

BRIDGE TO INDEPENDENCE

I: INTRODUCTION

Nature of the Research Problem

Children and Youth with Special Health Care Needs (CYSHCN) are defined as having, or being at risk of having, a chronic medical, behavioral or other problem that requires care beyond that needed by children without special needs. A small subset of CYSHCN (< 1%) can be described as Children with Medical Complexity (CMC). The Special Needs Program (SNP) at Children's Hospital of Wisconsin (CHW) partners with families and children, primary care physicians (PCP), specialists, other providers, community services and insurers to ensure seamless in- and outpatient care for CMC with extremely high medical fragility. These children typically have 7 specialists, conditions involving 5 organ systems, technology dependence, multiple community services and significant care coordination challenges. They make up less than 0.005% of children followed at CHW, but account for 17.5% of payments to the institution. After enrollment in the SNP, hospital days decreased by half, outpatient clinic visits increased by 50%, and payments decreased by \$5-7 million annually. In addition, family and provider satisfaction with the SNP was generally high. Despite this decrease in healthcare costs, reimbursement for care coordination from insurers is poor and the SNP runs a deficit of close to \$1.5 million. Thus, the SNP like other Complex Care Programs throughout the USA has a limited capacity to serve the needs of the growing population of CMC.

Purpose, Scope and Methods of Investigation

The overall goal of this research is to determine whether systematic care coordination education for families and PCPs increases their comfort and ability to care for CMC in turn leading to earlier discharge from the SNP and increased capacity to care for more patients.

The initial Specific Aims of the proposal were to:

- 1) Develop, implement and evaluate a Care Coordination Curriculum for families
- 2) Develop, implement and evaluate care coordination tools for the PCPs
- 3) Evaluate the effects of Curriculum and tools on capacity, sustainability, and potential replicability of a care coordination program

Between February 1, 2008, and April 30, 2010, a Control Group of families and PCPs of children admitted to the SNP were enrolled in the study. The Control Group received standard care from the SNP including ad hoc care coordination teaching for families. Concurrently, a novel Care Coordination Curriculum consisting of 12 modules addressing key areas of coordination was developed by content and adult education experts. The goal of the Curriculum was to teach skills that could be broadly applied rather than addressing specific tasks. Between May 1, 2010, and April 30, 2012, Control Group data continued to be collected and the Intervention Group were recruited. The Intervention Group received similar care from the SNP as the Control Group except that structured teaching based on the Care Coordination Curriculum began. We anticipate continuing to collect data from the Intervention Group for up to 2 more years in order to evaluate the impact of the Curriculum. In addition, we continue to collect criticism and feedback on the Curriculum and anticipate revising it and translating it into Spanish within the next 2 years.

For several reasons, we did not address Specific Aim #2 (develop new care coordination tools for the PCPs). Most importantly, there was concern that this would confound interpretation of the effects of the Care Coordination Curriculum. Therefore, PCPs for both Control and Intervention patients were provided with routine SNP support and detailed care plans for the patients. In addition, the Intervention Group received copies of the Curriculum if desired.

Data were collected at enrollment, 9-12 months after enrollment, and 21-24 months after enrollment (or at discharge) for both Control and Intervention groups. These included:

- 1) Family Care Coordination Competency; Peds QL Family Health Care Satisfaction; and Peds QL Family Impact questionnaires.
- 2) CHW Resource Utilization (admissions, hospital days, clinic visits, short stay admissions, ED visits, charges and payments); SNP care coordinator time; duration of enrollment.
- 3) PCP self-assessed comfort and competency.

Data collection for the Intervention Group is ongoing. At this point we have baseline data for both groups and complete longitudinal data for the Control Group only. In addition, we have been collecting and continue to collect evaluations of the Care Coordination Curriculum by families, coordinators, and others interested in providing care coordination (e.g. members of the Academic Pediatric Association Complex Care Special Interest Group, and providers interested in developing Complex Care Programs to whom the Curriculum has been freely available).

Nature of the Findings

Baseline data collected from both the Control and Intervention Groups provides a comprehensive picture of the medical and non-medical characteristics of highly fragile CMC, the skills and burden of their families, and the comfort and competency of their PCPs. The longitudinal Control Data describes outcomes in patients cared for by the SNP and families receiving ad hoc care coordination education. This will serve as the basis for later comparison with the Intervention Group when that data has been collected. The Curriculum has been completed and disseminated widely. The reception has been positive with wide support for the approach of teaching broad coordination principles. The need for new modules addressing: 1) end of life planning; and 2) caregiver burden and family support has been noted.

II: REVIEW OF THE LITERATURE

CMC and CYSHCN in general are likely to have unmet needs and to benefit from care coordination across the continuum from home to the hospital. Families want to participate as full partners in the care of their children. Thus, they require the information, education and skills to interact with medical providers, community agencies, and insurers. There is evidence that education can empower families of CYSHCN to play a greater role. However, the skills needed by families of CMC have not been evaluated and the impact of structured care coordination education on the abilities and quality of life of families of CMC is unknown.

