Practise-Based Care Coordination: the Outcomes of Care Coordination Activities in an Inner-City Pediatric Clinic

Giorelly Jacqueline Prado
*University of Connecticut Health Center*

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Practice-based Care Coordination: 
The Outcomes of Care Coordination Activities in an Inner-City Pediatric Clinic

Giorlly Jacqueline Prado

B.S., Trinity College 2004

A Thesis

Submitted in Partial Fulfillment of the
Requirements for the Degree of
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Master of Public Health Thesis

The Outcomes of Care Coordination Activities in an Urban Pediatric Clinic

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2009
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Introduction

The pediatric population in the United States continuously faces challenges in obtaining sufficient access to quality health care and related services. These challenges are particularly experienced by children* and youth with special health care needs (CYSHCN). According to the Institute of Medicine (IOM), access to health care is “the timely use of personal health service to achieve the best possible health outcomes.” Inadequate health outcomes for segments of the child population, such as immunization delays, underline a public health concern.

In 2001, the federal Maternal and Child Health Bureau (MCHB) proposed a model of care with six core elements to address the fragmentation within the systems of care that are involved in pediatric care delivery. Access is highlighted in the second element of the proposed model. During the past decade, a system of care coordination in a “medical home” has gained popularity as a mechanism to address the access problem and to improve both efficiency and quality. Care coordination provides families with a comprehensive method to overcome barriers to access and to obtain the quality of care to meet the child’s needs. Furthermore, it facilitates the partnership between the medical provider and the families. Both private and public sectors implemented care coordination mechanisms to control cost, while increasing the quality of care, patient satisfaction and improving disease outcomes.

This study describes and analyzes the implementation of the care coordination measurement tool (CCMT) in an inner city, Medicaid predominant, pediatric primary care clinic with practice-based care coordinators. The CCMT quantifies the time it takes

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* In accordance to federal and state policies, references to “child” or “children” in this document include infants, children, and adolescents under 18.
to complete care coordination activities and the outcome(s) achieved or prevented as a result of the activity. The purpose of this study is to ascertain: (1) the characteristics of the patients receiving care coordination activities, (2) the non-reimbursable activities and the outcomes associated with care coordination provided by non-clinical practice-based care coordinators and (3) how care coordination activities vary according to patient level and age. The data will be analyzed in two formats: (1) quantitatively by providing frequencies and percentages on a sample of care coordination encounters and (2) qualitatively by describing two study patients that received care coordination during the study period.
Chapter 1

BACKGROUND

The American Academy of Pediatrics (AAP) defines care coordination as the "process that links patients and their families with appropriate services and resources in a coordinated effort to achieve good health". Care coordination involves an array of services such as assessment, monitoring support, and advocacy to engage and assist families to navigate the US healthcare system. Moreover, unlike case management, care coordination engages the family in a care plan and involves the integration of other systems beyond healthcare, such as social and educational systems.

Care coordination is recommended as an essential element of an integrated system of healthcare for all children, in particular, children and youth with special health care needs (CYSHCN). As defined by the federal MCHB, CYSHCN are children who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and require services, beyond those generally required by children. It is important to note that this definition includes children who are not diagnosed with a condition, but are "at risk" of developing such condition. CYSHCN comprise nearly 12-18% of the pediatric population in United States and may account for 80% of pediatric health care expenditure.

CYSHCN have a multitude of medical requirements and even the most committed families can be overwhelmed if the care is not synchronized. Moreover, unnecessary or duplicate test procedures, conflicting information from multiple providers and increased health care cost can be experienced when there is poorly coordinated care.

Primary care providers, along with families with CYSHCN agree that the optimal setting for care coordination is within a medical home model. The medical home model
is described by the AAP as a provision where care is accessible, continuous, comprehensive, family-centered, compassionate, culturally effective and coordinated with specialized services provided outside primary care.\textsuperscript{11,12} Homer, et al.,\textsuperscript{13} shows that CYSHCN receiving care in a medical home model experienced better outcomes, such as better health status, timeliness of care, family-centeredness and improved family functioning, than children receiving care in non-medical home settings. Moreover, CYSHCN with access to medical homes experienced significantly less delayed or forgone care, fewer unmet health care needs and significantly fewer unmet family needs.\textsuperscript{14}

However, there are barriers that prevent access to medical homes. Difficulty in accessing a medical home increases by the patient’s race/ethnicity, poverty level\textsuperscript{9} but no differences are found in regards to geographical locations.\textsuperscript{15} In addition, insufficient or restricted time of medical staff, incomplete knowledge of available community resources and financial barriers were known to delay the development of medical homes in primary care settings.\textsuperscript{14}

The 2005 AAP\textsuperscript{6} recommended the following as desirable characteristics of an effective care coordination within a medical home model: (1) the development of a care plan, (2) accessibility to a central record or database of the patient’s medical information contained at a primary care practice, (3) exchange of information between provider and family, (4) the linkage to community resources, (5) consultations between primary care and subspecialties and (6) the cooperation of other community organizations to address the care plan.
Chapter II

DIMENSIONS OF CARE COORDINATION

A. Implementations in Different Settings:

Typically, a system of care for CYSHCN may filtrate beyond the primary care center into the home, school and other community-based care systems, creating multiple settings for services. The role of coordinating care is shared among various providers, including physicians, nurses, social workers, payer-based case managers, special education teachers and school nurses. Often times, care coordination is implemented from three independent settings: payer-based, community-based, and provider-based. Patients are prone to experience replication of services and overlapping of responsibilities if services are not properly coordinated.

Under the payer-based care coordination model (i.e. insurance companies, managed care organizations), the purpose of care coordination varies from that of the family. The payer aims to maximize care while controlling cost; whereas the family’s focus is to obtain the best care possible.\textsuperscript{16} The payer-based care coordination also referred to as case management, consists of case managers working directly with the payer to limit the financial risk of the payer.\textsuperscript{6} A payer-based case manager provides care coordination with a financial incentive to manage risk and maximize quality.\textsuperscript{17} Thus, the payer-based care coordination creates a dual goal of containing costs while improving the distribution and utilization of limited resources.\textsuperscript{18} One of the limitations of payer-based care coordination is that insurance companies can restrict access to health care services. Insurance plans provide patients with access to health care services that are within a certain coverage plan. If the insurance plan changes so does the coverage and the services
the patient qualifies for. This restriction is seen as a barrier to many families of CYSHCN that need a range of medical and non-medical services.¹⁹

In the community-based or agency-based care coordination model, the priority is on policy development and research.¹⁶ Community-based care coordination is provided by federally funded programs such as State Title V and early intervention and special education program. In this setting, community agencies aside from the clinic provide the care coordination.¹⁶ A recent survey²⁰ showed that most (59%) State Title V programs utilized the agency-based model of care coordination in which the care coordinator was located in a state agency rather than within the same clinic where the patient received primary-care services. Wood²¹ demonstrated the agency-based model is not the most effective method of meeting the needs of the family within a medical home model. In this model, it is unlikely for the provider, care coordinator, and family to meet and discuss the care plan for the patient.²¹

In the provider-based care coordination model, the primary care physician has the leading role in providing care coordination.²² The role as both the physician and care coordinator can create a conflict of interest. A conflict may arise from the providers’ requirement of balancing the needs of the family/patient and the policies of the payers.¹⁶ Gupta, et al.,²³ found that 71% of primary care physicians provided a medical home; however, only 24% were involved in hospital discharge planning and even less (only 19%) coordinated medical and educational needs with the patient’s school. Some of the reasons for the limited support of primary care physicians include time availability, lack of staff, and inadequate reimbursement for non-reimbursable activities. Szilgauli, et al.,²⁴ emphasized the need for available personnel with dedicated time to provide the care.
coordination. Although the provider-based care coordination model supports the primary care practice as the setting for care coordination to occur, it is not the most effective model when the primary care physicians are the sole care coordinators. The role of other clinical staff as practice-base care coordinators is shown to be more effective. This emphasizes of care coordination being done in primary care setting but by practice base care coordinators create perfect setting to provide a medical home for the patient.

