

Care Coordination in a Medical Home in Post-Katrina New Orleans: Lessons Learned

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Abstract This is a prospective study to evaluate ability of a nurse care coordinator to: (1) improve ability of a pediatric clinic to meet medical home (MH) objectives and (2) improve receipt of services for families of children with special health care needs (CSHCN). A nurse was hired to provide care coordination for CSHCN in an urban, largely Medicaid pediatric academic practice. CSHCN were identified using a CSHCN Screener. Ability to meet MH criteria was determined using the MH Index (MHI). Receipt of MH services was measured using the MH Family Index (MHFI). After baseline surveys were completed, Hurricane Katrina destroyed the clinic. Care coordination was implemented for the post-disaster population. Surveys were repeated in the rebuilt clinic after at least 3 months of care coordination. The distribution of demographics, diagnoses and percent CSHCN did not significantly change pre and post Katrina.

Psychosocial needs such as food, housing, mental health and education were markedly increased. Essential strategies included developing a new tool for determining complexity of needs and involvement of the entire practice in care coordination activities. MHFI showed improvement in receipt of services post care coordination and post-Katrina with $P < 0.05$ for 13 of 16 questions. MHI demonstrated improvement in care coordination and community outreach domains. Average cost was \$36.88 per CSHCN per year. There was significant improvement in the ability of the clinic to meet care coordination and community outreach MH criteria and in family receipt of services after care coordination, despite great increase in psychosocial needs. This study provides practical strategies for implementing care coordination for families of high risk CSHCN in underserved populations.

Eleanor Soltau has relocated to Atlanta, Georgia, after her involvement with this research.

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Introduction

Primary care in a medical home (MH) has many advantages for Children with Special Healthcare Needs (CSHCN) [1, 2]. According to the Maternal and Child Health Bureau and the American Academy of Pediatrics (AAP), a medical home provides healthcare that is “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective” [3]. CSHCN according to the Maternal and Child Health Bureau are children who “have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally [4]. This broad definition includes not only children with more severe disabling conditions, but children with common conditions such as asthma and attention deficit disorder. CSHCN that meet these criteria constitute approximately 13–20% of the population [5], but consume a disproportionate share of healthcare dollars [6–8]. Studies have demonstrated cost savings when primary care for CSHCN is implemented in a MH, primarily through decreased emergency room visits and hospitalizations [7, 9–12].

In February 2007 the American Academy of Pediatrics (AAP), American Academy of Family Practice, American College of Physicians and American Osteopathic Association developed the “Joint Principles of the Patient-Centered Medical Home (PCMH)” [13] and adopted the National Center for Quality Assurance (NCQA)—PCMH criteria as standards for practices [14]. As of February 2009, at least 30 states, including Louisiana, had proposed legislation to encourage the development of MHs for children [15]. Yet while care coordination is a key component of MHs for CSHCN, in traditional pediatric practices, time, staff limitations and reimbursement issues have posed significant barriers for its implementation [10, 16–19]. Research documenting successful models of care coordination in different populations is lacking [11, 20]. Such models are essential to assist pediatricians in providing MH’s that meet the needs of CSHCN. One method of providing care coordination in a practice is through the addition of a care coordinator. A care coordinator works with the physician and practice staff to link families to medical, public health, and community resources and advocate for their needs [17, 21–24]. Several studies have demonstrated the ability of a care coordinator to improve family satisfaction [4, 20] and a few have analyzed cost [11, 12, 19, 25], but none in a population with such high risk.

In Louisiana, 54% of CSHCN live in households below the federal poverty level, vs. 46.9% nationally [26]. Louisiana’s Medicaid eligible CSHCN have twice the unmet need for care coordination as those with private insurance (22.4 vs. 11.0%) [27]. Compared to the national average,

Louisiana CSHCN families spend more hours each week coordinating their child’s care (5–10 h/week, 8.9% US vs. 12.9%; $P < .05$). This study evaluates the ability of a nurse care coordinator to improve MH criteria in an urban, predominantly Medicaid pediatric practice in post-Katrina New Orleans, and to meet the needs of families of CSHCN when resources were disrupted, families displaced, and much of the healthcare infrastructure destroyed. Lessons learned in implementing care coordination for this high risk population are discussed.

Methods

In March 2005, after obtaining Institutional Review Board approval from Louisiana State University (LSU) Health Sciences Center and Children’s Hospital of New Orleans, Louisiana’s Title V Children’s Special Health Services (CSHS) Program hired a nurse to coordinate care for an urban, academic pediatric practice. The practice is located in downtown New Orleans on the city’s major bus route, next to a key Medicaid office, with the goal of providing comprehensive care to an underserved, largely Medicaid population. The clinic is the primary outpatient teaching practice, or “continuity clinic”, for 27 LSU pediatric residents, and is staffed by 5 general pediatric faculty and one developmental pediatrician.

Baseline surveys were completed and care coordination begun just before Hurricane Katrina struck in August 2005. The clinic received four feet of water. All computers, most medical records, study data, and the backup flash drive were destroyed. Only initial baseline aggregate results presented on a poster survived. When the rebuilt clinic opened in March 2006, care coordination resumed in the post-disaster environment.

