solution to this low quality care of CSHCN.

In addition to the mentioned descriptions of the medical home, there have been several other formulations of a medical home that specifically aim to serve the needs of

CSHCN and CMC. Cooley et al. argue for a unique medical home model for CSHCN since the, “comprehensive health needs of these children and adolescents do not fit with the services traditionally offered by the primary care system, which is designed for the 80% of children who do not have special needs” (Cooley & McAllister, 2004). A medical home designed for CSHCN will implement features that accommodate the unique chronic health care needs required by this patient population. Cooley et al.’s model for a medical home employs a perspective of the health care of CSHCN from the community viewpoint. In this vision, the medical home, “coordinates a set of relationships among health and educational professionals in varied settings, defines and interprets the role of multiple clinicians, and advocates for needed services and payer support” (See Figure 6) (Cooley & McAllister, 2004).

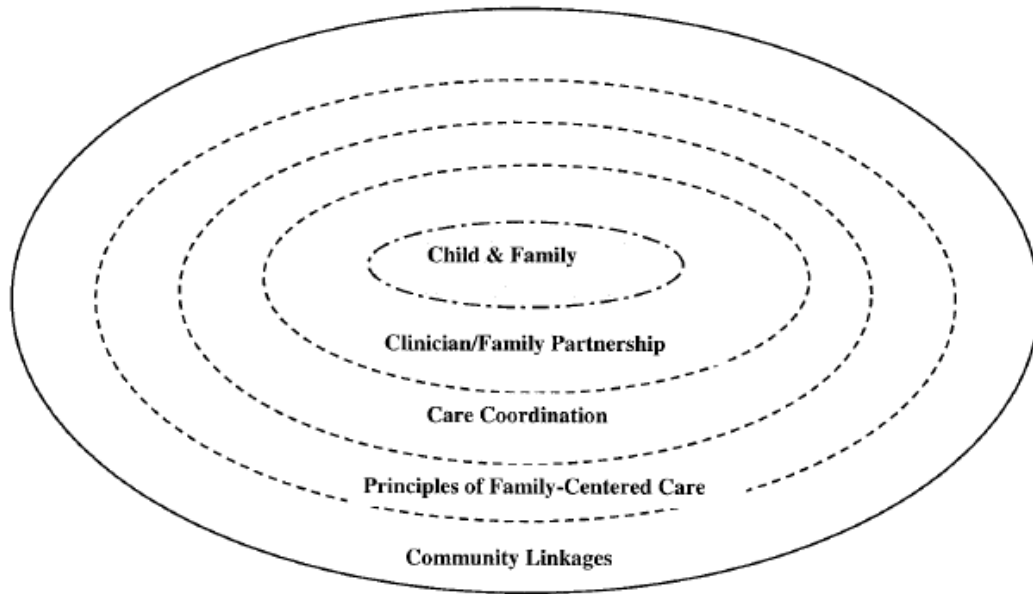


Figure 6. A model for the coordinative function of a medical home (Cooley & McAllister, 2004)

Cooley et al. also introduced a Medical Home Index (MHI) to function as a quantitative tool to assess a caregiver's ability to function as a medical home for CSHCN, containing 6 Domains and 25 Themes (See Table 2). The MHI summarizes some of the key features of the medical home and describes concrete tasks caregivers can provide to better fulfill the role of a medical home.

Domains	Themes
1. Organizational capacity	1.1 Mission of the practice 1.2 Communication/access 1.3 Access to medical records 1.4 Office environment 1.5 Family feedback 1.6 Cultural competence 1.7 Staff education
2. Chronic condition management	2.1 Identification of CSHCN 2.2 Care continuity 2.3 Continuity across settings 2.4 Cooperative management with specialists 2.5 Supporting transition to adult services 2.6 Family support
3. Care coordination	3.1 Role definition 3.2 Family involvement 3.3 Child and family education 3.4 Assessment of needs/plans of care 3.5 Resource information and referrals 3.6 Advocacy
4. Community outreach	4.1 Community assessment of needs of CSHCN 4.2 Community outreach to agencies and schools
5. Data management	5.1 Electronic data support 5.2 Data retrieval capacity
6. Quality improvement	6.1 Quality standards (structures) 6.2 Quality activities (processes)

Table 2. The Medical Home Index (Cooley & McAllister, 2004)

Perrin et al. describe the need for a multidisciplinary approach to caring for CSHCN, outlining a “family-centered community-based system of services” (See Figure 7) (Perrin et al., 2007). They argue for both “macro level” change, which involves agencies advocated for proper financing and access for CMC and their families, as well as “micro level” change, which involves better integration of CMC with resources in their community. Similar to the model postulated by Cooley et al., Perrin et al.’s model highlights the need to coordinate the needs of CMC with other resources in the community that are not limited to just health care. In addition to the medical needs of CMC, a proper family-centered medical home would help CMC and their families access services that address other unmet needs like housing, employment, and transportation.