The literature suggests that primary care clinics are more effective in meeting the needs of the CYSHCN families when a practice-based care coordinator is present. The New Hampshire Center for Medical Home Improvement (CMHI) research, based on 13 years of interventions and interviews of over sixty primary care sites, argued that an internal practice-based care coordinator was crucial for improving the medical home model in the practice. The Massachusetts Consortium for Children with Special Health Care Needs conducted a three-year study that recommended that care coordination be housed within the context of a medical home. Wood, et al., showed that families with practice-based care coordinators rated quality of care significantly higher than did families in the comparison practices that relied on agency-based care coordination services. The practice-based care coordinators were perceived as more supportive and families reported fewer barriers to care for services.

McAllister, et al., illustrated the steps to plan and implement a system with a practice-based care coordinator providing the framework of the structure, processes, and required training that must be in place. The author suggest the following steps to establish practice-based care coordination in health care team: (1) articulate a care-coordination definition and vision, (2) use a framework for practice-based care coordination, (3)
declare a facilitative, team-based care coordination model approach, (4) develop, test and implement a care coordination-service capacity, (5) strategically integrate care coordination services into team-based primary care and (6) evaluate care coordination. The study also emphasized that practice-based care coordination should be delivered within a family-centered approach. Other studies also recommended a family-centered approach where the family manages its own care of the patient with professional assistance provided at the family's discretion.

B. Characteristics and Training of Care Coordinators:

Few studies have focused on the parameters that outline the appropriate education and experiences of practice-based care coordinators. There is no specific discipline for care coordinators and various studies have cited nurses, nurse practitioners, and social workers as the designated care coordinators. The training and education is based on who provides the services. A recurring suggestion is to draw from multiple disciplines in order for the care coordinators to obtain an array of skills that complement the daily care coordination activities.

In addition to the education background, practice-based care coordinators must possess certain characteristics in order to efficiently meet the needs of the patient/family. Some of the characteristics of an ideal care coordinator are culturally competency, ethical astuteness, and excellent communication and listening skills. These characteristics reflect the responsibilities care coordinators possess including advocacy, accessibility, support and coordination of services.

Additional research is needed in the area of care coordination competencies. In the meantime, there are resources available to provide guidelines for qualification.
requirements. The Center for Medical Home Improvement (CMHI) developed a description of the care coordination job position. This sample highlights the qualifications of the care coordinators along with their responsibilities. The suggested qualifications included a Bachelor’s degree in nursing, or social work, or the equivalent. However, these are only suggestions, and the care coordination programs have the flexibility to decide what characteristics the care coordinator should possess.

This study was interested to investigate the role a non-clinical care coordinator will play in a busy inner city pediatric clinic. The study selected practice-based care coordinators with no formal medical training and essential care coordination characteristics such as cultural competent, and excellent bilingual communication skills to provide the care coordination services. The purpose for non-clinical care coordinator is to show that they can perform the same care coordination activities as clinical care coordinators.

C. Measurements of Care Coordination:

The Medical Home Index was the first to measure the capability of primary care offices to provide care coordination to CYSHCN patients. The Index consists of twenty-five themes of primary care office activities arranged among six domains on an eight-point scale. The domains included organizational capacity, chronic condition management, care coordination, community outreach, data management and quality improvement. Each theme which varied across the domain was scored across four levels of achievements as partial or complete depending on whether the performance met some activity or all activity within the level. During the study, a physician or non-physician staff member completed the assessment and provided a 90-minute interview, in
which the scores of the tool were reported. The greater the score, the more capable the practice was in a given theme such as assessment of care plans and advocacy.

Another tool used to measure the types of care coordination activities for CYSHCN in primary care practices was the Care Coordination Measurement Tool (CCMT). The CCMT was first developed for a single community pediatric practice pilot study in 2001 (see Appendix A) and then modified for a broader eight-month follow-up study in 2003 (see Appendix B). The purpose of the tool is to record the amount of time spent on care coordination encounter by clinical staff (such as nurses, nurse practitioners) on patient levels from simple to complex. The care coordination encounter is further divided into four components: the focus of the encounter, the care coordination needs, the activity to fulfill the needs and the outcomes.

In the follow-up study, the original CCMT was reviewed and recommendations were made by a committee of experts. The complexity subscale was renamed “patient level” and stratified into one of four levels; the attributes subscale was expanded to include social services and renamed “focus of encounter,” a “care coordination needs” subscale was added and the outcome subscale was expanded to “outcomes occurred” and “outcomes prevented.”

Both studies found that care coordination services were used by patients of all complexity levels, but more time per encounter was spent for more complex patients. These studies also calculated the cost involved in providing care coordination activities to CYSHCN.

D. Impact of Care Coordination:
Despite the development of the care coordination model and measurement tools, there is a lack of empirical evidence reflecting the impact of care coordination. Only a handful of studies aimed to evaluate the impact of care coordination on healthcare utilization, parent satisfaction, cost or outcomes for CYSCHN.

Two comparison studies focused on hospitalization and care coordination. Criscione, et al.,34 demonstrated that individuals receiving coordinated care experienced shorter lengths of stay than individuals in standard care. Liptak, et al.,35 reported that length of stay and associated cost was lower in the pediatric hospital with coordination program versus comparison hospitals.

Palfrey, et al.,33 performed one of the most comprehensive studies that used pre/post surveys on parents to measure the impact of a medical home model with a nurse practitioner as the care coordinator. The authors looked at the satisfaction of parents, work/school days missed, care use, and cost in six different pediatric practices with care coordinators. This study found a statistically significant decrease in parents missing work days and patients’ hospitalization admissions when care coordination was provided. Furthermore, the authors calculated a cost of $400 per patient for care coordination.33

Farmer, et al.,15 conducted pre/post parental survey in three primary care practices using the same medical home model as proposed by Palfrey et al. This study was the first to investigate the impact of care coordination in rural hospitals. The study found reduced parent’s missed work days, children school absences and ambulatory care visit for the three primary care practices with care coordination services.

Antonelli & Antonelli4 provided an insight into the cost associated with care coordination performed by the clinic staff in one primary care practice for a period of
ninety-five days in Boston. The authors developed the care coordination measurement tool and demonstrated the non-reimbursable care coordination activities recorded for CYSHCN. The authors calculated the cost of practice-based personnel on the basis of time spent on the care coordination elements multiplied by the average salary of the office personnel performing the service; which ranged between $22,809 and $33,048 per year or $51-71 per child.4.

Damiano, et al.,36 further analyzed cost in terms of outpatient cost. The medical home model was not found scientifically related to the outpatient cost, indicating medical home may influence more inpatient than outpatient cost.34

These studies that have focus on the impact of care coordination are necessary to validate the importance of care coordination for further health policy change. No known published studies have demonstrated the outcomes achieved or prevented as a result of the care coordination activities performed by non-clinical, practice-based care coordinators in an urban pediatric clinic. The present study was designed to address this gap in our knowledge about the impact of care coordination activities performed by non-clinical practice-based care coordinators within an inner city, Medicaid predominant pediatric primary care clinic.
Chapter III

METHODOLOGY

A. Study Setting:

1. Charter Oak at Connecticut Children Medical Center (CCMC)

The primary care center at Connecticut Children Medical Center (CCMC) merged with the federally qualified community center, The Charter Oak Health Center, Inc., to share services and leadership. Charter Oak at CCMC provides sub-specialty care to the 15,000 children living within the city of Hartford and the thirty surrounding towns; this number comprises 40% of Hartford’s child population and about two thirds of Hartford’s children insured by the Connecticut Health Insurance for Uninsured Kids and Youth (HUSKY) insurance program. There are 7.0 Full-Time Equivalent (FTE) child health physicians, 5.3 FTE nurse practitioners, and 9.5 FTE nursing staff. The practice serves over 35,000 visits by children each year. There are three additional clinics that provide services independent to those of primary care services within this pediatric center. The Lead Clinic serves patients with exposure to lead, the Nancy Kids Clinic provides services specifically to CYSHCN, and the Adolescent Clinic serves children 12-18 years of age.

