Identifying Children with Lifelong Chronic Conditions for Care Coordination by Using Hospital Discharge Data

John M. Neff, MD; Holly Clifton, MPH; Kathleen J. Park, MD, MPH; Caren Goldenberg, MPH; Jean Popalisky, DNP, RN; James W. Stout, MD, MPH; Benjamin S. Danielson, MD

From the Center for Children with Special Needs (Dr Neff and Ms Popalisky), Knowledge Management (Ms Clifton), and Odessa Brown Children's Clinic (Dr Park, Ms Goldenberg, Dr Stout, and Dr Danielson), Seattle Children's Hospital, Seattle, Wash; Department of Pediatrics, University of Washington, Seattle, Wash (Dr Neff, Dr Park, Dr Stout, and Dr Danielson)
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Address correspondence to John M. Neff, MD, Seattle Children's Hospital, 1100 Olive Way, Suite 500, MPW8-3, Seattle, Washington 98101 (e-mail: john.neff@seattlechildrens.org).
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ABSTRACT

BACKGROUND: Children with lifelong chronic conditions (LLCC) are costly, of low prevalence, and a high proportion of patients at children's hospitals. Few methods identify these patients.

OBJECTIVES: We sought to identify children with LLCC in hospital discharge data for care coordination by using clinical risk groups (CRGs), to evaluate the accuracy of this methodology compared with a chart review and to investigate accuracy according to condition groups.

METHODS: CRG software identified LLCC children who receive care at a primary care clinic, Odessa Brown Children's Clinic, by using Seattle Children's Hospital discharge data.

RESULTS: There were 5356 active Odessa Brown Children's Clinic patients with at least 1 clinic encounter in 2006–2007. Six hundred two (11.2%) patients were admitted to Seattle Children's Hospital, and 1703 (31.8%) were seen only in the emergency department over 7 years (2001–2007). One hundred sixty-four (7%) were identified to have a LLCC. In a blind review of 200 (33.2%) children with inpatient encounters, the specificity of the CRG designation to LLCC was 95.0% (95% confidence interval [CI], 90.0%–98.0%), sensitivity 76.3% (95% CI, 63.4%–86.4%). Mental health conditions formed the largest group that was chart-review positive and CRG negative (7 of 14). Children hospitalized before 13 months of age were the second largest group (3 of 14). Clinical review placed the 164 patients in these condition groups: sickle cell disease, 43 (26.2%), neurological, 37 (22.6%), mental health, 22 (13.4%), malignancies, 4 (2.4%), other 52 (31.7%), and no chronic condition 6 (3.7%).

CONCLUSION: This study demonstrates a unique way to identify children with LLCC for care coordination by using hospital administrative data.

KEYWORDS: care coordination; children's hospitals; chronic conditions; clinical risk groups; medical home

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WHAT'S NEW

This paper describes a unique method to identify children with serious lifelong chronic conditions by using a children's hospital discharge data. These children have conditions of low prevalence, utilize significant hospital resources, and have not been well studied as a group.

INTRODUCTION

Children with chronic conditions represent a significant proportion of children in the United States.[1] Identification of these children has been problematic because of the various methodologies used and the diversity, low prevalence, and different trajectories of individual chronic conditions.[2–10] Each method has it strengths and limitations.[2,3] Asthma is frequently used for outcome studies but is not representative of other chronic conditions that have different use patterns.[11] Health plans mine administrative data of enrolled members to target disease management efforts but have focused on adult conditions such as hypertension, type 2 diabetes, and cerebrovascular, cardiovascular, or chronic obstructive pulmonary diseases.[12,13]