Empowering families to better coordinate care for their children may have the added benefit of increasing the capacity of Complex Care Programs like the SNP to follow more patients. These programs exist because the complexity and fragility of CMC often overwhelms the resources of PCPs trying to provide Medical Homes. The SNP extends the Medical Home by partnering with families and PCPs and others to ensure seamless in and out patient care. We have previously shown that after enrollment in the SNP there is a decrease in inpatient days and health care costs and similar findings have been shown by other Complex Care Programs. However, the population of CMC is increasing and the number of Complex Care programs is small. Moreover, the cost of high intensity care coordination / comanagement coupled with poor remuneration for these services markedly limit capacity to care for these children. Thus, it is essential to find other ways to safely and effectively build capacity. We hypothesized that combining structured care coordination teaching with high quality care coordination and co-management would lead to empowered and educated families who could ultimately provide expert care coordination for their children. This in turn would reduce the census of the SNP leading to increased capacity to

enroll more CMC. Without new strategies to increase capacity of care coordination services as advocated by the AAP, MCHB and Healthy People 2010, the costs to the children, their families and society at large will surely increase.

III: STUDY DESIGN AND METHODS

Study Design / Population

A quasi-experimental design was used in which families and PCPs of children admitted to the SNP between 5/1/08 and 4/30/10 were offered enrollment in the Control Group and those admitted between 5/1/10 and 4/30/12 were offered enrollment in the Intervention Group. The Control Group received ad hoc care coordination teaching while a Care Coordination Curriculum was developed. The Intervention Group received structured teaching based on the Curriculum. Families were not required to participate and could withdraw from the study without leaving the SNP at any time. SNP clinical personnel were unaware which patients were enrolled in the study and all received similar services and education whether or not they participated.

Table 1. SNP Admission criteria

Complexity Criteria	
Major	≥ 5 specialists, ≥ 3 organ systems
Minor	Disease uncertain or unknown PCP does not admit child to CHW Socioeconomic factors Distance > 25 miles to tertiary center
Fragility Criteria	
Major	≥ 2 admissions and ≥ 10 hospital days or ≥ 10 clinic visits in prior year
Minor	≥ 1 admissions, ≥ 5 days hospitalized, and ≥ 5 clinic visits in prior year Anticipated frequent tertiary center use based on predicted disease trajectory Technology dependence / Home nursing

Sample Selection

A sample of convenience was used based on the number of patients admitted to the SNP. Criteria for the SNP are shown (Table 1). A total of 112 patients were enrolled (Control 60, Intervention 52). Another 59 patients admitted to the SNP were not enrolled (7 ineligible because a sibling was in the SNP (1), a legal guardian was not available to consent (3), or they had previously been in the SNP (3); 8 declined participation; 11 were discharged prior to 9 months in the SNP; and 33 were not available to be consented during the first 3 months after admission to the SNP.

Instruments Used

Data were collected at enrollment, 9-12 months and 21-24 months for:

- 1) Families: Peds QL Healthcare Satisfaction Survey and Family Impact Survey, and SNP Care Coordination Competency Questionnaire
- 2) PCPs: SNP Care Coordination Comfort and Competency survey.
- 3) Patients: CHW resource use (admissions, hospital days, clinic visits, short stay visits, emergency room visits, charges and payments) pre and post enrollment. SNP Care Coordinator time post enrollment.
- 4) All: Curriculum evaluation form for comment on content and presentation.

Statistical Techniques Employed

The Peds QL questionnaires are validated tools with scoring systems. SNP Family Care Coordination Competency Questionnaires consisted of 23 questions with a “best”, “acceptable”, and “unacceptable” answer (scored of 2, 1, or 0, respectively). Scores within 6 care coordination domains were determined. PCP care coordination comfort and competency questionnaires were scored on a Likert scale. All questionnaires and resource use data were compared at the different study points (baseline, 9-12 months and 21-24 months) within and between groups. Descriptive statistics and non-parametric tests were generally used because of non-normally distributed data (differences considered significant at $p < 0.05$).

IV: DETAILED FINDINGS

All Subject Demographics

There were no differences between the Control and Intervention Groups (Table 2). Racial/ethnic mix reflects that of the population in general with over 70% of patients from outside Milwaukee. Patients had high medical complexity as indicated by the multiple organ systems involved requiring multiple specialists in addition to their PCPs.