2. Description of Health Outreach for Medical Equality Project:

The Charter Oak at CCMC also houses an initiative funded by the Department of Social Services (DSS), the Hartford Foundation for Public Giving, the Children’s Fund of Connecticut and CCMC to provide care coordination and outreach services to primary care patients by non-clinical care coordinators. The Health Outreach for Medical Equality (H.O.M.E.) project is a response to the decline of the annual well-child care usage among children enrolled in the State of Connecticut’s HUSKY Part A, which provides services
for low-income children under age 19. In federal fiscal year (FFY) 2001, only 54% of Connecticut children and youth under 21 years of age insured by HUSKY A received their expected EPSDT screen.38

The H.O.M.E. program hired and trained four care coordinators, 2.0 FTE practice-based care coordinators located at Charter Oak at CCMC and 2.0 FTE community-based care coordinators located at the Hispanic Health Council to provide care coordination services to the families referred to the H.O.M.E. program. The H.O.M.E. program selected the care coordinators based on their non-clinical background and their care coordination characteristics as culturally sensitive, bilingual and the ability to coordinate services and capabilities of linking families to diverse resources. The practice-based care coordinators provide the initial care coordination at the clinic, and the community-based care coordinators provide the outreach services by locating families at their homes. The practice-based care coordinators refer patients to the community-based care coordinators if the family's contact information is unavailable or no longer working.

Patients must 1) receive primary care services at Charter Oak at CCMC, 2) have HUSKY A insurance and 3) are under the age of 16 at admission to be eligible for H.O.M.E. services. The patient can also have any of the following concerns: pattern of missed primary care appointments, significant delay in receipt of immunizations, transferred care among providers or provider sites, special circumstances as foster care or high-risk newborns and urgent need due to medical test results or other emergent situation. The patient is eligible to H.O.M.E regardless of his/her involvement in other programs such as Nancy Kids Clinic, as long as he/she meets the eligibility requirements. The provider is the one who identifies the care coordination need and refers the patient to
the program. Once in the H.O.M.E. program, the patient is assigned a care coordinator who completes an intake, and constructs a care plan based on the medical needs of the patient and social needs of the family. The care coordinator provides services until all the needs from the care plan are met. The project initiated services in January 2007.

3. Care Coordinators for this Study:

This study selected the two practice-based care coordinators as the participants due to their involvement with the clinic and their initial interaction with the patients. Both practice-based care coordinators had no formal medical training, had minimal educational requirement of a high-school degree, had at least two years of experience working in a health care related setting and/or with children, and were culturally and language concordance with their patients.

The author of this study served as a practice-based care coordinator and participated in the data collection and in providing services to families. Throughout the data collection process, an independent consultant reviewed the data to ensure high standard of quality.

B. Measurement Instrument:

The Care Coordination Measurement Tool (CCMT) (see Appendix C) utilized in this study was a modification of the CCMT used in Antonelli, et al. The original CCMT was reviewed by the nurse practitioner and nurse staff at Charter Oak at CCMC. Their major recommendation was to change the format to include check boxes to make it more user-friendly. This modified CCMT was approved by the CCMC IRB.
C. Data Collection:

The two practice-based care coordinators attended a half-hour training session on the CCMT form. During the training, the practice-based care coordinators received a training manual, a specific participant identification code, and instructions on how to complete the form, on how provide a code for each patient and on how to identify the patient’s complexity level. Unlike previous studies that used the CCMT, the practice-based coordinator determined the patient complexity level instead of the primary care physicians. Both care coordinators signed consent forms to participate in the research. The data collection began on May 5, 2008 and ended on June 16, 2008. Each encounter with the H.O.M.E. patients was recorded in real time on the CCMT forms. Data was recorded during regular office hours for six consecutive weeks. At least one care coordinator was present during the entire study period. Staff was able to integrate CCMT to usual daily routine.

D. Variable Measurement

Specific variables from the CCMT that were measured for study purposes were:

*Patient Age* was extrapolated from the patient study code (which included the first three letters of the last name, the first two letters of the first name and the patient’s age in years: DOEJA00). The patient age was then divided into the four pediatric developmental milestones; infants 0-2, preschool 3-5, preadolescent or middle childhood 6-11 and adolescent 12-16. Age group 0-2 includes infants (0-1) and toddlers (1-2) age group; and will be referred to as infants from here on. This variable was measured to identify if care coordination activities varied according to the age group of the patient.
Patient Level measured the complexity level of each patient. The patient levels were defined as follows: Level I: Non-CSHCN without complicating family or social issues, Level II: Non-CSHCN with complicating families or social issues, Level III: CSHCN without complicating families or social issues and Level IV: CSHCN with complicating family or social issues. A checklist for determination of CSHCN and examples of complicating families or social issues was found in the training manual. The patient level was measured to identify if care coordination activities varied according to the patient's complexity level of needs.

Time Spent measured the combined total number of minutes required to complete all the care coordination activities for each encounter. The time spent was separated into seven time ranges (< 5, 10-19, 20-29, 30-39, 40-49 and 50 and greater). The last three time ranges were combined into one group; 30 and greater to provide a greater frequency.

Focus of Encounter measured the primary focus area. The focus of encounter included: Mental Health, Educational/School, Growth/Nutrition, Clinical/Medical Management, Intake/Assessment, Developmental/Behavioral, Legal/Judicial, Referral Management, and social Services (i.e. housing, food, clothing, insurance and transportation). From the list of nine, the care coordinators checked all that applied to each encounter.

Care Coordination Needs documented all the areas of need to satisfy the care coordination encounter. The care coordination needs included: Make Appointments, Facilitated with Prescriptions, Supplies, Services, etc., Coordination Service (schools,
agencies, payers etc), Follow-Up Referrals, and Reconcile Discrepancies. From the list of five, the care coordinators checked all that applied to each encounter.

*Activities to Fulfill the Need* applied to all the activities the care coordinators performed to meet the needs of the encounter. From a list of eighteen activities (see Appendix C), the care coordinators selected all the activities required to complete the care coordination need.

*Outcome(s)* prevented measured the outcome prevented as a result of the care coordination activities performed. The outcomes prevented included: Visit to Pediatric Office/Clinic, Visit to ER, Subspecialist visit, Lab/ X-ray, Hospitalization, Specialized Therapies (PT, OT, etc). From a list of six, the care coordinators choose only one if applicable for each encounter. The outcomes occurred measured all the outcomes that occurred as a result of the care coordination activities. From a list of fifteen outcomes occurred (see Appendix C) the care coordinator selected all that apply.

**E. Data Analyses**

*Quantitative Data Analysis*

Data analyses were conducted using the SPSS software, version 16.0. Descriptive statistics were calculated using frequencies and percentages; differences between age group and patient level were determined using cross tabs with the age group and patient level in the column and the encounter characteristics in the row. In order to determine the study patient, the duplicate cases were identified and only the first case for each patient study code (PSC) variable was indicated as the primary case. Since the PSC variable was
the same for all the multiple encounters per patients, the primary case indicated the first encounter found for each patient study code.