MH Rating

The Medical Home Index (MHI) [28] is a validated, self-rating tool for quality improvement within the practice. It consists of 25 items or themes divided into six domains of practice activity that are critical to the quality of care in a medical home: 1. Organizational capacity; 2. Chronic condition management; 3. Care coordination; 4. Community outreach; 5. Data management; 6. Quality improvement. Questions are scored across four levels of achievement corresponding to a continuum of quality: 1. Good basic pediatric care; 2. Responsive care; 3. Proactive care; 4. Comprehensive care. Achievement can be partial or complete within each level, depending on the rater’s evaluation of activity within the practice compared to the description provided for each theme and level. Six pediatric faculty, the office manager, and the clinic nurse completed separate

baseline MHI's in March 2005 before Katrina and care coordination, and follow-up MHI's post care coordination in March 2007, 1 year after the clinic reopened.

Faculty Training

Following the baseline MHI survey, a 2-h workshop on MH concepts was held for clinic faculty and staff using training materials from the AAP Website. The slide set, "Common Elements", was presented with a case presentation of the care coordinator's own child with Down syndrome, whose doctor was "an excellent pediatrician, but whose practice was not a MH." AAP policies on MH and care coordination, Louisiana data on CSHCN, and a review of state and national MH initiatives were presented. The importance of teaching MH concepts to pediatric residents in continuity clinics as embraced in the Future of Pediatric Education II guidelines was emphasized [23, 29, 30]. MHI baseline results were presented.

Family Inclusion Criteria

A CSHCN Screener [5, 31] modified for literacy level (Table 1) was used to identify CSHCN in the practice. At baseline, a convenience sample of families of CSHCN identified by the screener who had been receiving primary care services in the clinic for at least 3 months were surveyed. After the flood, baseline families could no longer be identified. Therefore, new CSHCN families were identified, followed at least 3 months, and surveyed.

Case Complexity

The HOMES Complexity Index [32] was completed by parents of CSHCN identified by the screener at baseline to determine CSHCN case complexity and to appropriately target care coordination services. Since the HOMES failed to distinguish degree of complexity within the clinic population, the care coordinator developed a new tool to

determine intensity of care coordination needed for the post-disaster population (Appendix 1). Using this tool, CSHCN were considered Level 1 if they required simple referrals that could be managed by office staff and Level 2 if they had more complex needs requiring the care coordinator. For example, a child with asthma who had minimal emergency room visits or missed school days was Level 1. The same child with many missed school days or multiple emergency room visits in the past year was Level 2. An autistic child with an appropriate Individual Educational Plan (IEP) for special education receiving family support services, such as respite care, was Level 1; the same child receiving inadequate school services or with frequent school expulsions was Level 2. CSHCN frequently changed levels as their needs changed, indicated by the color sticker on the chart. Care coordinator caseload was therefore fluid, depending on families' ever-changing needs.

Care Coordination Activities

After CSHCN were identified by the CSHCN Screener, the care coordinator met with the family in the exam room while waiting for the physician. After a brief assessment, level of care coordination complexity was determined using the tool in Appendix 1. If the child met criteria for Level 2 complexity, an effort was made to identify immediate needs that could be met during the clinic visit. Further assessment was done after consultation with the physician, and a care plan developed. Because the clinic had no electronic medical record (EMR), a separate care coordination chart was created and kept in the coordinator's office. Children who did not meet criteria for Level 2 complexity had care coordination needs handled by the physician and front desk staff. To encourage physicians to make Level 1 referrals, information and forms for routine referrals were wall-mounted for ease of use. The coordinator held quarterly MH meetings to develop clinic procedures and to discuss community resources. She also arranged for Families Helping Families to hold "IEP

Table 1 CSHCN Screener (Modified from CAHMI <http://www.cahami.org>)

1. Does your child need or use *medicine* prescribed by a doctor?
List *prescription* medicines your child takes on a *regular basis*:
2. Does your child need or use more *medical care* than other children the same age?
3. Does your child have trouble *doing things most children the same age can do*?
4. Does your child need or get special therapy, such as *physical therapy, occupational, or speech therapy*?
5. Does your child need *counseling or treatment* for behavior problems, emotional problems or delays in walking, talking, or activities that other children his age can do?
6. If you answered yes to any question, has this problem lasted or is it expected to last at least 12 months?

Interpretation: If medicines listed in Question 1 are indicative of a chronic condition or the answer to Question 6 is yes, the child is considered a CSHCN

Clinics” to teach families how to obtain special education services in the fragmented school system.

Family Receipt of Services

The MH Family Index (MHFI) [33] was used to measure services received. Slight modifications were made to ensure a 6th grade reading level. The coordinator was trained to conduct the survey using a scripted approach to minimize bias. After obtaining informed consent, the survey was given to the family to complete in the waiting room. Families were offered help and if requested, questions were read aloud. Demographic characteristics, medical information, care coordinator contacts, and MHFI results were entered into a Microsoft ACCESS database.

Determination of Sample Size

A sample size of 150 was yielded to compare two proportions using a two-sided test to detect differences of 25%, with alpha set at 0.05 and 80% power. It was hypothesized that 50% of families surveyed at baseline would respond positively on average for all questions in the MHFI. Calculations were adjusted 20% to account for response bias and participant attrition.

Data Analysis

A two independent sample test for binomial proportions was used to determine if there were significant differences in responses for the MHFI pre- and post care coordination. The 4-point Likert scale (never, sometimes, often, always) was collapsed into two categories: never or sometimes and often or always. Only proportions approximating the normal distribution for binomial data were tested. Alpha was set at 0.05 for statistical significance. For the MHI, the median score for each question within a domain and then the average median for each domain were calculated separately for pre and post surveys. Microsoft Excel was used for MHFI and MHI calculations.