According to the authors, the ultimate goal of the medical home is, “to promote the healthy development and well-being of the child and family” (Perrin et al., 2007).

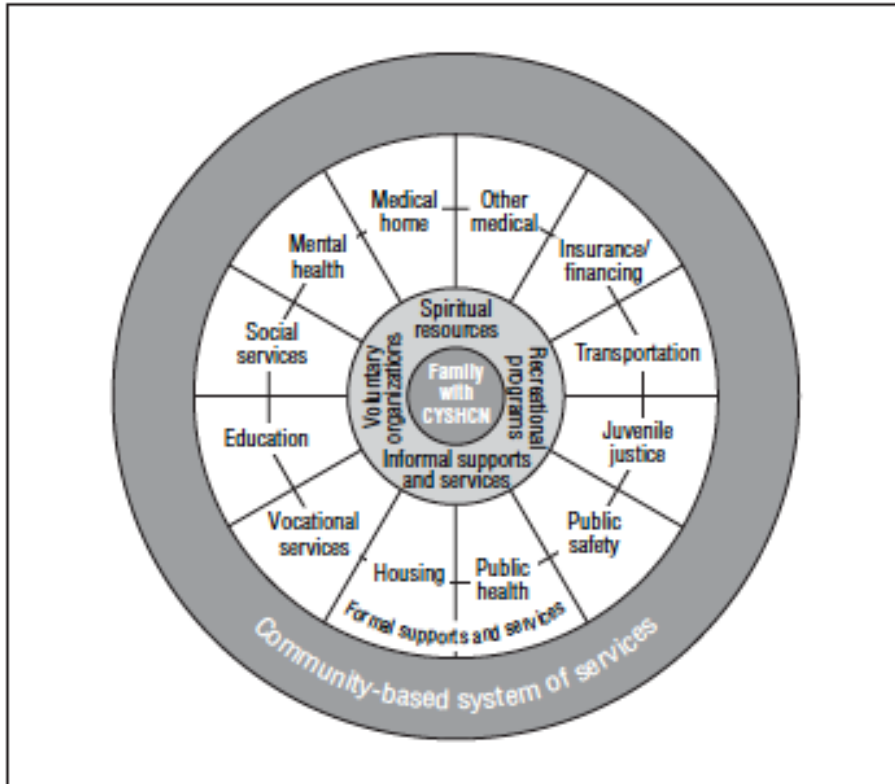


Figure 7. The approach of Perrin et al. in modeling community-based services for CSHCN(Perrin et al., 2007)

Chen et al. compiled a separate list of quality measurements to be used to assess the quality of a patient-centered medical home for CMC (Chen, Schrager, & Mangione-Smith, 2012). These 35 measures were grouped into the categories of general primary, patient/family centeredness, chronic care, coordination of care and transition of care.

Although these various definitions may vary slightly, they share many of the same common features. As summed up by Roberts et al., the adequate health system to support CSHCN and their families will be: (1) responsive to family challenges, (2) created in a

collaborative manner, (3) respective of cultural backgrounds, (4) accessible, (5) affordable, and (6) organized and coordinated (Roberts, Behl, & Akers, 2004). This system of a medical home will be coordinative, multidisciplinary, patient- and family centered, and help integrate CMC with their various health needs. As modeled in Figure 8, this system of health care will allow its delivery to be more efficient.