The most widely accepted definition of a chronic condition in children is the definition of children with special health care needs (CSHCN) developed by a Maternal and Child Health Bureau work group: "Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[14] This broad definition has been incorporated into a questionnaire instrument, the CSHCN Screener, that defines a chronic condition as lasting at least a year and does not include children at risk.[15,16] The CSHCN screener, as part of *The National Survey of Children with Special Health Care Needs*, has been used widely to describe CSHCN.[17–19] Based on these surveys, it is estimated that from 13% to 19% of children have health care special needs.[17] The most common chronic conditions identified among CSHCN are allergies (53%), asthma (38%), attention deficit/hyperactivity disorder (30%), depression, anxiety or emotional

problems (21%), migraine/frequent headaches (15%), and mental retardation (11%). Each of the remaining categories has a prevalence of 5% or less.[18] The chronic conditions identified by the CSHCN survey are dominated by those that are highly variable in manifestation. The use of this survey for outcome measures is expensive and has not been evaluated for longitudinal outcome studies at a clinic or individual level. The lack of uniform methods to identify and stratify children according to complexity of conditions and to track outcomes is reflected in the limited number of children's measures in the National Committee on Quality Assurance Health Effectiveness Data and Information Set; these care measures relating to chronic childhood conditions include only asthma, attention-deficit/hyperactivity disorders, diabetes, and mental illness.[20]

An alternate way of categorizing children could be according to the expected complexity and trajectory of certain chronic disease groups, constructed such that it could be used routinely in administrative data sets. Children with chronic conditions that are potentially lifelong and expected to utilize significant health care resources over an extended time period are rarely identified as a group. These conditions include type 1 diabetes, sickle cell diseases, genetic defects, chronic encephalopathy, and cerebral palsy. The children could benefit from longitudinal, coordinated care, a principal component of a medical home.[21,22] Because of their low prevalence and lack of consistent identification methods, they have not been targeted as a group for care coordination.[11]

Children with potentially lifelong chronic conditions (LLCC) are served by many health plans and systems, with each plan representing a small fraction of the total pool of such children. Children's hospitals, in contrast, because of their unique mission and high concentrations of special services and professionals, serve as magnets for LLCC.[10] Children with LLCC currently are not consistently identified in children's hospitals because methodology is lacking to identify individual patients by chronic condition groups.

The objectives of this study were as follows: 1) to describe a method that uses administrative data to identify children with LLCC who are cared for at a children's hospital, with the intent to provide them coordinated care in a medical home, 2) to evaluate the accuracy of this method compared with a chart review, and 3) to investigate the accuracy according to condition groups.

Seattle Children's Hospital has been selected because of its wide referral base and its comprehensive specialty services. A previous review of medical records of a random sample of discharges from Seattle Children's Hospital in 2000 showed that over 58% of patients had a special health care need, and 41% were dependent on technology.[23] This suggests that Seattle Children's Hospital is a magnet for LLCC.

Odessa Brown Children's Center has been selected because of its close affiliation with Seattle Children's Hospital and the diverse population of children that it serves.

Clinical risk groups (CRGs) has been selected as an identification instrument for LLCC because of its ability to select and stratify individual children according to the presence and type of chronic conditions, to use health care plan administrative data, and to track individual patients.[6,24,25]

METHODS

In this study we combined the use of hospital discharge data from Seattle Children's Hospital and Odessa Brown Children's Clinic. We selected patients whose primary care occurs at Odessa Brown Children's Clinic, and hospitalization and emergency department care are likely to be at Seattle Children's Hospital. Active Odessa Brown Children's Clinic patients are defined as those who have been seen in the clinic at least once during a 2-year period, 2006 and 2007. Because of the close affiliation of these two institutions, we assumed that any active patient of the clinic with LLCC was likely to have been seen in the emergency department or hospitalized at Seattle Children's Hospital at least once over 7 years (from 2001 through 2007). This time frame also represents the extent of hospital discharge data available for analysis.

Approval was obtained from the Seattle Children's Hospital Institutional Review Board.

ODESSA BROWN CHILDREN'S CLINIC

Odessa Brown Children's Clinic is a community clinic that is integrated with Seattle Children's Hospital and provides comprehensive medical, dental, and mental health care services in Seattle's Central District, an historically African American neighborhood. Approximately 80% of patients are covered by Medicaid; the majority are children of color. It is considered a medical home for the community. The clinic and Seattle Children's Hospital use common medical record numbers for each patient.