Table 2. Demographics/Characteristics at Enrollment (All SNP patients)

	Control Group (n= 60)	Intervention Group (n=52)
Age at enrollment (d)	Mean = 1383.18±1750.64, Median = 576.00	Mean = 1655.85±1789, Median = 765.00
Sex	23 = Female, 37 = Male	23 = Female, 29 = Male
Race / Ethnicity	1 = Asian , 9 = Black, 8 = Hispanic, 1 = American Indian, 3 = Multi-racial, 38 = White	0 = Asian, 8 = Black, 3 = Hispanic, 1 = American Indian, 3 = Multi-racial, 37 = White
Distance	15 = <25 miles, 44> 25 miles	17 = <25 miles, 35> 25 miles
Language	52 = English, 8 = Spanish	50 = English, 2 = Spanish
Technologies	Mean = 1.28±1.01, Median = 1.00	Mean = 1.42±1.26, Median = 1.00
# of specialists	Mean = 6.28±2.66, Median = 6.50	Mean = 6.96±2.08, Median = 7.00
# organ systems	Mean = 5.45±2.13, Median = 6.00	Mean = 5.46±1.58, Median = 5.00

Baseline Data Control and Intervention Groups**Resource Utilization at Enrollment**

Data were analyzed for all patients up to 3 years prior to admission in the SNP and for as long as they remained in the SNP. Pre-enrollment periods were similar for Control (576 +/- 389 days, median 523 days) and Intervention (699 +/- 380 days, median 699 days) Groups. Data for each patient were normalized to the number of days pre- admission to the SNP (e.g. number of hospital days divided by total days prior to admission in the SNP) up to a 3 year maximum. There were no differences between Groups. Therefore total baseline data were also calculated and will be used in publications to describe the characteristics of the population (Table 3).

Table 3. Health Care Resource Utilization Prior to Admission (n=112)

	Control n = 60	Intervention n = 52	All Baseline n = 112
	Mean +/- SD per pre-enroll day	Mean +/- SD per pre-enroll day	Mean +/- SD per pre-enroll day
Admissions	.008 +/- .008	.006 +/- .006	.007 +/- .007
Hospital Days	.265 +/- .40	.13 +/- .24	.2 +/- .3
Clinic Visits	.038 +/- .034	.042 +/- .032	.039 +/- .033
ED Visits	.002 +/- .005	.002 +/- .003	.002 +/- .004
23 Hour Admissions	.002 +/- .005	.002 +/- .002	.002 +/- .004
Charges	1834 +/- 2845	1220 +/- 2589	1549 +/- 2735
Payments	1005 +/-1586	661 +/- 1399	846 +/- 1505

Peds QL Surveys at Enrollment

Scores on the Peds QL Family Impact Survey and the Health Care Satisfaction Survey responses did not differ between the Control and Intervention Groups at enrollment (response rates were 90% in both groups). Combined data for both groups were also tabulated (Tables 4 and 5).

Table 4. Peds QL: Family Impact at Enrollment

	Control n=54	Intervention n= 47	All Baseline n = 101
PedsQL Family Impact Domain	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
Physical Functioning	49.76 ± 21.8 (50)	56.94 ± 18.13 (54.2)	52.50 ± 20.26 (54.2)
Emotional Functioning	55.85 ± 21.7 (55)	60.74 ± 17.44 (60)	58.02 ± 19.81 (55)
Social Functioning	54.36 ± 23.9 (56.3)	59.44 ± 17.77 (56.3)	56.68 ± 21.16 (56.3)
Cognitive Functioning	64.53 ± 19.98 (65)	67.55 ± 18.53 (65)	65.99 ± 19.18 (65)

Communication	58.33 ± 21.45 (58.3)	66.67 ± 20.63 (66.7)	62.05 ± 21.36 (58.3)
Worry	43.40 ± 19.87 (45)	56.91 ± 16.73 (55)	49.60 ± 19.54 (50)
Daily Activities	36.48 ± 30.54 (33.3)	54.61 ± 28.33 (50)	44.64 ± 30.81 (50)
Family Relationships	56.70 ± 26.38 (60)	63.94 ± 25.47 (60)	59.90 ± 26.03 (60)
Total	52.86 ± 17.09 (51.4)	60.61 ± 11.84 (59.7)	56.39 ± 15.25 (54.2)
Parent HRQL Summary	53.93 ± 16.39 (51.8)	60.69 ± 13.03 (58.8)	57.04 ± 15.15 (55)
Family Functioning	49.12 ± 24.10 (50)	60.44 ± 23.19 (59.4)	54.18 ± 24.25 (53.1)

Table 5. Peds QL: Health Care Satisfaction at Enrollment

	Control n = 54	Intervention n = 47	All Baseline n = 101
PedsQL HCS Domain	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
Information	66.07 ± 24.55 (75)	67.96 ± 20.04 (65)	70.45 ± 20.70 (72.5)
Inclusion of family	79.42 ± 25.78 (93.8)	82.08 ± 19.97 (87.5)	81.82 ± 20.85 (90.6)
Communication	76.07 ± 25.66 (81.3)	76.90 ± 20.52 (75)	77.75 ± 19.55 (79.2)
Technical skills	78.86 ± 23.72 (83.3)	77.24 ± 22.05 (75)	74.62 ± 20.65 (75)
Emotional needs	62.50 ± 34.52 (75)	65.28 ± 29.80 (71.9)	60.53 ± 29.71 (50)
Overall satisfaction	82.52 ± 21.55 (91.7)	83.94 ± 18.86 (91.7)	84.47 ± 17.31 (87.5)
Total	74.45 ± 23.86 (83.3)	75.81 ± 18.10 (81.3)	75.95 ± 18.60 (82.3)

Family Care Coordination Questionnaire at Enrollment

The SNP developed a multiple choice questionnaire addressing 6 domains of care coordination in 23 questions. Each question had a best, several acceptable, and at least 1 unacceptable answer with values of (2, 1, and 0, respectively). Questionnaires were scored for each domain. Scores at enrollment did not differ between groups and combined scores were also tabulated (Table 8). The Control response rate to this questionnaire was lower (69%) because a different survey was initially used then revised within months of starting the study.