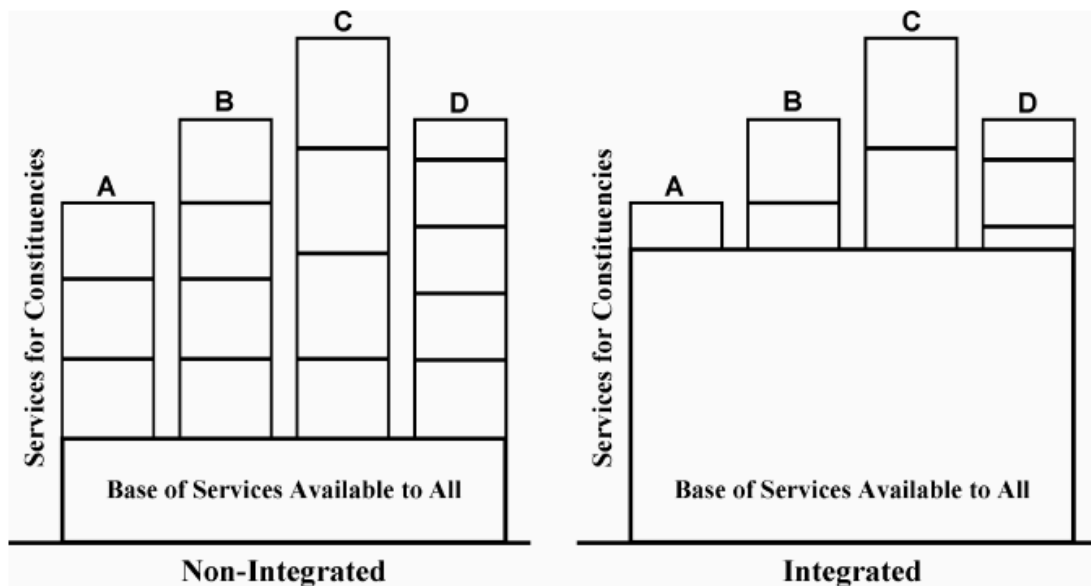


Figure 8. Integration of health care delivery for CSHCN (Roberts et al., 2004)

Overall, these researchers agree that CMC will thrive most when cared for in a primary care, medical home setting. Ideally, these settings will be able to identify the wide-ranging needs of CMC and their families and possess the resources to connect CMC and their families to services throughout the community. These outpatient settings will be patient- and family-centered, putting first the needs of CMC in a way that is respectful and culturally aware. Possibly the most important role of these medical home settings

will be their coordinative and communicative function, serving to help CMC navigate through the various health care systems from which they receive care.

Clinician attitudes towards the medical home

Most clinicians agree that primary care physicians (PCPs) should play a crucial role in the coordination of care of CMC. As demonstrated by Van Cleave et al., when surveying a sample of pediatricians, 65% agreed that primary care settings were the best environments for medical homes for CSHCN to be based; 43% of those survey felt subspecialty services were the best environment for these medical homes (Van Cleave et al., 2016). According to another study, 71% of pediatricians and 60% of family medicine practitioners reported that the chronic clinical decisions for CSHCN were made by the child's specialist after receiving input from the child's primary care physician, with most of this communication occurring directly. A majority of PCPs felt positively about their relationships with specialists. When PCPs were asked about how their relationship with specialists could be improved, they most frequently responded with the development of an "active care plan, "written emergency care plan," "consultation letter," and a "condition-specific 'fact sheet.'" The authors of the study also surveyed PCPs on difficulties managing the care of CSHCN, and frequently reported factors were "not enough time," and "limited personal knowledge of conditions."

According to a 2004 survey, 71% of pediatricians report coordinating the care of their patients who have special health care needs (See Table 3) (Gupta, O'Connor, & Quezada-Gomez, 2004). However, far fewer pediatricians reported performing specific coordination tasks, such as integrating a patient's care plan with the ones developed by

other providers or communicating with a patient's discharge team. According to Gupta et al., commonly cited barriers were a lack of time, lack of support agencies in the area, and difficulty communicating.

Services Provided	CSHCN (n = 740)			Children Without Special Needs (n = 670)		
	Always	Sometimes	Rarely/ Never	Always	Sometimes	Rarely/ Never
Extra time is scheduled for an office visit when seeing a child with special needs.	45.5	43.4	11.1	—	—	—
Someone in the practice serves as the primary coordinator of medical care.	71.8*	23.2	5.0	76.5*	17.6	5.9
As part of coordinating a child's care, someone in the practice contacts the school about the child's health and educational needs.	23.7†	60.9	15.4	17.8†	57.2	25.0
When a medical care plan is developed for a child, it is integrated with the care plans developed by other providers, agencies, and organizations.	49.1†	45.5	5.4	41.0†	49.3	9.7
When a child is referred to a specialist, someone in the practice assists the family in setting up the appointment.	61.4†	34.9	3.8	59.1†	36.0	4.9
After a visit to a specialist, time is scheduled with the child's family to discuss the results of the visit.	18.8†	53.2	28.0	15.0†	52.8	32.2
When a child is hospitalized, a meeting is set up with the discharge planning team to assist with the child's transition back to the community.	23.7†	34.3	41.9	19.3†	31.6	49.1
Someone in my practice discusses potential needs that families might have for services, such as financial services, respite care, equipment, transportation, etc.	41.0†	45.7	13.3	31.2†	46.2	22.6

* $P < .05$ for differences between "always."
† $P < .001$ for differences between "always."