CRG APPLICATION

Clinical Risk Groups (CRGS) is a risk adjustment method developed by 3M Health Information Systems (Salt Lake City, Utah), and the National Association of Children's Hospitals and Related Institutions. CRGS has been used with health plan data to identify and stratify individuals into condition and severity groups but has not previously been used to analyze patients in hospital discharge data.[6,24,25] CRGS, along with the definitions manual and description of methodology, can be purchased from 3M Health Information Systems. No-cost research licenses for the use of the software are also available.

The use of CRGS in health plan data has been described in previous publications.[24,26] CRGS uses data, typically obtained from medical claims data, to assign each person to a single, mutually exclusive hierarchical risk category according to the presence of a chronic condition and the type and severity of the chronic condition. CRGS stratifies the population by both health status and condition severity.

The assignment process is as follows: each diagnostic and procedural code is classified into 1 of approximately 540 episode diagnostic or procedural categories (EDC/EPC). There are approximately 270 acute and 270 chronic

EDC/EPCs. Each EDC/EPC is assigned to 1 of 6 EDC/EPC groups: dominant chronic, moderate chronic, minor chronic, chronic manifestation, significant acute and acute. Dominant chronic EDC/EPC conditions are defined as potentially lifelong, serious chronic medical conditions that often result in progressive deterioration of health and that contribute to debility, death, and future need for medical services. Moderate chronic EDC/EPC conditions are defined as conditions that are not likely to be progressive or lifelong, and that are highly variable but could contribute to individual debility, death, or future need for medical services. Minor chronic EDC/EPC conditions are defined as those that can generally be manageable with few complications. The acute EDC/EPC conditions are self-limited and probably will not last a year. After EDC/EPC assignment, an individual with 1 or more chronic EDC/EPC is assigned a single primary chronic disease for each body system, major diagnostic category with a chronic condition. This assignment follows hierarchical clinical logic that takes into account the presence and severity of the chronic condition. An individual will be assigned a primary chronic disease for every major diagnostic category that has a chronic condition. The final step is to assign the CRG. CRGs is classified into 9 hierarchically ordered CRG core health status groups: 1) acute, 2) significant acute, 3) minor chronic, 4) multiple minor chronic, 5) moderate and dominant chronic, 6) nonminor chronic conditions in 2 body systems, 7) dominant chronic conditions in 3 or more body systems, 8) malignancy, and 9) catastrophic with severity stratification. This process takes into account the presence of catastrophic conditions and malignancies, primary chronic diseases, and other factors.

For purposes of this study, the 9 CRG core health status groups were mapped as follows: the 2 acute core health status groups into a nonchronic group; the minor through moderate chronic core care health status groups into an episodic chronic group; the dominant chronic through catastrophic core health status groups into a lifelong group. The 3 final study groups (Table 1) were as follows: 1) nonchronic conditions, 2) episodic chronic conditions, and 3) LLCC. The episodic chronic group represents illnesses, such as asthma and attention-deficit/hyperactivity disorders, and depression, that are likely to have highly variable clinical patterns, and with treatment or natural aging are not expected to be lifelong. The lifelong group represents illnesses that are likely to significantly impact health and have more persistent and lifelong manifestations, such as type 1 diabetes, chromosomal abnormalities, sickle cell disease, cystic fibrosis, and chronic encephalopathy.

Table 1. CRG Mapping to Study Groups*

Nine CRG Core Health Status Groups	Study Clinical Groups
1. Acute 2. Significant acute	1. Nonchronic conditions
3. Minor chronic 4. Multiple minor chronic 5a. Moderate chronic	2. Episodic chronic conditions
5b. Dominant chronic 6. Pairs (chronic conditions in 2 body systems) 7. Triplets (chronic conditions in three or more body systems) 8. Metastatic malignancies 9. Catastrophic	3. Lifelong chronic conditions

*CRG = clinical risk group.