Table 6. Family Care Coordination Survey.

FCCS Domain	Control Baseline n = 39	Intervention Baseline n = 47	All Baseline n = 101
	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
Emergency Planning	0.60 ± 0.53 (0.50)	0.85 ± 0.59 (1.00)	0.72 ± 0.57 (0.50)
Child's Health Condition	1.35 ± 0.45 (1.33)	1.37 ± 0.44 (1.33)	1.36 ± 0.44 (1.33)
Treatments	1.48 ± 0.42 (1.67)	1.50 ± 0.40 (1.67)	1.49 ± 0.41 (1.67)
Health Care Providers & Appointments	1.59 ± 0.29 (1.67)	1.61 ± 0.32 (1.67)	1.60 ± 0.30 (1.67)
Benefits and Resources	1.03 ± 0.57 (1.00)	1.21 ± 0.63 (1.25)	1.11 ± 0.60 (1.25)
Transitions	0.53 ± 0.84 (0.00)	0.48 ± 0.81 (0.00)	0.51 ± 0.82 (0.00)

PCP Self-Assessed Comfort and Competency at Enrollment

A self-assessed comfort and competency survey was developed and sent to PCPs of children enrolled in the Control or Intervention Groups. Responses were based on a 5 point Likert Scale with 5 = always and 1 = never. PCPs with more than 1 patient in the study only received 1 survey. The “competency” rather than “comfort” segment of the questionnaire is shown in Table 7. There were no statistical differences between groups and all baseline data were tabulated.

Table 7. PCP Self Assessed Competency

5 = always, 1 = never	Control n = 36	Intervention n = 29	All baseline n = 65
I am able to...	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
...provide routine pediatric care for this child.	4.74±0.92 (5)	4.41±1.15 (5)	4.59±1.03 (5)
...provide acute care for the special needs of this child	4.00±1.10 (4)	4.03±0.91 (4)	4.02±1.01 (4)
...coordinate care when this child is out of the hospital.	4.03±1.11 (4)	4.00±0.93 (4)	4.02±1.02 (4)
...coordinate care when this child is admitted to the hospital.	2.53±1.41 (3)	3.90±2.11 (3)	3.20±1.90 (3)
...work with the schools for this child.	3.09±1.51 (3)	4.42±2.28 (4)	3.81±2.06 (4)
...help family obtain insurance/benefits for this child.	2.80±1.30 (3)	3.25±2.35 (3)	3.02±1.88 (3)

...work with community agencies and services for this child.	3.64±1.08 (4)	3.48±1.12 (4)	3.56±1.10 (4)
...communicate with this child's specialists.	4.26±1.02 (4.5)	4.21±0.90 (4)	4.24±0.96 (4)
...communicate with the family about plans and goals.	4.38±0.99 (4.4)	4.34±0.94 (5)	4.37±0.96 (5)
...order therapies and write prescriptions for this child.	4.29±1.00 (4.5)	4.31±0.66 (4)	4.30±0.82 (4)
...handle/troubleshoot child's medical equipment/technologies.	2.94±1.34 (3)	3.11±1.23 (3)	3.02±1.28 (3)
...bill and code for care coordination services	2.30±1.47 (2)	2.25±1.27 (2)	2.28±1.37 (2)