Table 3. Barriers to care coordination of CSHCN reported by outpatient pediatricians (Gupta et al., 2004)

V. DATA ON THE CURRENT USAGE OF THE PATIENT-CENTERED MEDICAL HOME AMONG CHILDREN WITH MEDICAL COMPLEXITY

There have been various attempts to measure the primary care and medical home usage of CSHCN and CMC. Given the subjectivity and various definitions of the medical home, the latter measurement has been more difficult to achieve.

General primary care usage, on the other hand, is a more objective metric to measure. Overall, for CMC with Medicaid, roughly 60% had at least one primary care visit in a year, with the median number of visits being five (Berry et al., 2014). 66% of children in this group had at least one specialty care visit in a year, with the median number being two (Berry et al., 2014). In addition, 3% of CMC with Medicaid received home health care (Berry et al., 2014). There still seems to be a staggering number of CMC without adequate primary care access, with roughly 40% of those on Medicaid forgoing regular PCP visits.

As mentioned, there have also been previous attempts to quantify PCMH prevalence usage amongst CMC. Due to the varying definitions of the exact definition of a medical home, results on PCMH usage have been inconsistent. For example, one report from 2004 concluded the prevalence of CSHCN with a medical home could range from 44% to 74%, depending upon which criteria were used to define a medical home (Bethell, Read, Brockwood, & American Academy of Pediatrics, 2004). The authors of this study used parent-reported data from the Nation Survey of CSHCN (NS-CSHCN) to evaluate the “medical homeness” of the child’s care. Since the NS-CSHCN only survey limited data, it was not possible to measure all the components of a medical home as outlined by

the American Academy of Pediatrics. The use of self-reported data is another limiting factor in this study. These researchers found the medical home category with the lowest quality performance amongst CSHCN was “coordinated care.” Additionally, the researchers found no significant association between having a personal care provider and the likelihood of receiving care satisfying the requirements of being a medical home.

Another study in 2004 utilized the same data set as Bethell et al. in order to measure the prevalence of CSHCN receiving care that satisfied the five criteria of a medical home as defined by the American Academy of Pediatrics: “1) having a usual place for sick/well care, 2) having a personal doctor or nurse, 3) experiencing no difficulty in obtaining needed referrals, 4) receipt of needed care coordination, and 5) presence of family-centered care” (Strickland et al., 2004). These researchers used far fewer medical home criteria than did Bethel et al. Using this definition of the medical home, Strickland et al. determined 53% of CSHCN had access to a medical home. The difference in results between these two studies when analyzing the same data set to measure medical home usage illustrates the difficulty in measuring such an outcome.

VI. THE RELATIONSHIP BETWEEN THE USE OF THE PATIENT-CENTERED MEDICAL HOME AND THE HEALTH OUTCOMES OF CHILDREN WITH MEDICAL COMPLEXITY

Medical home usage in general pediatric patients

For pediatric patients in general, there is some inconsistency in the literature as to whether the use of a medical home improves health care outcomes. Several studies have demonstrated that the provision of primary care with at least some elements of the medical home serve to reduce the rate of preventable medical events. There is evidence that increased primary care use among pediatric patients without special health care needs is correlated with lower rates of avoidable hospitalizations and emergency department visits, as well as improved self-reported quality metrics (Gadomski, Jenkins, & Nichols, 1998; Long, Bauchner, Sege, Cabral, & Garg, 2012). One prospective cohort study conducted by Collier et al. determined that children who had a “usual source of sick and well care” before being hospitalized were less likely to be readmitted within 30-days (Collier et al., 2015). However, other studies have demonstrated the opposite relationship, with increased aspects of primary care in pediatric patients associated with higher rates of 30-day readmissions (Collier, Klitzner, Lerner, & Chung, 2013).