Results

Study Participant Characteristics Pre- and Pos Care Coordination

At baseline there were 2,858 patients in the practice. Of the 212 families screened, 40% of children were CSHCN. When the clinic reopened in March 2006, 52% of children coming to the practice were CSHCN. The percent decreased steadily to 38% by April 2007, the end of the study period. By December 2007, there were 5,146 children in the practice; 2,287 (44%) were new to the practice since Katrina. Of these, only 32% were CSHCN.

The baseline sample includes data from the first 68 consecutive surveys conducted pre- care coordination, in March and April 2005. Subsequent survey data was lost in the flood. After Katrina, the first 150 families with CSHCN that consented to participate were enrolled in the study. After 3 months, between October 2006 and April 2007, 92 of these families completed the MHFI. Sex, race, payer type, resident city, and level of care for the 150 CSHCN identified post-Katrina were nearly identical to those surveyed (Table 2).

Demographics and diagnoses for the study samples surveyed at baseline and post care coordination were similar (Table 3). At baseline, 91% of the total clinic population was enrolled in Medicaid; the percent CSHCN enrolled in Medicaid at that time is unknown. At follow-up, 93% of the total clinic population and 98% of 149 CSHCN were enrolled in Medicaid.

Complexity of Care Coordination

Pre-Katrina the HOMES Complexity Index yielded an average score of 7.22 on a scale of 1–10, with 7–10 indicating high complexity.

Post-Katrina, there were 1,598 recorded contacts (phone calls and visits) for the study sample during the first 12 months after the clinic reopened; 61% were care coordinator contacts and 39% were physician contacts. For Level 1 patients 55% were with the care coordinator; for Level 2 patients 82% were with the care coordinator. Table 4 shows percent of each type of encounter for the

Table 2 Comparison of post-Katrina CSHCN families followed and CSHCN families surveyed

Indicators	CSHCN identified post-Katrina n = 150	CSHCN surveyed n = 92
Sex	62% Male; 38% female	62% Male; 38% female
Race	77%—African American	78% African American
Payor type	98% Medicaid	98% Medicaid
Residence city	78%—New Orleans	78%—New Orleans
Level of care	Level 1—86%; Level 2—14%	Level 1—86%; Level 2—14%

Table 3 Comparison of Surveyed Families of CSHCN Pre- and Post-RN-CC

	Pre-RN-CC <i>n</i> = 81 (54%)	Post-RN-CC <i>n</i> = 92 (62%)
Race	92% African American 8% Caucasian	94% African American 5% Caucasian 1% Other
Sex	27% Female 73% Male	35% Female 65% Male
Payor type	Unavailable	98% Medicaid 1% Private insurance 1% TriCare
Average age	7 years old (Range 0–16 years)	6 years old (Range 0–20 years)
Top five primary diagnoses	38% Asthma 11% ADHD 7% Cerebral palsy 6% Developmental delay 4% Autism	27% Asthma 19% ADHD 10% Developmental delay 8% Cerebral palsy Autism 6% Prematurity Speech delay

five most common diagnoses seen. A complete list of patients by diagnosis and encounter type is included in Appendix 2.

Referrals

Types of referrals included educational (Part C Early Intervention, Special Education, and 504 Accommodations), public health (Office for Citizens with Developmental Disability (OCDD) Waiver List, Personal Care Services, Title V CSHS), family support, and subspecialty including mental health. Wall-mounted Level 1 referral forms included early intervention, OCDD, school letters, mental health referrals, and family support groups.

MHFI

The final analysis was limited to 22 questions which provided complete and comparable pre- and post care coordination data. The response rate for the MHFI was 84.0% in 2005 and 61.3% in 2007. The average number of questions answered was 74.8 and 93.3%, respectively. The proportion of respondents who answered “often” or “always”, or “yes” is displayed in Table 5. Of the 22 indicators, 19 significantly improved. Significantly more families perceived their physician to be accessible when needed and to communicate well with them and with their child (questions

Table 4 Comparison of RN-CC and physician contacts for top 5 diagnoses of 149 patients

Diagnosis	RN-CC contacts	Physician contacts
Cerebral palsy	185 (84.5%)	34 (15.5%)
Developmental delay	93 (62%)	57 (38%)
Autism	47 (59.5%)	32 (40.5%)
ADHD	135 (56.3%)	105 (43.8%)
Asthma	201 (52.5%)	182 (47.5%)

1, 3a, 3b, 6), even though over 85% of families were satisfied in these areas at baseline. Families also perceived their physician to be more family-centered (questions 4, 5, 6). Post care coordination, more families thought the office staff knew who they were (question 2a), even though 44% were new to the practice. While 85% of baseline families felt that staff involved in their child’s care knew their child’s condition, history, and concerns, 94% thought this was true after addition of the care coordinator (question 14). Post care coordination, more families reported receiving care coordination (questions 8, 9, 10a, 10b, 11a–d), and help in communicating with their child’s school (question 12), connecting them with parent support groups (question 15) and finding adult services for youth in transition (question 16). The three questions that did not show significant improvement exceeded 85% satisfaction at baseline.

MHI

Table 6 shows baseline and follow-up scores on the MHI with the corresponding level for each domain. Post care coordination, improvements in Care Coordination and Community Outreach domains were achieved. For all other domains, level did not change.