Family Care Coordination Curriculum Development

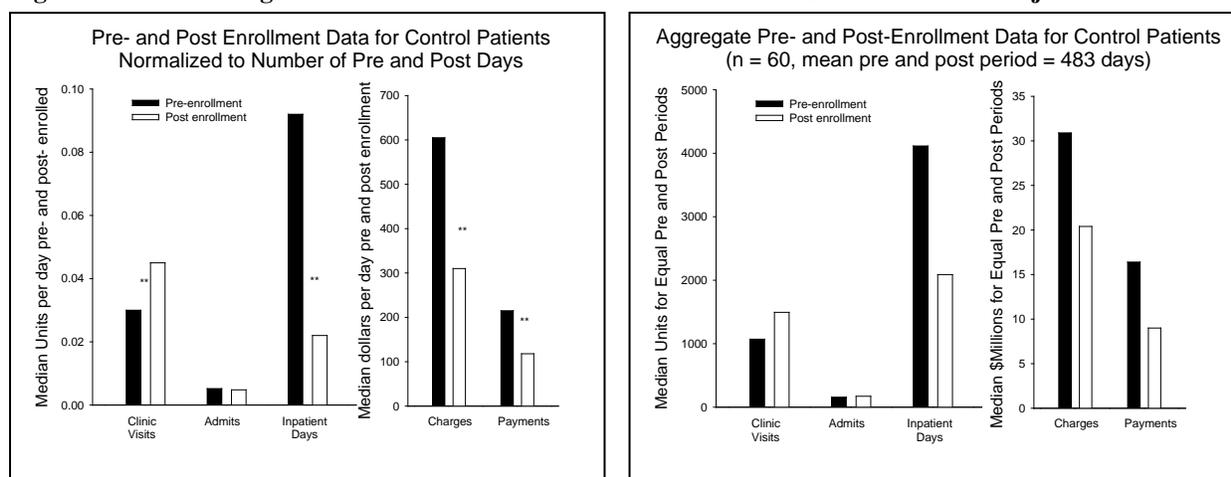
The Family Care Coordination Curriculum was developed while longitudinal Control Group data were collected. The curriculum design process was based on Cennamo and Kalk's (2005) collaborative model. The design team, comprised of an adult educator, a pediatric advanced practice nurse, a nurse educator, and a graphic designer/ editor, met weekly cycling through the phases of Define, Design, Demonstrate, and Develop, and revisited each of the essential elements of the curriculum design. After defining the needs of the families, templates for the learner materials and instructor guides were developed. The initially planned seventeen modules were condensed into a more manageable twelve modules. During the Demonstrate phase, the drafts of the modules were tested with nurse care coordinators (future instructors), the family advisory group (potential learners), and outside evaluators. Once feedback was received, the design team entered the Develop phase.

The outcomes of the initial 4 phases of the Curriculum design process were the learner materials and instructor guides for the 12 care coordination modules: Appointments; Advocacy; Common Problems; Communication; About your Child's Health Condition; Community Resources; Emergency Planning; Equipment and Supplies; Health Benefits; Personal Health Records; Routine Treatments and Transitions. We repeated the design, develop, and demonstrate phases for each module, often spiraling back through more than one phase at a time as we worked simultaneously on multiple modules. Throughout the curriculum design phases, we used formative and summative approaches to evaluate the materials. The design team built feedback loops into every deliverable, actively seeking comments, criticisms, and suggestions from subject matter experts, colleagues, and potential learners. This included sharing the Care Coordination Curriculum with multiple centers and making it available from the SNP (sjohanin@mcw.edu) or at http://www.simoneconceicao.me/simoneconceicao.me/Bridge_to_Independence.html.

Post Enrollment Longitudinal Data: Control Group Only **Resource Utilization in the Control Group Post Enrollment**

Of the 60 Control patients, 5 patients were enrolled for ½ to 1 year, 15 for 1-2 years, 21 for 2-3 years and 19 for over 3 years (mean 576 days, median 524 days). Data normalized to the number of days pre- and post-enrollment are shown in (Figure 1). This allowed statistical comparison using a non-parametric paired t test (Mann Whitney Rank Sum). Differences were considered significant at $p < 0.05$ in this analysis.

Aggregate data were also measured for equal pre and post enrollment periods (i.e. data for a similar number of days pre and post enrollment were compared for each child to obviate the normalization procedure needed when unequal pre and post enrollment periods were used). As seen in Figure 2, aggregate data for a mean of 483 days (median 377 days) showed a 39.5% increase in clinic visits, 49% decrease in hospital days, and \$7.3 million decrease in payments to CHW for 60 patients. It should be noted that the patients remained very fragile with 2088 inpatient days and over \$9 million in tertiary center payments even after enrollment in the SNP.

Figures 1 and 2. Change in resource utilization after enrollment in the SNP in Control Subjects

Longitudinal Changes in Peds QL Surveys

There was a modest improvement in Family Impact scores (approximately 8 points) and little change in the Health Care Satisfaction over time. In the interests of space, only the Total, Health Related Quality of Life and Family Function results for Family Impact Survey and the Overall Satisfaction and Total Score for the Health Care Satisfaction Survey are shown (Table 8).

Table 8. Longitudinal Changes in Peds QL Scores in Control Families

PedsQL Family Impact	Control Baseline n = 51	Control 9-12 mo n = 41	Control 21-24 mo n = 37
	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
Total	52.86 ± 17.09 (51.4)	54.85 ± 18.59 (52.42)	58.09 ± 18.63 (55.71)
Parent HRQL Summary	53.93 ± 16.39 (51.8)	58.03 ± 19.16 (57.50)	60.98 ± 19.75 (57.50)
Family Functioning	49.12 ± 24.10 (50)	52.21 ± 22.98 (53.13)	55.83 ± 23.21 (50)
PedsQL Health Care Satis	Control Baseline n=51	Control 9-12 mo n=41	Control 21-24 mo n= 37
	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
Overall satisfaction	82.52 ± 21.55 (91.7)	81.10 ± 25.41 (83.3)	80.74 ± 19.77 (80.3)
Total	74.45 ± 23.86 (83.3)	74.01 ± 25.20 (79.2)	77.77 ± 15.83 (81.6)

Longitudinal Changes in Family and PCP Care Coordination Competency

There was no change in Family Care Coordination Scores (Table 9) or the PCP Self Assessed Competency scores (Table 10) over the 2 years of enrollment in the Control Group.