*Qualitative Data Analysis*

Two patients were selected in accordance to their age group and patient level. Case studies were performed describing in details the care coordination encounters recorded for each patient and a summary of the care coordinator experience with the patient.
Chapter IV

RESULTS

A. Characteristics of Care Coordination Encounters:

During the 30-day study period, a total of 656 encounters were recorded, representing 292 study patients that received care coordination. A summary of the number of study patients (at first encounter) and total encounters recorded is shown in Table 1. The table is arranged by patient age group and patient level.

<table>
<thead>
<tr>
<th>Characteristics:</th>
<th>No of Patients</th>
<th>No of Encounters</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2</td>
<td>114 (39.0)</td>
<td>267 (40.7)</td>
</tr>
<tr>
<td>3-5</td>
<td>79 (27.1)</td>
<td>184 (28.0)</td>
</tr>
<tr>
<td>6-11</td>
<td>61 (20.9)</td>
<td>128 (19.5)</td>
</tr>
<tr>
<td>12-16</td>
<td>38 (13)</td>
<td>77 (11.7)</td>
</tr>
<tr>
<td><strong>Patient Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level 1</td>
<td>20 (6.8)</td>
<td>43 (6.6)</td>
</tr>
<tr>
<td>Level 2</td>
<td>116 (39.7)</td>
<td>211 (32.2)</td>
</tr>
<tr>
<td>Level 3</td>
<td>98 (33.6)</td>
<td>258 (39.3)</td>
</tr>
<tr>
<td>Level 4</td>
<td>56 (19.2)</td>
<td>142 (21.6)</td>
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<tr>
<td>Missing</td>
<td>2 (0.7)</td>
<td>2 (0.3)</td>
</tr>
</tbody>
</table>

Out of 292 study patients served during the study period, 39% of the study patients at the first encounter were infants, 27% were pre-school age, 21% were pre-adolescents, and 13% were adolescents. The infant age group had the largest distribution among the study patients, and represented 41% of all encounters.
Pertaining to the patient level, 7% of the study patients represented patient level I, 40% represented patient level II, 34% represented patient level III and 19% represented patient level IV. Although patient level II had the largest distribution among the study patients, patient level II only represented 32% of all encounters. Patient level III (39%) represented the largest distribution among all encounters. Since the number of patient was derived from the first encounter, this may indicate that the encounters recorded for level III patients occurred with the same level III patients. Thus there is a discrepancy seen between the distribution of patient level III in the encounters and number of patients.

Now looking at both Level III and IV patients we find 53% of the study patients represented CYSHCN patients. These study patients received 61% of all reported encounters. Moreover, 59% of the study patients had complicating families or social issues (level II & IV), which received 54% of all encounters. As a result, complicating family or social issues were established as indicators for requiring care coordination.

The number of minutes spent with each encounter as a function of patient age group and patient level is represented in Table 2. The majority of time spent for each age group and patient level was between 5 to 19 minutes; the care coordinators spent 5-9 minutes for 260 (39.6%) of all encounters and 10-19 minutes for 80 (27.4%) of all encounters. A total of 72.8% of all encounters for the patient age group and patient level fell within this range.

Further analysis of the age group shows that the care coordinators spent the majority of time between the 5-19 time range across all the age groups. The care coordinators spent 75.8% with the 12-16 age group, 75.7% with the 6-11 age group, 75.3% with the 0-2 age group and 66.3% with the 3-5 age group. This suggests that
encounters across age groups were completed between 5-19 minutes per encounter. In addition, the care coordinators spent the longest time, 20-29 minutes and greater than 30 minutes with age group 3-5, 14.1% and 7.6% respectively. This suggests that the care coordination encounters for children in the 3-5 age group required longer time to complete.

The care coordinators spend most of the time in 5-19 minutes with level I (81.4%) and level IV (76.1%) patients. The care coordinators spend the longest time, 20-29 minutes and > 30 minutes with Level II patients (14.2%, 7.0% respectively). This indicates that patients with complicating families or social issues require longer time for care coordination encounters.

<table>
<thead>
<tr>
<th>Time Spent</th>
<th>Patient Age (%)</th>
<th>Patient Level (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-2</td>
<td>3-5</td>
</tr>
<tr>
<td>&lt;5</td>
<td>26</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>(9.7)</td>
<td>(10.3)</td>
</tr>
<tr>
<td>5-9</td>
<td>115</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>(43.1)</td>
<td>(29.9)</td>
</tr>
<tr>
<td>10-19</td>
<td>86</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>(32.2)</td>
<td>(36.4)</td>
</tr>
<tr>
<td>20-29</td>
<td>28</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>(10.5)</td>
<td>(14.1)</td>
</tr>
<tr>
<td>&gt;30</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>(2.6)</td>
<td>(7.6)</td>
</tr>
<tr>
<td>Total</td>
<td>267</td>
<td>184</td>
</tr>
<tr>
<td></td>
<td>(100)</td>
<td>(100)</td>
</tr>
</tbody>
</table>

The focus of the encounters in relation to the patient age group and patient level is shown in Table 3. The majority of the encounters (50.8%) had a primary focus of clinical/medical management. In this study, a “clinical/medical management” focus
referred to encounters with the focus in scheduling appointments, facilitating in ordering prescriptions, coordinating medical services, and activities specific to the medical needs of the patient. The other major focus of encounters included: referral management (34.9%), social services (10.7%) and educational/school (6.1%). The “referral management” focus consisted of managing referrals to community agencies such as Birth to Three, Help Me Grow, etc that families had barriers accessing. The “social services” focus referred to housing, food, clothing insurance, transportation and/or intake assessment.

Patients in the age group 0-2 had the most encounters with a clinical/medical management focus (61%). Age group 3-5 had the highest distribution of encounter with a social services focus (14.7%) and educational/school focus (10.9%). The 6-11 and 12-16 age groups had the most encounters with a referral management focus; 41.4% and 41.6% respectively. This indicated that during the study period, the care coordinators focused on referring pre-adolescents and adolescents to community agencies more frequently than expected.

Patients with no special health care needs (level I and level II) experienced more encounters with a referral management focus, 79.1% and 55.5% respectively. Interestingly, the special health care need of the patient did not play a role in referrals to community agencies. Conversely, CYSHCN (level III and level IV) patients experienced more encounters with a clinical/medical management focus, 65.5% and 62.7% respectively than patients without special health care needs. Furthermore, encounters with a social services focus (i.e. housing, food, clothing, insurance, transportation) were seen in larger percentages for level II (12.3%) and III (11.2%) patients. This indicates the a
social services focus was seen across patient levels regardless of their special health care needs or family or social issues.

| TABLE 3 Focus of Encounter by Patient Age Group & Patient Level for Encounter (N=656) |
|-------------------------------------------------|-------------------------------------------------|-----------|-----------|-----------|-----------|-----------|-----------|
| Focus of Encounter                              | Patient Age Group (%)                          | Patient Level (%) |
|                                                 | 0-2     | 3-5     | 6-11     | 12-16    | I         | II        | III       | IV        | Total     |
| Clinical/Medical                                | (61)    | (44.6)  | (44.5)   | (40.3)   | (11.6)    | (33.2)    | (65.5)    | (62.7)    | (50.8)    |
| Referral                                        | (32.2)  | (31.5)  | (41.4)   | (41.6)   | (79.1)    | (55.5)    | (19.8)    | (19.0)    | (34.9)    |
| Management                                      | 27      | 27      | 9        | 7        | 1         | 26        | 29        | 14        | 70        |
| Social Services                                 | (10.1)  | (14.7)  | (7.0)    | (9.1)    | (2.3)     | (12.3)    | (11.2)    | (9.9)     | (10.7)    |
| Education/School                                | 3       | 20      | 9        | 8        | 2         | 9         | 13        | 15        | 40        |
|                                                 | (1.1)   | (10.9)  | (7.0)    | (10.4)   | (4.7)     | (4.3)     | (5.0)     | (10.6)    | (6.1)     |
| *Total                                          | 656     |         |          |          |           |           |           |           | (100)     |

* Total includes all the focus of encounters recorded during the study. Any values with <6.0% of all encounters were too small to discuss and were excluded from the tables.