Cost

The contract for the care coordinator was \$76,128 per year. By the end of 2007, the care coordinator was coordinating a practice of 5,146 patients with 2,064 CSHCN at an average cost of \$36.88 per CSHCN per year.

Discussion

Care coordination in the MH for high risk CSHCN populations presents special challenges. Our population of urban, poor CSHCN was high risk before Hurricane Katrina. After Katrina, eighty percent of the city was flooded, the population was displaced, and basic services including all utilities, transportation, and phone service were disrupted for months. Despite this loss of city and healthcare infrastructure, there

Table 5 Percent positive responses from the medical home family index

	2005 %, 95%(CI) <i>n</i> = 68	2007 %, 95%(CI) <i>n</i> = 92	<i>P</i> -value
1. My child can see the doctor or I can speak to the doctor when I need to	66% (55%, 78%)	94% (90%, 99%)	<0.0001
2a. When I call the office staff knows who we are	42% (30%, 54%)	76% (68%, 85%)	<0.0001
2b. When I call the office staff appreciates our needs and what we ask for	89% (81%, 97%)	94% (89%, 99%)	0.28
3a. My doctor communicates well with me	86% (78%, 95%)	99% (93%, 100%)	0.005
3b. My doctor communicates well with my child	86% (76%, 96%)	100% (96%, 100%)	0.003
4. My doctor asks me to share with him/her my knowledge and experience as the parent/care giver of my child	72% (61%, 83%)	86% (78%, 94%)	0.02
5. My doctor asks how my child’s condition affects our family. (Example: the way it affects my child’s brothers and sisters, the time my child’s care takes, lost sleep, extra expenses, etc.)	54% (42%, 67%)	76% (67%, 85%)	0.006
6. My doctor listens to my concerns and questions	92% (86%, 99%)	100% (98%, 100%)	0.02
7. We plan for my child’s care by writing down important things to remember, treatments my child needs, or phone numbers	86% (78%, 95%)	84% (76%, 91%)	0.64
8. My doctor and staff work with our family to create a written plan of care for my child	31% (20%, 43%)	75% (66%, 84%)	<0.0001
9. I receive a copy of my child’s care plan whenever it is changed	32% (20%, 44%)	78% (70%, 87%)	<0.0001
10a. My doctor and the office staff use and follow through with care plans they have created	37% (24%, 50%)	90% (84%, 96%)	<0.0001
10b. My doctor and the office staff look at and change the care plan as needed	40% (26%, 53%)	89% (83%, 95%)	<0.0001
11a. My doctor has a staff person or “care coordinator” who helps me with difficult referrals, payment issues, activities that need follow up	47% (34%, 60%)	87% (80%, 94%)	<0.0001
11b. My doctor has a staff person or “care coordinator” who helps me find needed services. (Such as transportation, equipment, or home care.)	48% (34%, 61%)	83% (75%, 91%)	<0.0001
11c. My doctor has a staff person or “care coordinator” who makes sure that the planning of care meets my child’s and my family’s needs	67% (55%, 79%)	91% (85%, 97%)	0.002
11d. My doctor has a staff person or “care coordinator” who helps each person involved in my child’s care communicate with each other	54% (41%, 67%)	84% (76%, 92%)	0.0002
12. When I ask for it, my doctor or office staff help me to explain my child’s condition to school personnel or child care providers*	58% (45%, 71%)	85% (77%, 93%)	0.0003
13. Someone at the office is available to review my child’s medical record with me when I ask to see it	86% (78%, 95%)	99% (93%, 100%)	0.005
14. Office staff who is involved in my child’s care know about my child’s conditions, history and things that concern us and what is important to us	85% (76%, 93%)	94% (87%, 94%)	0.16
15. Office staff helps connect me with family educational or assistance organizations and places in my area or state where I can receive information about my child	37% (26%, 49%)	87% (80%, 94%)	<0.001
16. My doctor assists me in finding adult health care services for my child	38% (26%, 50%)	82% (73%, 92%)	<0.0001

was significant improvement in the ability of the clinic to meet MH criteria and in family receipt of services. Key strategies for implementing care coordination for this high risk population are discussed below.

Stratification by complexity and Care Coordinator Caseload

The most difficult part of implementing care coordination even before the hurricane was determining how one nurse could coordinate care for the 40% of children identified by the screener (estimated to be 1,143 patients). This is high

compared with an average of 26.9% found by Gupta [16]. Pre-Katrina Louisiana had the second highest percent CSHCN of any state, with the highest risk CSHCN living in urban areas [27]. CSHCN from high risk populations have a greater need to be linked to community and public health resources such as special education, early intervention, therapies, waiver services, family support services, and SSI disability. In our clinic, the average HOMES Complexity Index for CSHCN identified was in the most complex range. Hence, methods for triaging by complexity and targeting care coordination services described in the literature for less high risk populations were of no use for

Table 6 Comparison of 2005 and 2007 medical home index results for 8 clinic staff