Table 9. Family Care Coordination Questionnaire

FCCS Domain	Control Baseline n = 39	Control 9-12 mo n = 41	Control 9-12 mo n = 37
	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
Emergency Planning	0.60 ± 0.53 (0.50)	0.65 ± 0.57 (.50)	0.85 ± 0.59 (1.00)
Child's Health Condition	1.35 ± 0.45 (1.33)	1.41 ± 0.48 (1.33)	1.37 ± 0.44 (1.33)
Child's Treatments	1.48 ± 0.42 (1.67)	1.36 ± 0.47 (1.33)	1.50 ± 0.40 (1.33)
Health Care Providers and Appts	1.59 ± 0.29 (1.67)	1.55 ± 0.29 (1.67)	1.61 ± 0.32 (1.67)
Benefits and Resources	1.03 ± 0.57 (1.00)	1.07 ± 0.55 (1.25)	1.21 ± 0.63 (1.25)
Transitions	0.53 ± 0.84 (0.00)	0.36 ± 0.71 (0.00)	0.48 ± 0.81 (0.00)

Table 10. PCP Self Assessed Competency

I am able to...	Control baseline n= 36	Control 2 nd assessment n= 26	Control 3 rd Assessment n= 27
	Mean ± SD (Median)	Mean ± SD (Median)	Mean ± SD (Median)
...provide routine pediatric care	Mean = 4.74 ± 0.92 (5)	Mean = 4.75 ± 0.70 (5)	Mean = 4.58 ± 0.58 (5)
...provide acute care	Mean = 4.00 ± 1.10 (4)	Mean = 4.04 ± 1.02 (4)	Mean = 4.08 ± 0.91 (4)
...coordinate care when this	Mean = 4.03 ± 1.11 (4)	Mean = 3.96 ± 0.98 (4)	Mean = 4.23 ± 0.71 (4)

...coordinate care when in hosp	Mean = 2.53±1.41 (3)	Mean = 3.08±1.38 (3)	Mean = 2.75±1.39 (2.5)
...work with the schools	Mean = 3.09±1.51 (3)	Mean = 3.57±1.21 (4)	Mean = 3.73±1.16 (4)
...help family obtain insurance	Mean = 2.80±1.30 (3)	Mean = 3.08±1.32 (3)	Mean = 3.00±1.26 (3)
...work with community	Mean = 3.64±1.08 (4)	Mean = 3.60±1.08 (4)	Mean = 3.65±1.02 (4)
...communicate with specialists.	Mean = 4.26±1.02 (4.5)	Mean = 4.20±0.91 (4)	Mean = 4.08±0.80 (4)
...communicate re plans & goals	Mean = 4.38±0.99 (4.4)	Mean = 4.28±1.06 (5)	Mean = 4.27±0.7 (4)
...order therapies and Rx	Mean = 4.29±1.00 (4.5)	Mean = 4.12±0.97 (4)	Mean = 4.16±0.85 (4)
...troubleshoot med equip	Mean = 2.94±1.34 (3)	Mean = 3.08±1.2 (3)	Mean = 2.92±1.32 (3)
...bill and code for care coordination services ...	Mean = 2.30±1.47 (2)	Mean = 2.96±1.34 (3)	Mean = 2.27±1.46 (2)

V: DISCUSSION AND INTERPRETATION OF FINDINGS

Conclusions drawn from Baseline Findings / Comparison with Other Studies

Children enrolled in the study had very high medical complexity and fragility with frequent admissions, long hospital stays, and high healthcare costs (Tables 2 and 3, combined data). The level of fragility and complexity of this population as well as their tertiary center payments is somewhat greater than that reported by several others (Berry et al, 2011; Casey et al 2011). In addition, this study extends previous work by providing a description of the impact of medically fragile CMC on families. The Peds QL Family Impact Module assesses domains of quality of life (Table 4, combined data) and reveals that quality of life is considerably lower (10 or more points in most domains) in the SNP families than families of children in an inpatient convalescent hospital (Varni et al, 2004) or with cancer (Scarpelli et al, 2008). Families also had about 15 point lower Health Care Satisfaction scores (Table 5, combined data) than that reported by parents of severely disabled children in a convalescent hospital (Varni et al, 2004).

We assessed family care coordination skills using a questionnaire developed by the SNP and reviewed by our Family Advisory Group, SNP Care Coordinators, and Family Resource Center. Although not externally validated, there was greater than 80% agreement among experts for the best and unacceptable answers to each question. Questions with over 60% agreement were considered “acceptable”. The low scores in most care coordination domains argue a need for improved education and skills in the families of these children (Table 6, combined data).

The PCP survey was a non-validated comfort and competency survey that was reviewed by SNP personnel and our PCP advisory group. PCPs generally reported that they provided well child care and managed routine childhood illness. However, median scores of 3 or less indicate that at least half rarely or never: managed equipment, billed for their services, or helped with insurance and school (Table 7 combined data). *Collectively the baseline data provided a snapshot of the medical and non-medical needs of the patients and their families and PCPs.*

Conclusions drawn from Care Coordination Curriculum Development

The Curriculum is now in its Delivery Phase. Evaluation and revision of the Curriculum will be completed after we have collected data from the 52 families who receive the structured Curriculum and from all who have requested copies of the Curriculum at different institutions.