There were 690 needs recorded for the patients served, of which 64.6% of all needs were follow-up on referrals. This need was recorded any time the care coordinators were engaged in activities that followed up on the initial referral. Other needs of the encounters with percentages larger than 6.0% included reconcile discrepancies (14.3%), coordination services (10.4%), and well child appointment (7.0%).

The care coordination need in relation to the patient age group and patient level is shown in Table 4. Among all encounters, the follow-up referral need had relatively the same percentages with small increments as the age group increased. The adolescent had a 78% of encounters with follow up referral need. The adolescent age group also had the highest percentage for reconcile discrepancies (16.9%) followed by both the infant and preschool age groups; 15.4% and 15.2% respectively. On the other hand, the pre-school age group experienced the highest percentages for coordination services (15.2%). These
results indicate that the younger that patient the larger the array of care coordination needs they will experience. Not surprisingly, the infants group had the highest well child appointment need (11.2%). This makes sense due to the critical immunization requirements for infants between 0-2 years of age.

Interestingly, non-CYSHCN patients (Level I and Level II) experienced the highest percentage of follow up referral needs, 72.1% and 73.5% respectively. Moreover, non-CYSHCN without complicating families or social issues (Level I) patients experienced the highest percentage of reconciled discrepancies needs. This indicates that having either a special health care need or a family-based stressor may influence the type of care coordination need. Coordination of services was highest among CYSHCN (Level III and Level IV), 11.2% and 12.0% respectively than non-CYSHCN (level I and Level II), 0% and 10% respectively.

| TABLE 4 Care Coordination Need by Patient Age Group & Patient Level for Encounter (N=656) |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Care Coordination Need          | 0-2  | 3-5  | 6-11 | 12-16 | I    | II   | III  | IV   | Total |
| Follow-up                       | 155  | 120  | 89   | 60    | 31   | 155  | 148  | 89   | 424   |
| Referral                        | (58.1)| (65.2)| (69.5)| (77.9)| (72.1)| (73.5)| (57.4)| (62.7)| (64.6)|
| Reconcile                       | 41   | 28   | 12   | 13    | 10   | 25   | 37   | 22   | 94    |
| Discrepancies                   | (15.4)| (15.2)| (9.4)  | (16.9)| (23.3)| (11.8)| (14.3)| (15.5)| (14.3)|
| Coordination                    | 22   | 28   | 11   | 7     | 0    | 21   | 29   | 17   | 68    |
| Services                        | (8.2) | (15.2)| (8.6)  | (9.1)  | (0)  | (10) | (11.2)| (12.0)| (10.4)|
| Well-child Appt                 | 30   | 12   | 4    | 0     | 1    | 27   | 11   | 7    | 46    |
|                                | (11.2)| (6.5)| (3.1)  | (0)    | (2.3) | (12.8)| (4.3) | (4.9) | (7.0) |
| *Total                          | 267  | 184  | 148  | 57    | 43   | 211  | 258  | 142  | 656   |
|                                | (100)| (100)| (100) | (100) | (100)| (100)| (100)| (100)| (100) |

* Total includes all the care coordination needs recorded during the study. Any values with < 6.0% of all encounters were too small to discuss and were excluded from the tables.
The activities performed to fulfill the needs of the encounters are summarized in Table 5. There were 1,172 activities recorded for the 656 encounters. The most performed activity was telephone encounters with parents/family with 67.1% for all patients. Besides contacting parents, the care coordinators spent 44.4% of the encounters developing and modifying care plans and 26.5% conferring with the primary care physician. These results are not surprising given that one of the main roles of care coordinators is to facilitate the partnership between patient, families and provider by focusing on the needs of the care plan.

Interestingly, contacting parents/families was relatively the same among all age groups. Age group 0-2 and 3-5 had the highest percentages for contacting families, 69.3% and 68.5% respectively. But it was closely followed by 6-11 age group and 12-16 age group, 63.3% and 62.3%. The care coordination activity of developing care plans was highest among the 6-11 age-group (51%) and closely followed by the 0-2 age group (45.3%) and 3-5 age group (40.2%). The 0-2 age group had the highest percentages of in conferring with primary care physicians (31.8%), while 3-5 age group had the highest percentage in contacting specialist (12.0%). Both 0-2 age group and 3-5 age group had high percentages for contacting agencies, 10.1% and 9.8% respectively.

When looking at the care coordination activities by patient levels, Level II and Level III patients had the highest percentages for contacting parents, 69.2 and 69.8% respectively. This may indicate that neither special health care need nor complicating families play a role in performing this activity. Conversely, having a special health care need plays a role for contacting agencies, whereas not having a health care needs affects the percentages of developing care plans. CYSHCN had highest percentages for
contacting agencies, 12.4% and 14.1% respectively, whereas, non-CYSHCN (Level I & Level II) have a greater percentage for developing care plans, 65.1% and 57.3% respectively. Furthermore, patients with special health care needs but without complicating families or social issues had the highest distribution of contacting a specialist. This makes sense since patient with special health care needs are referred mostly to agencies and specialist more frequently. On the other hand, conferring with the primary care physician was seen as an activity mostly performed for patient level II. This makes sense since as seen in the previous table; level II patient had a high need for well child appointments. And the care coordinator had to meet with the primary care physician to arrange the well child appointment accordingly to the provider’s schedule.

TABLE 5 Activities to Fulfill Care Coordination Need by Patient Age Group & Patient Level (N=656)

<table>
<thead>
<tr>
<th>Care Coordination Activities</th>
<th>Patient Age Group (%)</th>
<th>Patient Level (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-2</td>
<td>3-5</td>
</tr>
<tr>
<td>Telephone</td>
<td>185</td>
<td>126</td>
</tr>
<tr>
<td>parent/family</td>
<td>(69.3)</td>
<td>(68.5)</td>
</tr>
<tr>
<td>Develop/ Modify</td>
<td>121</td>
<td>74</td>
</tr>
<tr>
<td>CP</td>
<td>(45.3)</td>
<td>(40.2)</td>
</tr>
<tr>
<td>Confer PCP</td>
<td>85</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>(31.8)</td>
<td>(24.5)</td>
</tr>
<tr>
<td>Contact</td>
<td>24</td>
<td>22</td>
</tr>
<tr>
<td>Specialist</td>
<td>(9.0)</td>
<td>(12.0)</td>
</tr>
<tr>
<td>Contact Agency</td>
<td>27</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>(10.1)</td>
<td>(9.8)</td>
</tr>
<tr>
<td>Total</td>
<td>267</td>
<td>184</td>
</tr>
<tr>
<td></td>
<td>(100)</td>
<td>(100)</td>
</tr>
</tbody>
</table>

* Total includes all the care coordination activities recorded during the study. Any values with <6.0% of all encounters were too small to discuss and were excluded from the tables.
B. Relationship of activities to Outcomes:

A summary of the outcomes occurred distribution arranged by patient age groups and patient level is shown in Table 6. The care coordinators recorded 912 outcomes from the 659 encounters. In this study the most recorded outcome occurred was “met family needs” (41.8%), which was mainly observed for age group 3-5 (46.7%) and for level II patients (50.7%). This outcome was achieved when the care coordinator intervention addressed the family needs, questions or concerns and did not provide any of the other outcomes categories. The other outcomes that occurred most frequently included: reconciled discrepancies (30%), referral to subspecialties (24.7%), pending outcomes (17.7%), and referral to agency (9.3%).