MHI domains	Themes	Score (2005)	Score (2007)	Level (2005)	Level (2007)
Organizational capacity	Mission, communication, access, medical records, environment, family feedback, cultural competence, staff education	1.25	1	Level 1: Complete	Level 1: Complete
Chronic condition management	Identify CSHS, continuity of care across settings, cooperative mgmt with specialists, transition to adult services, family support	1.5	1.75	Level 2: Partial	Level 2: Partial
Care coordination	Role definition, family involvement, child and family education, assessment of needs and plan of care, resource information and referrals, advocacy	1.25	2.0	Level 1: Complete	Level 2: Complete
Community outreach	Community assessment of needs of CSHCN, community outreach to agencies and schools	1.0	1.5	Level 1: Partial	Level 2: Partial
Data management	Electronic data support, data retrieval capacity	1.25	1.25	Level 1: Partial	Level 1: Partial
Quality improvement	Quality standards (structures), quality activities (processes)	1.25	0.625	Level 1: Complete	Level 1: Complete

our practice. After Katrina, the percent CSHCN rose to 52% before slowly decreasing to less than the pre-Katrina rate. Therefore a new tool for stratifying by complexity was developed (Appendix 1). This permitted the care coordinator to focus on CSHCN with more complex needs while enabling the rest of the practice to coordinate care for the less complex Level 1 CSHCN. Our experience underscores the importance of stratifying by complexity for high risk CSHCN populations.

Second, the entire practice became engaged in care coordination activities. This represented a major shift in responsibilities. No longer were community and public health referrals viewed as the sole responsibility of the care coordinator. Physicians were frequently not familiar with many public health resources, or how to advocate for special education services. To facilitate this transition, quarterly meetings were held to discuss available resources and directions and forms for referrals were placed in convenient wall-mounted displays. Families Helping Families, a family advocacy group, held “IEP clinics” to educate families about school services. When a Level 1 CSHCN had difficulties, such as in obtaining an IEP or mental health services, they were changed to Level 2 and the care coordinator was consulted. By using this fluid stratification system and working together, all CSHCN in the practice received coordinated care, as evidenced by the MHFI results.

Concept of MH and Care Coordination Among Clinic Staff

Before completing the MHI, most faculty assumed that they provided a MH for their patients by following Bright Futures guidelines, teaching comprehensive care to residents, and meeting the state’s expanded Medicaid

requirements for Community Care, which linked children to the practice as their “MH” and required that specialty care be coordinated through the practice. However, baseline MHI results indicate that the clinic had much room for improvement. Clinic faculty and staff rated the clinic as lowest in every MHI domain (Table 6). Repeat results 2 years later indicated clinic advancement of one level in the domains of care coordination and community outreach, the areas targeted by the care coordinator. In a practice with less intense care coordination needs, the care coordinator could have focused on other MHI or NCQA criteria as well, utilizing processes for quality improvement developed by the Center for Medical Home Improvement [34]. Despite the inability to address other medical home criteria, this clinic received NCQA level 1 certification soon after the completion of this study.

Improvement from level 1 to level 2 in the care coordination domain of the MHI represents a significant change in priorities within the practice. Pre-Katrina, educational and psychosocial needs were frequently missed in the provision of primary care, even after MH training. Post-Katrina, psychosocial needs could not be ignored: depression and post traumatic stress disorder were common, schools were slow to re-open, special education services were very limited, parents were frequently separated, and many families were stressed by living in Federal Emergency Management Agency trailers or sharing close quarters with relatives. As the clinic struggled to meet these psychosocial and educational needs, care coordination became a collaborative activity. Physicians who were previously focused on acute care were more motivated to make many community referrals. The small improvement in MHI represents a major shift in practice priorities, as together the practice sought to address the post-disaster needs.

Improved Receipt of Services

After the addition of the care coordinator, families reported services were more accessible, family-centered, and coordinated (Table 5). There were no other changes to the practice after Katrina that increased physician accessibility (such as increased hours of operation or email access) or family-centeredness. This association between care coordination and favorable family-provider relations was also found in the 2005–2006 National Survey of CSHCN, where data showed that families who reported receiving adequate care coordination were also more likely to say their care was family-centered, and that they experienced partnerships with professionals, were satisfied with services, and had ease of access to needed referrals [35].

The care coordination activities listed in the MHFI questions are all activities that are more likely to be neglected in a traditional practice during times of healthcare shortage and limited resources. Even with the care coordinator, providing continuity of care was particularly difficult post-Katrina. Displaced families were highly mobile, and destruction of phone and postal service infrastructure made locating and communicating with patients difficult for over a year post-Katrina. The lack of community resources, particularly mental health, made meeting recognized needs difficult. Finally, since most clinic charts were lost in the flood, lack of an EMR made access to previous medical records impossible for most returning patients. Without the addition of the care coordinator prior to Hurricane Katrina, it would have been extremely difficult to provide more than basic clinical care after Katrina. For these reasons, improvement in receipt of services is particularly impressive.

While the demographics and top five diagnoses of the returning clinic population were surprisingly similar to pre-Katrina, their need to be connected with community and public health resources was much greater. Because the care coordinator could meet these needs, satisfaction with the clinic improved. Many of the risk factors of the returning population are the same as those associated with the Medicaid population: homelessness, underserved, low income, and highly mobile [36, 37]. CSHCN as a group are disproportionately poor and disadvantaged [38]. This study underscores the importance of care coordination in the MH for high risk, underserved CSHCN populations.