Conclusions drawn from Longitudinal Data in the Control Group

As in our prior publication (Gordon et al, 2007), there was a significant decrease in hospital days, increase in clinic visits and decrease in tertiary center health care costs after enrollment in the SNP (Figures 1 and 2). However, the graduation rate from the SNP of Control

patients was low (only 33% of patients left in less than 2 years). Unless reimbursement for the intensive care coordination and co-management needed to achieve the outcomes described improves, the only way to increase capacity will be to increase this graduation rate.

Increasing the graduation rate has the potential to increase the caregiver burden on families and the work of PCPs who wish to provide Medical Homes without the support of the SNP. Our data suggest that although hospital days decreased and clinic visits increased after enrollment in the SNP, family quality of life and health care satisfaction remained low (Table 8). Moreover, there was little evidence that family care coordination skills or PCP care coordination competency improved over time (Tables 9 and 10). ***Whether adding the structured teaching and resources available in the Care Coordination Curriculum will improve Family and PCP care coordination abilities and whether this impacts time to graduation from the SNP will be evaluated as data from the Intervention Group is collected and analyzed.***

Study Limitations

The major limitations and challenges of the study were:

- 1) Underestimating the time it would take to create the Curriculum. We had originally planned to complete it in less than 2 years, but it took over 2 years. However, we felt it better to develop a strong Curriculum rather than meet an arbitrary timetable. Since it took 2 years to enroll a sufficiently large Control group the delay in completing the Curriculum did not alter the flow of the study. We anticipate continuing to collect data and revising the Curriculum over the next 2 years.
- 2) We did not develop the PCP tools originally planned in Aim 2. In part this was due to concern that the tools could confound analysis of the impact of the Curriculum. In addition, the effort required to develop the curriculum occupied more time and personnel than initially anticipated and precluded their working on the Tools. We do plan to complete a “Billing and Coding” manual for PCPs and have updated care plans that will be provided to PCPs.
- 3) We used 2 data collection tools (Family Care Coordination Competency and PCP Comfort and Competency) that have not been externally validated. The lack of change in Control Family and PCP coordination competency may reflect imperfections in these tools. However, the small longitudinal change in Peds QL scores argues that there was simply little change in family attitudes and abilities over time. We plan to improve and validate the tools since none exist for the highly fragile CMC families and PCPs.
- 4) The Grant involved a steep learning curve and forging new collaborations, particularly between the adult education and health care members of the team. A few unforeseen challenges included the departure and replacement of our initial research coordinator and the loss of 2 physicians from the SNP.
- 5) An as yet unresolved issue is the recognition that the Nurse Care Coordinators and Families have little time to address the Curriculum the planned structured 1 on 1 format because of patient and child care responsibilities, respectively. Therefore, we provide families with the 12 modules of the curriculum early after enrollment in the study and the nurses review them on the families’ time table. Future efforts will examine other ways to deliver and evaluate the Curriculum.

Possible Applications of Findings to MCH Health Care Delivery Situations

The major findings to date are that the partnership between the SNP and families, PCPs and other providers markedly reduced inpatient days, increased clinic visits and decreased healthcare costs. However, these outcomes had little impact on Family quality of life, health care satisfaction, or care coordination competency. Thus, improving care giver burden through other means (e.g. financial compensation for caregiving, respite care, psychological support) require investigation. The striking impact of intensive care coordination and co-management provided by nurses and physician in the SNP on healthcare costs suggests that expansion and evaluation of different care coordination models is needed to meet the growing population of CMC.

Policy Implications

Unlike adult populations in which the impact of coordination can be assessed by a series of well-known measures (e.g. hemoglobin A1c in diabetes). Children with multiple chronic conditions often have disparate and sometimes unique diagnoses. The criteria used for enrollment in the SNP limit the population to the approximately 0.005% of children admitted to hospital who account for 17.5% of tertiary center payments. The potential benefit of Complex Care Programs to pediatric patients and their families as well as their impact on healthcare costs have been described in several recent studies. Data from this research further supports the need for care coordination and co-management programs. It also suggests measures for assessing efficacy of the model that are appropriate to children with chronic conditions and could be widely applied. MCHB support for efforts to develop national or international consensus on best practices in care coordination is needed.

Suggestions for Further Research

- 1) The current research is not complete. Although funding is no longer available, we anticipate continuing to collect data on the Intervention Group and criticism about the Curriculum. We will revise and translate the curriculum within the next 2 years based on the data and criticism.
- 2) In this grant, teaching was envisaged as a 1 on 1 process between families and nurse care coordinators. We have recently been awarded a Healthier Wisconsin Partnership Project grant (\$200,000 Jan 1, 2012- Dec 31, 2013) to test the hypothesis that Lay Trainers (predominantly parents of CMC) can be trained to teach the Curriculum Modules to other families in Group settings.
- 3) A formal assessment of the longitudinal impact of the Curriculum at multiple centers using varied teaching techniques (e.g. lay trainers or nurse educators, on-line versus in person, etc.) would be a useful investigation and could lead to a well-developed and valuable tool for care coordinators everywhere. Preliminary discussions with centers caring for CMC in Boston, Chicago, Arkansas, Palo Alto, and Toronto have begun.