Medical home usage in CSHCN and CMC

While the association between primary care use and health care utilization may be mixed for all pediatric patients in general, there seems to be clearer trends for CSHCN

and CMC. Among children with chronic conditions, those who visited primary care practices with higher medical home index (MHI) scores were found to have fewer hospitalizations (Cooley, McAllister, Sherrieb, & Kuhlthau, 2009). Another recent study examining the effect of a primary care Accountable Care Organization (ACO) found that longer periods of primary care was significantly associated with decreased 30-day readmissions among pediatric patients at hospitals other than the discharging hospital; there was no significant association between length of primary care service and 30-day readmissions at the discharging hospital, however (Christensen & Payne, 2016).

More recently, there have also been studies that have examined the relationship between care with aspects of the medical home and the health care utilization of children with complex or otherwise chronic conditions. For example, Berman et al. analyzed the effect of a hospital-based primary care clinic on the health outcomes of children with multisystem disorders (Berman et al., 2005). After enrollment in this primary care clinic, children had shorter hospital stays for non-intensive purposes. However, there was no other change in the utilization of other hospital services, like subspecialty, ancillary, or emergency department visits. In addition, after visiting the primary care clinic, children were more likely to visit the surgical services.

Klitzner et al. implemented aspects of comprehensive care coordination found in medical homes into a resident teaching clinic and evaluated the effects on pediatric patients with medical complexity (Klitzner, Rabbitt, & Chang, 2010). Components included the provision of moderate length appointments, a liaison for families, and a resource for families to consolidate health information for their child. For children

enrolled in this program, there was a significant decrease in the number of visits to the emergency department. For the other measurements, such as hospital admissions, visits to urgent care, and average length of stay, there was no change in rates for the one-year follow up period.

A similarly structured study examined the effect of a tertiary care program which partners families of CMC with a special needs nurse case manager and special needs physician on health resource utilization (Gordon et al., 2007). These health care professionals would help patients with treatment plans, facilitate communication between various providers, and act as a general advocate for the patient and their needs. When comparing the pre-enrollment and post-enrollment measurements, there was a decrease in hospitalization rates and length of hospital stays but an increase in the use of outpatient clinic services (See Figure 9).