All the age groups had relatively similar percentage for the outcome meeting the family needs although 0-3 age group had the highest percentage (46.7%) than the rest of the age groups. It is important to note that this outcome could have been selected when the care coordinator achieved other outcomes such as reconcile discrepancies such resulting in an overlap of results. The care coordinators recorded to reconcile discrepancies as an outcome that occurred in high percentage for 12-16 age group (36.4%) and for 3-5 age group (32.1%). Referral to subspecialties was recorded as a outcomes that occurred mostly for patients ages 3-5 and 6-11, 27.2% and 32.8% respectively. Pending outcomes occurred mostly for age group 0-2 and 6-11, 18.7% and 19.5% respectively, whereas referral to agencies occurred more frequently for age group 0-2 and 3-5, 10.9% and 10.3% respectively.

In terms of patient level, Level II patients had the highest percentage (50.7%) for “met family needs” outcome. Whereas Level II, III & IV patients had relatively the same
percentages for reconcile discrepancies, 30.3%, 30.6% and 31% respectively. Interestingly, Level II patient had the highest distribution for encounters with referral subspecialties (28.9%) followed by Level I (25.6%) and Level III (25.2%) patients. It was interesting to find Level IV patients with the least percentage (17.2%) although one would expect these patients to be referred to subspecialties more frequently. This may just indicate that the Level IV patients were not being referred to subspecialties as frequently during the 30-day study period. Level I patient experienced a higher percentage for pending outcomes (23.3%) and referral to agency (11.6%) compared to the other patient levels.

<table>
<thead>
<tr>
<th>Outcomes Occurred</th>
<th>Patient Age Group (%)</th>
<th>Patient Level (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-2</td>
<td>3-5</td>
</tr>
<tr>
<td>Met</td>
<td>109</td>
<td>86</td>
</tr>
<tr>
<td>Family Needs</td>
<td>(40.8)</td>
<td>(46.7)</td>
</tr>
<tr>
<td>Reconcile</td>
<td>76</td>
<td>59</td>
</tr>
<tr>
<td>Discrepancies</td>
<td>(28.5)</td>
<td>(32.1)</td>
</tr>
<tr>
<td>Referral</td>
<td>55</td>
<td>50</td>
</tr>
<tr>
<td>Subspecialties</td>
<td>(20.6)</td>
<td>(27.2)</td>
</tr>
<tr>
<td>Pending</td>
<td>50</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>(18.7)</td>
<td>(15.2)</td>
</tr>
<tr>
<td>Referral</td>
<td>29</td>
<td>19</td>
</tr>
<tr>
<td>Agency</td>
<td>(10.9)</td>
<td>(10.3)</td>
</tr>
<tr>
<td>Total</td>
<td>267</td>
<td>184</td>
</tr>
</tbody>
</table>

* Total includes all the outcomes occurred recorded during the study. Any values with <6.0% of all encounters were too small to discuss and were excluded from the tables.
C. Case Studies

Patient A was a one year old female CYSHCN who was in need of various subspecialties appointment including neurology, genetics, and audiology. Patient A lived with a single mother who had a hearing impairment and required a sign language interpreter to attend the patient’s appointments. Patient A had been referred to HOME for the care coordinator to assist the family with the subspecialty appointments and a referral to the Birth-to-Three program. Patient A was designated a Level IV due to the child’s medical complexity and complicating family situation. This patient represented the 0-2 age group.

The patient was referred to HOME program a couple of weeks prior to the study but the care coordinator was still on the process of contacting the family to complete the intake. At this point the care coordinators had unsuccessfully contacted the family through the phone and had mailed a welcome packet to the house with the pending appointments of the patient. The patient had a pending well child appointment coming up and the care coordinator was going to meet the family during the appointment to complete the intake and introduce the program. The well child appointment was scheduled during the study period.

This patient had eight care coordination encounters during the study period. A total of nine foci of encounter were recorded: clinical/medical management (n=3), social services (n=1), referral management (n=4), educational/ school (n=1). A total of eight care coordination needs were recorded: follow up referral (n=2), reconcile discrepancies (n=3), coordination services (n=3). The care coordination activities completed to fulfill needs included: telephone discussion with parent (n=5), confer with primary care
physician (n=2), develop/modify written care plan (n=1), contact agency (n=4), and contact school (n=1). The outcomes occurred as a result of these care coordination activities included: met family needs (n=4), advocacy for family/patient (n=1), referral to community agency (n=1), reconciled discrepancies (n=3), referral to specialist (n=1).

During the first care coordination encounter, the care coordinator met the family in the clinic during the patient’s well-child appointment, completed the intake, and verified pending subspecialties appointments. The care coordinator communicated with the mother through a sign language interpreter. The mother confirmed receiving the letter and was aware of the pending appointments. The mother requested for the care coordinator to verify that a sign language interpreter was present for the other pending appointments. The mother also provided an email as a method of communication. At this point, the mother shared her concerns regarding the evaluation from the Birth-to-Three program which stated that the patient had no speech or language concern and recommended the family to transfer services to the American School of Deaf (ASD). The care coordinator obtained the information of the case worker from the Birth-to-Three program. At this encounter the focus was clinical/medical and social services (for the intake completion), the need was referral follow up, the activities included talking to the parent, conferring with the primary care physician and developing a care plan, the outcome was recorded as meeting the family needs.

During the second encounter, the care coordinator contacted the Birth-to-Three program to verify the status of the referral and to request their evaluations on the patient. The care coordinator addressed the mother’s concern regarding the final evaluation with the case worker. The case worker was pending on the ENT results regarding medical
clearance for hearing aid and a letter from the mother to begin the transfer. The care coordinator e-mailed the mother regarding the conversation. This referral had a focus of referral management, the need was to reconcile discrepancies, the activities including contacting the family and agency and the outcomes was advocacy for family/patient.

The third encounter involved the care coordinator discussing the new information regarding Birth-to-Three program with the provider. The focus was clinical/ medical, the need was to reconcile discrepancies, the activity was to confer with the PCP, and the outcome was reconciled discrepancies.

The fourth encounter involved the care coordinator coordinating services with the Birth-to-Three program. The case worker emailed the care coordinator the forms to begin the transfer of services which the form did not have. And the care coordinator faxed the ENT results to the case worker. The focus of this encounter was referral management, need was the coordination of services, the activity included contacting the agency and the outcome was reconciled discrepancies.

The fifth encounter involved the care coordinator discussing the transferring process with the mother and the Birth-to-Three agency. The focus of encounter was referral management, the need was coordination of services, the activity included discussion with parent and agency and the outcomes included meeting the family needs and referral to community agency.

The sixth encounter involved the care coordinator coordinating services with the daycare that the mother wanted to enroll the patient. The mother needed the physical forms to be faxed to the daycare. CC obtained the information of the daycare and provided the missing forms. The focus included educational, the need was coordination
services, the activity included contacting the family and the school and the outcome was meeting the family’s needs.

The seventh encounter involved the care coordinator discussion with the American School of Deaf regarding the services the patient was going to obtain. The focus of this encounter was referral management, the need was to reconcile discrepancies, the activity was contact with agency and the outcome was meeting the family’s immediate needs and reconciled discrepancies.