Cost

Few studies have addressed the cost of care coordination and methods of computing cost are not uniform [11, 12, 25]. The cost of \$36.88 per year per CSHCN is low compared with that published in other studies. Palfrey estimated a cost of \$400 per patient using nurse practitioners who spent 8 h per week conducting care coordination for

complex CSHCN. This included the cost of bimonthly trainings and home visits, and appears to be a more intensive intervention designed for fewer patients [12]. Antonelli estimated the cost to the practice of non-billable care coordination activities of all staff to be between \$51 and \$71 per patient per year [25]. In our study the challenges of locating resources, finding transient patients, and meeting complex needs increased the time spent per patient. Dividing CSHCN by complexity and requiring faculty and staff to make referrals for less complex patients were essential strategies for managing the vast needs of this clinic population with one care coordinator. Including the time spent by other staff would have significantly increased the cost per patient. Practices with fewer CSHCN have been able to manage with a part time care coordinator [12, 19].

Absorbing these costs can be difficult for medical practices. None of the current procedural terminology codes for care coordination activities are reimbursable by Louisiana Medicaid, such as phone calls (98966-98968), team conferences (99368), and care plan oversight services (99374, 99375) [39, 40]. Reimbursement of these codes would help make care coordination more sustainable financially. This care coordinator was funded by the LA Title V block grant. Because of the success of this model, the LA Title V CSHS program currently offers both financial incentives for MHs to designate a care coordinator within the practice and technical assistance to implement care coordination. LA CSHS is working with LA Medicaid to improve reimbursement for care coordination activities, both in the current fee for service system and in the capitated system currently proposed for health care reform. It seems feasible that reimbursement of these CPT codes alone could cover the cost of \$36.88 per CSHCN.

Limitations of the Study

We initially planned to investigate the benefit of a care coordinator on patient care outcomes in our practice in New Orleans, not knowing that a natural disaster would occur between the pre- and post evaluations. While the major study design remained intact, Katrina forced us to revise our methodology to address both the loss of the baseline database and the environmental changes that we could not control. This imposed significant limitations on the study; however, it also provided an unprecedented opportunity to evaluate the impact of a care coordinator in a post-disaster environment with pre-disaster data to serve as a comparison group. Strategies to deal with such overwhelming needs had to be devised, and their effectiveness measured. Therefore, we were able to redirect our study to examine outcomes in a situation that would otherwise be difficult or impossible to investigate. The result was the development of an efficient

and effective model for care coordination when dealing with a high risk population with complex needs.

There were several limitations imposed by Katrina. Although demographics and diagnoses did not differ between the two populations surveyed, with patients unable to serve as their own controls, it is not known if unmeasured differences existed. Baseline surveys were not repeated after Katrina because it was felt that withholding care coordination for 3 months to re-establish a new baseline would have been unethical. After Katrina it was impossible to determine whether care coordination resulted in decreased emergency room visits or hospitalization rates, not just because identifying information was lost but because few hospitals were open.

Patients' perceptions of the clinic post-Katrina may be biased by the lack of other available medical care and gratitude at receiving any medical care at all. We believe that the MHFI questions were specific enough to measure receipt of MH related services with minimal bias.

Finally, there are methodology limitations unrelated to Katrina. One limitation is potential responder bias since the care coordinator distributed the family surveys. Another is that the method of analyzing MHI results individually and averaging them differs from that originally designed, which could threaten internal validity. An advantage of this method is that it allowed us to obtain individual impressions of the clinic, without allowing physicians and staff to bias each other.

Conclusions

Providing care coordination can be challenging for a busy pediatric practice, especially one with a high percent of CSHCN with complex needs and scarce community resources. This study demonstrates that the addition of a care coordinator can be an effective way to link CSHCN to public health, mental health, family support, educational, and community resources, even in a post-disaster

environment, and provides practical strategies for doing so. Essential strategies include stratifying CSHCN by complexity of need using a tool such as that presented in this study, and developing a team approach to maximize the efficiency of the care coordinator. Data suggest that the strategies used were successful in this population in improving family receipt of services and MH criteria in care coordination and community outreach domains. Care was perceived to be more accessible, more family-centered, and more coordinated. We believe that these strategies are applicable to other high risk CSHCN populations as well.

As more states are adapting MH legislation in efforts to decrease healthcare costs by decreasing emergency room visits and hospitalization rates, care coordination reimbursement strategies must also be incorporated into healthcare reform initiatives. Primary care providers do not reap the healthcare savings of care coordination; neither should they bear the cost. Since high risk populations, such as Medicaid eligible CSHCN, have greater need for care coordination, Medicaid reimbursement of care coordination activities in the MH is essential. Care coordination for CSHCN meeting the broader MCHB definition may involve 40% or more children in the practice, and therefore cannot be provided by referral to a care coordination agency. It must be provided in the MH. Only then can CSHCN receive the timely, comprehensive and coordinated care needed to optimize their potential while decreasing healthcare costs.

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Conflict of Interest Statement None.

Appendix 1

See Table 7.