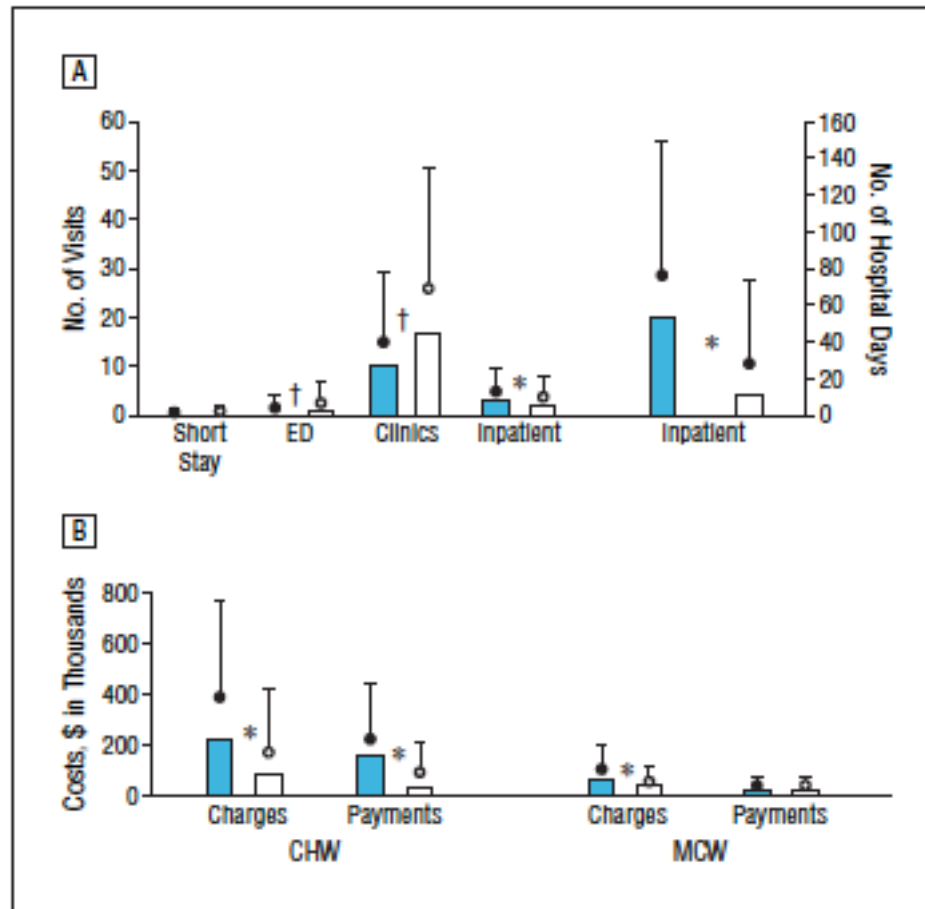


Figure 9. Effect of a tertiary-care medical home program on the resource utilization of CMC (Gordon et al., 2007)

Fewer studies have examined the effect of medical homes located in the outpatient setting on the health outcomes of CMC. Brittan et al. conducted a retrospective cohort analysis of CMC patients to determine the relationship between outpatient follow-up after hospitalizations and 30-day readmission rates (Brittan et al., 2015). CMC patients who received outpatient follow-up within 30 days of hospital discharge had half the odds of undergoing a 30-day readmission than CMC who did not receive outpatient follow-up. In addition, those children who received outpatient follow up later during the

30-day period after discharge were less likely to be readmitted than earlier follow-up visits.

Medical home implementation in children with serious chronic illnesses has been seen to have effects on aspects of care other than readmissions and ED visits, too. Mosquera et al. conducted a randomized clinical trial to evaluate the efficacy of a medical home program that provided “comprehensive care” to children with serious chronic illnesses (Mosquera et al., 2014). The children included in the study had high health care use and incidence of medical events like emergency department visits or hospitalizations. However, children with complex conditions who received primary care conducted by a specialist were excluded from the study. The services offered by the clinic included full-time staff by primary care clinicians, Spanish translation services, same day appointments, and nutrition and social work counseling. Children enrolled in this medical home program had lower rates of serious illness and incurred lower medical costs. In addition, children enrolled in this medical home program had lower rates of ED visits, hospitalizations, ICU admissions, and lowered lengths of inpatient stays.

Some studies have demonstrated an association a parent’s perception of their child’s medical status and the incidence of adverse medical events. For example, Berry et al. found that CMC whose parents were less confident about their child’s ability to be discharged from the hospital were more likely to experience a 30-day readmission (Berry et al., 2013). The implementation of a PCMH would provide family-centered care that would incorporate the feelings of CMC and their families into the health care process and achieve better health outcomes. According to Palfrey et al., after implementation of

elements of the medical home into pediatric practices, families of CMC reported improved ability to access care and navigate through the medical practice in order to get needed services for their children (Palfrey et al., 2004). In this intervention, families whose children had a greater degree of complexity and medical need were more likely to report greater satisfaction with their child's health care delivery after implementation of the medical home model. Not only did the medical home intervention decrease the number of hospitalizations incurred by the children, but parents also reported fewer days of missed work. Other studies have shown that families of CMC who reported high quality family-centered care were more likely to have lower rates of emergency department visits (Raphael, Mei, Brousseau, & Giordano, 2011). Implementation of a medical home model has been demonstrated to be a useful tool to improve the family-centeredness of care and patient satisfaction scores for Spanish speaking families of CSHCN as well (Hamilton, Lerner, Presson, & Klitzner, 2013).

While the results show slightly inconsistent results, there does seem to be more promise for the implementation of the medical home for CMC and CHSCN than was seen for general pediatric patients. These studies varied in the degree to which the intervention resembled a medical home, with some interventions simply entailing the use of PCP services while others created programs that aimed to fulfill the coordinative, patient-centered and communicative functions of a true medical home. In addition, there were inconsistencies in the health care outcomes, with some having positive effects on outpatient visits but no effect on inpatient health care utilization, and vice-versa. However, each study did tend to demonstrate at least one positive health care outcome

after implementation of the program of interest. These inconsistent results could be partially explained by the fact that each intervention was unique. Since the programs themselves varied in the degree to which each component of the medical home was fulfilled, the health outcome effects they would achieve would likely vary as well.