The final encounter during the study involved the care coordinator emailing the family the reminder for the pending neurology appointment coming up. The focus was clinical/medical, the need was to follow up referral, the activity was to contact the parent, and the outcome was referral to the subspecialties, in this case the neurologist.

These encounters created a challenge to the care coordinator due to the mother’s hearing impairment. Based on the needs of this family, care coordination helped to facilitate care in a way that was sensitive to the patient’s medical needs. In this case, the care coordinator invested time through several weeks to coordinate services between two different agencies, the Birth-to-Three and the American School of Deaf, to verify the patient was receiving the appropriate care she needed. These activities may not be performed by clinical staff due to the time consumption required, yet these activities were essential to meeting the medical care of the patient.

*Patient B* was an eleven-year old male, CYSHCN who was also patient of the Nancy Kids Clinic. Patient B lived with both parents, who had no social or complicating family concerns. Patient B was designated Level III and represented the 6-11 age group. Patient
B had been referred to HOME for the care coordinators to assist with various subspecialty appointments.

Patient B was already an established HOME patient by the time of the study period. The care coordinator and the family had worked together on various subspecialties appointment but due to the medical complexity of the patient; there were still more pending appointment. Patient B had two care coordination encounters during the study period.

Both care coordination encounters had a clinical/medical management focus. The care coordination needs included follow up referrals (n=2) and make subspecialty appointment. The activities to fulfill the needs involved telephone parent (n=2), contact specialist, develop/modify written care plan. The outcomes occurred in result of the care coordination activities included met family needs (n=2) and referral to subspecialties.

During the first encounter, the care coordinator met the family during an office visit and obtained an updated phone number. The care coordinator addressed the family’s concerns regarding the new subspecialty referrals to cardiology, genetics and an EKG. This encounter had a clinical/ medical fours, the need was follow up on referrals, the activity including discussion with the parent and the outcomes was recorded as meeting the family’s needs.

During the second encounter with the family, the care coordinator contacted the family to schedule subspecialty appointment. During this encounter, appointments for EKG, cardiology and genetics were scheduled with the family on the phone. The appointments were recorded in the reminder list and the care plan and process notes were updated. The focus of this encounter was clinical/medical, the need was to make

34
appointment and follow-up referrals, the activities included contacting the parent, contacting the specialist and modifying the care plan, the outcome was recorded as referral to subspecialties and meeting family’s needs.

The next encounter with the family would have occurred when the care coordinator contacted family with reminders for the appointment and another encounter would have occurred when the care coordinator confirmed that the appointments were kept, unless other concerns arose earlier. Again in this scenario, care coordination helped to facilitate care based on the patient’s medical needs.
Chapter V

DISCUSSION

The practice-based care coordination model provides a multidisciplinary framework that supports a family-centered approach to care coordination. This approach effectively delivers care coordination within primary care clinics by emphasizing a partnership between the families and their primary care physicians. This study describes the different types of non-reimbursable care coordination activities performed by non-clinical, practice-based care coordinators and the outcomes associated with these activities. Providing a descriptive analysis of the care coordination encounters addressed by non-clinical, practice-based care coordinators facilitates a framework to support such work to continue.

This study found that care coordination is provided across pediatric patient complexity levels and age groups. Specifically, the 0-2 age group received 41% of all encounters. Furthermore, level III patients received 39% of all encounters. Additionally, more than half (53.8%) of the study patients represented CYSHCN. The study results demonstrated that the care coordinators spent 72.8% of their time in the 5-19 minute range per encounter. This finding was consistent with previous work (Antonelli and Antonelli; Antonelli et al., 2008) In addition, the data demonstrated that age did not play a role during these short time encounters, since the time range was evenly distributed among the age groups. Conversely, the data demonstrated that age and patient level did play a role for longer encounters. The study found that the 0-2 age group, along with level II patients, had higher percentages for 20-29 minute and the greater than 30 minute time ranges.
This study found that the age and family-based social stressors influenced the type of focus, need(s), activities and outcome(s) of the patient’s encounters. Infants had the most clinical/medical management focus which made sense because they also had the highest need for well-child appointments, whereas pre-school age group had the highest percentage for social and educational focus, with coordinating of services as the need. The care coordinators recorded high percentages for contacting care physicians and contacting agencies for infants which resulted in referral to agencies and pending outcomes for this age group. The pre-school age group had high percentages for contacting specialist which resulted in reconcile discrepancies. Nevertheless, there were some elements of the encounters that remained the same across the age groups. All the age groups had close percentages for follow-up referrals as a need, contacting families and developing care plans as activities and meeting families’ needs as an outcome.

When the care coordination encounters were arranged by patient level, there were higher distribution among patient level II (32%) and III (39%). Again the elements of the encounters varied according to the patient level. Non-CYSHCN (Level I & Level II) patients had a higher distribution of referral management as a focus, follow up referral as a need, and developing care plan as an activity. In contrast, CYSHCN (Level III & Level IV) patients experienced a higher percentage of encounters with clinical/medical focus, coordinating services as a need and contacting agencies as an activity. The patient level did not play a role for encounters with social services as a focus or reconcile discrepancies, and referral to subspecialist as an outcome.

The majority of the care coordination encounters recorded in this study had a focus on either clinical or referral management, a need for follow-up referral, reconcile
discrepancies and coordination of services and the activities involved telephoning parents, developing care plans and conferring with primary care physicians. The outcomes achieved during the study period included meeting family needs, reconciling discrepancies, referring to subspecialties, pending outcomes, referring to agency and advocating.

The lack of formal medical training limited the practice-based care coordinators to only achieve certain outcomes rather than to prevent them. However, the non-reimbursable activities and achieved outcomes performed by the practice-based care coordinators displayed the non-clinical work that can often distract and consume medical staff in pediatric clinics. Other studies have shown achieved similar outcomes. Palfrey et al., reported improvements in having telephone calls answered, getting appointments, getting referrals to specialists, having prescriptions as a result of a designated nurse practitioner managing the care of CYSHCN patients. Wood et al., reported fewer barriers to health services and improvement in connecting to outside resources, after receiving care coordination services from the assigned practice-based nurse care coordinator.

There are several limitations in this study that should be acknowledged. First, the data collection process may have limited the results. The length of a thirty-day study period from the two-year H.O.M.E. initiative failed to provide sufficient time to adequately measure outcomes, resulting in 17.7% of pending outcomes. Furthermore, this snapshot of the H.O.M.E. pilot project limited the window of exposure to the multiple problems these patients may have presented with in a longer period of time. Second, the status of the H.O.M.E. initiative as a pilot project needs to be taken into
consideration. Data entry was a critical component for evaluation purposes of the pilot project. As a result, 4.4% of the total outcomes were not applicable outcomes to care coordination activities. In addition, other activities related to the pilot project such as weekly meetings or missed work days (due to sick days, vacation or personal days taken by the care coordinators) during the study period may have affected the collection period.

Third, the methodology was limited. There was no validation process used for the measurement tool. The methodology did not validate on how the care coordinators were completing the forms. It would have required observations made by other staff to verify that the care coordinators completed the forms accurately to the actual activities performed. This validation did not take place in this study because of the time constraints, lack of personnel and funding. In addition the activities and outcomes recorded were subjective to the training of the care coordinators.

Further studies must concentrate on preventable outcomes (such as hospitalization or emergency room visits) in order to determine the cost effectiveness of practice-based care coordination. The lack of formal medical training limited the practice-based care coordinators in this study model to record outcomes prevented that could measure the cost effectiveness of the model. To better measure expected and preventable outcomes, a “teamlet” approach, which includes collaboration between medical and non-medical staff, must be considered. A “teamlet” approach proposes that medical staff should work to their fullest potential and allows offloading tasks to non-clinical staff, also referred to as health coaches. Training the practiced-based care coordinators as health coaches, will potentially provide an improved strategy for the delivery of care coordination in a medical home model. Further studies should consider additional demographic
characteristic of the patients such as gender and socioeconomic group as well as the parents’ education level, literacy level, and primary language.