Table 7 Care coordination levels of care (LOC)

Level I Minimal intensity of services (0–4 h of staff time per month)	Level II Moderate intensity of services (5 or more hours of staff time per month)
Criteria	Criteria:
Routine diagnosis, care and sick visits	Complex diagnosis and/or mental, psychosocial issues
Routine exams	Multiple co-morbidities
Simple specialty or service referrals	Unstable conditions requiring multiple interventions (intense services)
Long term but stable diagnosis	Complex and/or unusual specialty needs
Periodic consultations, screenings and referrals	
Ongoing, long term services or therapies requiring referral updates and renewals	
Office visits at least every 6 months	

Table 7 continued

Level I Minimal intensity of services (0–4 h of staff time per month)	Level II Moderate intensity of services (5 or more hours of staff time per month)
Guideline examples: Annual well care visits and screenings Routine immunizations Simple to moderate behavioral health referrals and follow up Simple to moderate educational needs Mild to moderate Down’s syndrome Stable, custodial CP whose services are established requiring routine renewal of services	Guideline examples: Unstable or new diagnosis of moderate to severe CP, genetic disorders Potentially life threatening diagnosis Multiple ER visits/hospital admissions (three or more annually) Suspected child abuse, neglect Frequent noncompliance issues with caretaker or patient

Application of Criteria

Staff time includes time spent by MD, front office, care coordinator, faxing, referrals, phone calls etc

Level I—care coordination provided by physician and office staff with consultation as needed by RN-CC

Level II—care coordination provided by physician, office staff and RN-CC. Care plan is updated in the medical chart with each visit by the RN-CC

Additional Facts

LOC is assigned after initial consultation with physician and in the case of possible Level II, assessment by RN-CC

LOC is not static. Intensity of services can either increase or stabilize. LOC should be evaluated with each visit and more often as the patient’s condition changes

Color of chart sticker will be changed with changes in LOC and rationale documented in nurse’s notes

Appendix 2

See Table 8.

Table 8 Distribution of primary diagnoses by type of encounter

Diagnosis	Number of patients with primary diagnosis	RN-CC contacts	Office visits	Total contacts by diagnosis
Acquired deformity of limb, site NOS	1	9 (52.9%)	8 (47.1%)	13 (100%)
Attention deficit hyperactivity disorder	21	135 (56.3%)	105 (43.8%)	240 (100%)
Allergies	1	9 (69.2%)	4 (30.8%)	13 (100%)
Acute myelogenous leukemia	2	10 (62.5%)	6 (37.5%)	16 (100%)
Asthma	45	201 (52.5%)	182 (47.5%)	383 (100%)
Autism	5	47 (59.5%)	32 (40.5%)	79 (100%)
Behavior disorder	2	8 (72.7%)	3 (27.3%)	11 (100%)
Cerebral hemorrhage	1	6 (75%)	2 (25%)	8 (100%)
Cerebral palsy	10	185 (84.5%)	34 (15.5%)	219 (100%)
Chronic upper respiratory infection	1	1 (12.5%)	7 (87.5%)	8 (100%)
Cystic fibrosis	1	3 (50%)	3 (50%)	6 (100%)
Developmental delay	14	93 (62%)	57 (38%)	150 (100%)
Diabetes mellitus type I	1	7 (50%)	7 (50%)	14 (100%)
Down’s syndrome	1	16 (84.2%)	3 (15.8%)	19 (100%)
Drug withdrawal-neonatal	1	5 (38.5%)	8 (61.5%)	13 (100%)
Epidermolysis bullosa	1	4 (44.4%)	5 (55.6%)	9 (100%)
Failure to thrive	3	18 (42.9%)	24 (57.1%)	42 (100%)
General convulsive epilepsy	6	32 (66.7%)	16 (33.3%)	48 (100%)
Hearing loss	1	5 (62.5%)	3 (37.5%)	8 (100%)

Table 8 continued

Diagnosis	Number of patients with primary diagnosis	RN-CC contacts	Office visits	Total contacts by diagnosis
Hemangioma of unspecified site	1	4 (66.7%)	2 (33.3%)	6 (100%)
Hydrocephalus	1	4 (57.1%)	3 (42.9%)	7 (100%)
Hypertension	1	5 (71.4%)	2 (28.6%)	7 (100%)
Joint pain	1	15 (78.9%)	4 (21.1%)	19 (100%)
Mental retardation-moderate	1	15 (68.2%)	7 (31.8%)	22 (100%)
Neurofibromatosis	3	16 (76.2%)	5 (23.8%)	21 (100%)
Obesity	1	8 (66.7%)	4 (33.3%)	12 (100%)
Prematurity	5	26 (48.1%)	28 (51.9%)	54 (100%)
Quadriplegic	1	13 (92.9%)	1 (7.1%)	14 (100%)
Shaken Baby syndrome	2	17 (53.1%)	15 (46.9%)	32 (100%)
Sickle cell disease	2	6 (75%)	2 (25%)	8 (100%)
Sickle cell trait	1	0	9 (100%)	9 (100%)
Speech delay	10	40 (58%)	29 (42%)	69 (100%)
Spina bifida with hydrocephalus	1	14 (93.3%)	1 (6.7%)	15 (100%)
Total:	150	977 (100%)	621 (100%)	1,598 (100%)