VI: LIST OF PRODUCTS

Abstracts

- 1) Krauthoefer M, Kryfke R, Colby H, Jablonski D, Wachowiak C, Karvelas A, Juhlmann A, and Gordon J. Factors Influencing Health Care Satisfaction in Families of Medically Complex and Fragile Children. AAP NCE 2009 (Abstract and Poster, Washington D.C.)
- 2) Colby H, Jablonski D, Krauthoefer M, Wachowiak C, Juhlmann A, Karvelas A, Kryfke A, Gordon J, and Scanlon M. Family Care Coordination Competency. AAP NCE 2009
- 3) Wachowiak C, Kryfke R, Colby H, Krauthoefer M, Jablonski D, Karvelas A, Juhlmann A, Nanchal N, and Gordon J. Improving Family and Provider Satisfaction in a Care Coordination Program for Complex Fragile Children with Chronic Conditions. NCE 09

- 4) Krauthoefer M, Kryfke R, Colby H, Jablonski D, Juhlmann A, Karvelas A, Wachowiak C, and Gordon J. Health-Related Quality of Life in Families of Medically Complex and Fragile CYSHCN followed by an Academic Tertiary Center Care Coordination Program. Pediatric Academic Societies May, 2010 (Abstract and Platform Presentation Vancouver)
- 5) Kryfke R, Jablonski D, Krauthoefer M, Colby H, Juhlmann A, Karvelas A, Wachowiak C, and Gordon J. Care Coordination Competency of Families of Medically Complex and Fragile CYSHCN Newly enrolled in a Tertiary Center Care Coordination Program. Pediatric Academic Societies May 2010 (Abstract)
- 6) Jablonski D, Krauthoefer M, Kryfke R, Colby H, Juhlmann A, Karvelas A, Wachowiak C, and Gordon J. Primary Care Practitioner Self Assessed Comfort and Competency with Providing Care for Medically Complex and Fragile CYSHCN. PAS May 2010 (Abstract)
- 7) Conceição, S. C. O., & Juhlmann, A. Bridge to independence: A collaborative design model for developing curriculum for families of special needs children. Am Assoc Adult Continuing Ed Conf. Cleveland, Ohio. (November, 2009). (Abstract and Presentation)
- 8) Conceição, S. C. O., Colby, H., Juhlmann, A., & Johaningsmeir, S. Curriculum design for adult learners with an emphasis on health literacy. Midwest Res-to-Prac Conference in Adult, Cont and Comm Edu. 9/2010. Lansing, Michigan (Abstract and Presentation)
- 9) Conceição, S. C. O., Colby, H., Juhlmann, A., & Johaningsmeir, S. How health literacy can be incorporated into the design process using adult teaching and learning strategies. American Association for Adult and Continuing Education Conference. Clearwater, Florida. October, 2010 (Abstract and Presentation)

Workshops

- 1) Gordon, J., Colby, H., & Juhlmann, A. Scope of a Tertiary Center Care Coordination Program for Medically Complex and Fragile Children with Chronic Conditions. Annual Forum for Improving Children's Healthcare, NICHQ. Atlanta, GA. (March 2010)

Proceedings

- 1) Conceição, S. C. O., Colby, H., Juhlmann, A., & Johaningsmeir, S. Curriculum design for adult learners with an emphasis on health literacy_Midwest Research-to-Practice Conference in Adult, Continuing, and Community Education. September, 2010.

Chapters

- 1) Conceição, S. C. O., Colby, H., Juhlmann, A., & Johaningsmeir, S. Curriculum design in health education. In L. H. Hill (Ed.), *Adult Education for Health and Wellness*. New Directions for Adult and Continuing Education. (in press).

On Line

- 1) http://www.simoneconceicao.me/simoneconceicao.me/Bridge_to_Independence.html

Manuscripts in Preparation

- 1) Characteristics and Needs of Children with Medical Complexity and Fragility and their Families. Johaningsmeir S, Krauthoefer M, Colby H, Conceicao S, Gordon J. Planned Submission: October, 2012, to Academic Pediatrics
- 2) A Tertiary Care / Primary Care Partnership Program for Children with Medical Complexity and High Fragility at Ten Years. Gordon J, Colby H, Johaningsmeir S, Stachowiak P, Krauthoefer M, Jablonski D, Zabel G, and Wachowiak C. Planned Submission: October, 2012, to Pediatrics
- 3) Impact of a Structured Care Coordination Curriculum on CMC and their Families. Colby H, Conceicao S, Johaningsmeir S, Juhlmann A, and Gordon J. Planned Submission Early 2014 to Academic Pediatrics