This study demonstrated that non-clinical care coordinators can meet the needs of CYSHCN and low-income patients when integrated within primary care clinics. The findings in this study have important implications on improving the delivery, access and cost of pediatric primary care services. The non-clinical care coordinators accomplish activities that fall outside the traditional health care services, such as providing transportation, coordinating services, and reconciling discrepancies but can consume clinical staff and families. Delegating these non-reimbursable activities will allow clinical staff to concentrate on their roles and improve the quality of care delivery. In addition care coordination facilitates the access to primary care services by promoting family-centered care and helps steer pediatric families away from utilizing the emergency room for primary care services. As a result, care coordination plays an essential role in fostering a healthier pediatric population with a focus on preventative care in a cost-effective manner.

It is critical to look at the areas that will sustain and help continue the essential work of care coordination in primary care clinics. A way to do this is to compare the impact of the work from non-clinical practice-based care coordinators to another inner city primary care clinic without practice-based care coordinators. The comparison of measurable medical outcomes such as immunization rates, hospitalization admission or emergency room visits will test the value of care coordination not only in terms of its benefits to the families but also its cost effectiveness to health care organizations. It is also important to show that broader societal outcomes may occur due to care
coordination, particularly in allowing lower income, inner-city families to get involved in the medical needs of their child while being sensitive to the families’ social and cultural needs.
References:


14 Future of pediatric education task force. The future of pediatric Education II: organizing pediatric education to meet the needs of infants, children, adolescent and young adults in the 21st century, a collaborative project of the pediatric community. Pediatrics 2000; 105 (suppl): 162-212


33 McAllister JW, Presler E & Cooley WC. Medical Home Practice-Based Care Coordination. Center for Medical Home Improvement (CMHI).


### Appendix A

<table>
<thead>
<tr>
<th>Date</th>
<th>Patient Name</th>
<th>Complexity Level</th>
<th>Attribute</th>
<th>Activity Code</th>
<th>Outcome</th>
<th>Time Spent</th>
<th>Staff</th>
<th>Total Cost</th>
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**Complexity Level**

1. Minor
2. Moderate
3. Major
4. Critical

**Attribute**

1. Personal
2. Medical
3. Physical
4. Emotional
5. Socioeconomic
6. Psychological
7. Social
8. Nutritional
9. Environmental
10. Economic
11. Cultural
12. Educational
13. Legal
14. Spiritual
15. Religious
16. Other

**Activity Code**

1. Consultation
2. Examination
3. Treatment
4. Medication
5. Surgery
6. Rehabilitation
7. Therapy
8. Counseling
9. Education
10. Nutrition
11. Social Work
12. Psychological
13. Psychological
14. Other

**Outcome**

1. Improved
2. Stable
3. Declined
4. Other

**Time Spent**

1. Minutes
2. Hours
3. Days
4. Weeks
5. Months

**Staff**

1. Resident
2. Fellow
3. Nurse
4. Other

**Total Cost**

1. Dollars
2. Euros
3. Pounds
4. Other

UW Healthcare

Nursing Potentials

1. BSN
2. RN
3. APRN
4. Other

**Clinical Competence Code**

1. Required
2. Strongly Recommended
3. Other
## Appendix B

### APPENDIX: Medical Home Care Coordination Measurement Tool

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
<th>Primary Language</th>
<th>Rate</th>
<th>Rate</th>
<th>Targeted Needs</th>
<th>Access to Fill Needs</th>
<th>Prevented Chronic Condition</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

**Access to Fill Needs**

- Comprehensive Preventive Care
- Monitoring and Treatment
- Self-Management Support
- Patient Education
- Coordination of Care
- Communication
- Access to Health Care

**Prevented Chronic Condition**

- Diabetes Management
- Hypertension Management
- Asthma Care
- Depression Management
- Arthritis Management
- Chronic Pain Management
- COPD Management
- Congestive Heart Failure Management
- Kidney Disease Management
- Stroke Prevention
Appendix C

Medical Home Care Coordination Measurement Tool

<table>
<thead>
<tr>
<th>Participant Code:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Study Code and Age:</td>
<td>Site Code:</td>
</tr>
<tr>
<td>Initials:</td>
<td>Staff (RN, LPN, MD, NP, PA, MA, SW, cler):</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time Spent</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 5 minutes</td>
<td>5 to 9 minutes</td>
</tr>
<tr>
<td>20 to 29 minutes</td>
<td>30 to 39 minutes</td>
</tr>
<tr>
<td>50 minutes and greater</td>
<td>(*Please NOTE actual minutes if greater than 50)</td>
</tr>
</tbody>
</table>

Patient Level – (choose ONLY ONE)
- I - Non-CYSHCN, Without Complicating Family or Social issues
- II - Non-CYSHCN, With Complicating Family or Social issues
- III - CYSHCN, Without Complicating Family or Social issues
- IV - CYSHCN, With Complicating Family or Social issues

Focus of Encounter (choose all that apply)
- Mental Health
- Developmental /Behavioral
- Educational / School
- Legal / Judicial
- Growth / Nutrition
- Referral Management
- Clinical / Medical Management
- Social Services (ie. housing, food, clothing, ins., trans.)

Care Coordination Needs (choose all that apply)
- Make Appointments 
- Order Prescriptions, Supplies, Services, etc.
- Coordination Services (schools, agencies, payers etc.)
- Follow-Up Referrals
- Reconcile Discrepancies

Activity to Fulfill Needs (choose all that apply – continued on next page)

Telephone discussion with
- Patient
- Parent/family

Contact with Home Care Personnel
- Telephone
- Meeting
- Letter
- E-Mail
### Activity to Fulfill Needs (choose all that apply) (Cont.)

- Chart Review
- Confer with Primary Care Physician
- Contact with Agency: (eg. birth to 3, help me grow, SSI)
- Contact with Allied Health (eg. PT, OT, audiology)
- Contact with School
- Contact with Payer
- Contact with Pharmacy
- Contact with Specialist (eg. cardiology, GI, pulmonary)
- Develop / Modify Written Care Plan
- Form/Letter Processing: (eg. school, camp, or complex record release)
- Meeting/Case Conference
- Patient-focused Research

### Outcome(s)

**As a result of this care coordination activity, the following was PREVENTED (choose ONLY ONE, if applicable):**

<table>
<thead>
<tr>
<th>As a result of this care coordination activity, the following was PREVENTED (choose ONLY ONE, if applicable):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit to Pediatric Clinic</td>
</tr>
<tr>
<td>Visit to ER</td>
</tr>
</tbody>
</table>

**As a result of this care coordination activity, the following OCCURRED (choose all that apply):**

<table>
<thead>
<tr>
<th>As a result of this care coordination activity, the following OCCURRED (choose all that apply):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advised family/patient on home management</td>
</tr>
<tr>
<td>Reviewed labs, specialist reports, IEP's, etc.</td>
</tr>
<tr>
<td>Met family's immediate needs, questions, concerns</td>
</tr>
<tr>
<td>Ordered prescription, equipment, diapers, taxi, etc.</td>
</tr>
<tr>
<td>Reconciled discrepancies (including missing data, miscommunications, compliance issues)</td>
</tr>
<tr>
<td>Advocacy for family/patient</td>
</tr>
<tr>
<td>Not Applicable / Don't Know</td>
</tr>
<tr>
<td>Outcome Pending</td>
</tr>
</tbody>
</table>