References

- Strickland, B. (2004). Access to the medical home: Results of the national survey of children with special health care needs. *Pediatrics*, *113*(5), 1485–1492.
- Benedict, R. E. (2007). Quality medical homes: Meeting children's needs for therapeutic and supportive services. *Pediatrics*, *121*, e127–e134.
- American Academy of Pediatrics. (2002). The medical home. *Pediatrics*, *110*(1), 184–186.
- McPherson, M., Arango, P., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*(1), 137–139.
- Bethell, C. D., et al. (2007). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal*, *12*(1), 1–14.
- Chevarley, F. M. (2006). *Utilization and expenditures for children with special health care needs*. Rockville, MD: Agency for Healthcare Research and Quality.
- Newacheck, P. W., et al. (2004). Health services use and health care expenditures for children with disabilities. *Pediatrics*, *114*(1), 79–85.
- Newacheck, P., & Kim, S. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, *159*, 10–17.
- Liptak, G. S., et al. (1998). Effects of providing comprehensive ambulatory services to children with chronic conditions. *Archives of Pediatrics and Adolescent Medicine*, *152*(10), 1003–1008.
- Antonelli, R., et al. (2008). Care coordination for children and youth with special health care needs: A descriptive, multisite study of activities, personnel costs and outcomes. *Pediatrics*, *122*, e209–e216.
- Wise P. H., et al. (2007). A critical analysis of care coordination strategies for children with special health care needs. In *US Department of Health and Human Services*.
- Palfrey, J. S., et al. (2004). The pediatric alliance for coordinated care: Evaluation of a medical home model. *Pediatrics*, *113*(5 Suppl), 1507–1516.
- American Academy of Pediatrics, et al. (2007). Joint principles of the patient-centered medical home. American Academy of Pediatrics.
- Patient Centered Primary Care Collaborative, National Committee for Quality Assurance. (2007). *Health care leaders to use new national criteria for patient-centered medical home*. Washington, DC: National Committee for Quality Assurance.
- Arvantes, J., American Academy of Family Physicians. (2009). *States take lead in adopting medical home model*. American Academy of Family Physicians.
- Gupta, V. B., et al. (2004). Care coordination services in pediatric practices. *Pediatrics*, *113*(5 Suppl), 1517–1521.
- American Academy of Pediatrics, Committee on Children with Disabilities. (2005). Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, *116*, 1238–1244.
- Kelly, A., et al. (2007). A medical home center: Specializing in the care of children with special health care needs of high intensity. *Maternal and Child Health Journal*, *12*, 633–640.
- Snow, J. (2005). *Care Coordination Final Report: Children with Special Health Care Needs Financing Initiative*. Boston, MA: John Snow Inc.
- McAllister, J. W., et al. (2009). Improvement in the family-centered medical home enhances outcomes for children and youth with special healthcare needs. *Journal of Ambulatory Care Management*, *32*(3), 188–196.
- Healthways, Johns Hopkins Medical Institutions. (2005). *Improving care coordination through physician/disease management collaboration*. In: Fifth Annual Disease Management Outcomes Summit Ft. Lauderdale, FL.
- McAllister, J., et al. (2007). Practice-based care coordination: A medical home essential. *Pediatrics*, *1120*, e723–e733.
- American Academy of Pediatrics, Committee on Children with Disabilities. (1999). Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, *104*(4), 978–981.
- Antonelli, R. C., et al. (2009). *Making care coordination a critical component of the pediatric health system: A multidisciplinary framework*. The Commonwealth Fund.

25. Antonelli, R. C., & Antonelli, D. M. (2004). Providing a medical home: The cost of care coordination services in a community-based, general pediatric practice. *Pediatrics*, *113*, 1522–1528.
26. Child and Adolescent Health Measurement Initiative. (2009). *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. (<http://cshcndata.org/Content/Default.aspx>). Last accessed April 2010.
27. Child and Adolescent Health Measurement Initiative. (2008). *2005/2006 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. (<http://cshcndata.org/Content/Default.aspx>). Last accessed April 2010.
28. Cooley, W., et al. (2003). The medical home index: Development and validation of a new practice-level measure of implementation of the medical home model. *Ambulatory Pediatrics*, *3*(4), 173–180.
29. The future of pediatric education II. (2000). Organizing pediatric education to meet the needs of infants, children, adolescents, and young adults in the 21st century. A collaborative project of the pediatric community. Task Force on the Future of Pediatric Education. *Pediatrics*, *105*(1 Pt 2), 157–212.
30. Behrman, R. E. (2001). Special article: Postgraduate education for pediatricians. *Pediatrics*, *107*(3), 553–557.
31. Bethell, C., et al. (2002). Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics*, *2*, 38–47.
32. Exeter Pediatric Associates, et al. (2001). "HOMES" complexity index. Lebanon, NH: Center for Medical Home Improvement.
33. Center for Medical Home Improvement. (2001). The medical home family index: Measuring the organization and delivery of primary care for children with special health care needs 2001. Lebanon, NH: Crotched Mountain, Center for Medical Home Improvement.
34. Cooley, W. C., & McAllister, J. W. (2004). Building Medical Homes: Improvement Strategies in Primary Care for Children with Special Healthcare Needs. *Pediatrics*, *113*(5), 1499–1506.
35. Turchi, R. M., et al. (2009). Care coordination for CSHCN: Associations with family-provider relations and family/child outcomes. *Pediatrics*, *124*(4 Suppl), 428–434.
36. Van Dyck, P. C., et al. (2004). Prevalence and characteristics of children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, *158*(9), 884–890.
37. Pierce, L., et al. (2007). *Highly mobile children and youth with disabilities: Policies and practices in five states*. Project Forum, National Association of State Directors of Special Education.
38. Newacheck, P., et al. (1998). An epidemiological profile of children with special health care needs. *Pediatrics*, *102*(1), 117–123.
39. American Medical Association. (2010). *Current Procedural Terminology CPT 2009: Professional Edition*. Chicago, IL: American Medical Association.
40. McManus, M., et al. (2003). *Medical home crosswalk to reimbursement*. In: Maternal and Child Health Bureau, (ed.). US Dept of Health and Human Services, Child Health Policy Research.