VII. CONCLUSION AND RECOMMENDATIONS

The use of patient-centered medical homes seems to be a promising health care intervention to improve the health care outcomes of children with medical complexity. Overall, the current literature suggests that increasing the aspects of care for CMC that fulfill the components of a medical home will have a protective effect against preventable medical events like hospital readmissions or emergency department visits. In addition, the provision of patient- and family-centered care seemed to improve the satisfaction of CMC and their families regarding their health care experience. When evaluating literature on the use of medical homes for pediatric patients, it is necessary to remain aware of the differences in health characteristics between CMC and the average pediatric patient. As compared to the average pediatric patient, CMC are more likely to receive fragmented, low quality health care. As a result, interventions that improve the coordination and integrative functions of their primary care will have a greater and more positive effect on CMC than would be seen if implemented for the average pediatric patient. However, while the studies examining the relationship between medical homeness of care and health care outcomes for CMC showed some promise, it was difficult to which specific aspect of their care was improved since the evaluated studies had varying results. Future studies will have to more explicitly define which aspects of the medical home are being implemented in their intervention in order to unravel clearer relationships with health care outcomes.

The studies that have been conducted to measure the prevalence of primary care and medical home usage amongst CMC demonstrate that there is much progress to be

made in implementation of these programs. Although the exact number varies due to differences in definition of a medical home, roughly half of all CSHCN receive care that does not satisfy any of the criteria of the medical home (Bethell et al., 2004). Although this information may be discouraging, an optimistic perspective would focus on the vast progress that can be made to improve the care of CMC. While some studies discussed the possibility that preventing medical events like readmissions and emergency department visits for certain populations may be impossible due to the complexity and severity of their chronic illness, the large gaps in primary care amongst groups like CMC demonstrate these external risk factors must still be modified before such conclusions can be made. Creating systematic expansions in the ability of CMC to access high quality primary care that caters to their unique needs could create vast improvements in their health care experience and reduce the prevalence of preventable medical events.

For future studies on this topic, it will be important to keep several themes in mind, as discussed below.

CMC vs. CSHCN

Although it is easy to group CMC in the same category as CSHCN, as they do share many similar health care characteristics, it is important to realize they are still two distinct populations with their own specific needs and nuances. Many of the studies evaluated in this thesis examined CSHCN in general and attempted to extrapolate the results from these studies to make conclusions about CMC. It might be slightly inaccurate to do so, since the medical situations of CMC are typically more severe than those of

CSHCN. There is a need for more studies to evaluate the effects of interventions like PCMH on CMC specifically. Since this group has such wide gaps in care, studies that evaluate pediatric patients in general or even CSHCN may miss conclusions that could have been reached if the interventions were targeted towards CMC.

Multiple Definitions of the Medical Home

One challenge in evaluating the prevalence of the medical home and its effects was that there is no single, clear definition of a medical home. Therefore, it was difficult to compare studies to one another and determine a single value for measurements like medical home prevalence since each study used slightly different criteria. In order to conduct studies in a more standardized fashion, a clear and consistent definition of a medical home should be established. Ideally, there would be objective metrics that could correlate with the degree to which different aspects of the medical home are satisfied. Many of the current definitions of the medical home utilize vague concepts like “coordination” or “integration,” without much further clarification. There will need to be some concrete measurements associated with these domains in order to achieve quantifiable results.

Additional challenges result from the fact that there is no centralized database of measurements that can be used to measure certain domains of medical homeness, such as patient-centeredness. In order to make these types of measurement, there is a need for family surveys, which are often times not utilized when collecting Medicaid or other data. Therefore, it may be necessary for health care providers or other health care

organizations to begin collecting self-reported patient data so certain aspects of the medical home which depend not upon processes but experience can be measured.

An alternative view may be that there is no single, all-encompassing definition of a medical home. From this perspective, care providers should not attempt to fulfill a single, limited set of medical home criteria but rather incorporate as many aspects of medical homeness into their practice; the more components they incorporate, the higher the quality of care they provide will be.

Barriers to medical home implementation

There have been some attempts to explore some of the barriers care providers may face when attempting to implement medical homes (Gupta et al., 2004). Many of the studies that have been conducted to evaluate the effect of medical home implementation on health care outcomes have been conducted in academic or other hospital settings. While these locations may be suitable for initial studies, the true effects of the medical home will be seen in the PCP outpatient clinic setting, where it is recommended that CMC base their medical home (American Academy of Pediatrics, 2002). If such studies are difficult to implement, it is important to question why. There is a possibility that PCPs based in outpatient settings may not have the resources or adequate training to provide primary care for complex patients. Further research on possible barriers to medical home implementation in the outpatient setting must be conducted in order to determine the support needed for these providers to make medical home implementation a reality.

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