Analysis of Hospital Discharge Data

Seattle Children's Hospital discharge data from the years 2001 through 2007 was processed using Clinical Risk Groups version 1.5 (3M Health Information Systems, Salt Lake City, Utah). The input file included patient level (patient identifier, date of birth, and gender), patient-diagnosis level (diagnosis and procedure codes and dates), provider type, and site of service. The CRG software generated an output file containing information that stratified individual patients by complexity of diseases and primary chronic conditions. The CRG output file was merged with hospital discharge data to evaluate use of hospital services by health status groups. Each patient was assigned in a nonduplicative fashion to 1 of the 3 study groups, with no severity leveling.

To determine the distribution of chronic conditions and use of hospital services, an analysis of the complete Seattle Children's Hospital discharge data for 2007 was performed, identifying individual patients according to the 3 study groups.

Patient Selection From Odessa Brown Children's Clinic

Odessa Brown Children's Clinic patients who had been seen at least once in the medical or mental health clinic during years 2006 and 2007 were cross-matched to hospital and emergency department discharge data for 2001 to 2007.

Validation

To determine the accuracy of this identification method according to clinic records, a nurse with expertise in children with chronic conditions performed a blind review of 200 Odessa Brown Children's Clinic charts, randomly selected from the clinic's patients hospitalized at Seattle Children's Hospital. Selecting charts only from those hospitalized provided some stratification that favored those with LLCC and diminished some incomplete and inconsistent coding practices observed from the emergency department. Coding for hospitalized patients was performed by trained personnel by using up to 25 diagnostic fields. The selection of 200 charts was determined in part by the availability of resources and estimated to provide a statistically valid 95% confidence interval (CI).[27] Statistical software used was R statistical software, version 2.10.1 (R Foundation for Statistical Computing, Vienna, Austria).[28] Confidence intervals are based on exact binomial test.[29] The reviewer focused on children who had a LLCC, using the criteria of "does this child have a condition(s) that can be expected to be lifelong or a malignancy?"

Table 2. Seattle Children's Hospital Inpatient Utilization of Individual Patients by Condition Group, 2007

	Patients No. (%)	Discharges No. (%)	Hospital Days No. (%)
Nonchronic	2335 (30.2)	2451 (22.6)	7109 (11.7)
Episodic chronic	2212 (28.7)	2592 (23.9)	10 320 (16.9)
Lifelong chronic conditions	3174 (41.1)	5786 (53.5)	43 460 (71.4)
Total	7721 (100)	10 829 (100)	60 889 (100)

To determine the clinical accuracy of the CRG condition group designation, the Odessa Brown Children's Clinic clinicians performed a not blinded review of all identified LLCC patients in his/her primary care panel and provided a clinical designation of the primary chronic condition. Instructions were to verify those patients categorized as "medically complex" and identify any who were incorrectly categorized. The definition the clinicians used, in addition to medically complex, was "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

RESULTS

There were 7721 individual patients admitted to Seattle Children's Hospital in 2007 who accounted for 10 829 discharges and 60 889 patient days. There were 3174 (41.1%) individual patients classified as LLCC who accounted for 53.5% of discharges and 71.4% of total patient days (Table 2).

Of the 5356 children seen at Odessa Brown Children's Clinic at least once in 2006 or 2007, 2305 (43.0%) had at least 1 encounter at Seattle Children's Hospital from January 2001 through December 2007: 1703 (31.8%) were seen in the emergency department only (no admissions) and 602 (11.2%) were hospitalized. Table 3 shows the classification of these patients by the 3 study groups over 7 years. There were 164 classified as LLCC (7.1%): 149 hospitalized and 15 seen only in the emergency department.

BLINDED REVIEW

Of the 200 children in the chart validation sample, there was agreement for both the positive and negative in 179 and disagreement in 21. Using the chart review as the gold standard, there were 7 CRG false-positive patients and 14 CRG false-negative patients, with a CRG specificity of 95.0% (95% CI, 90.0%–98.0%) and a CRG sensitivity of 76.3% (95% CI, 63.5%–86.4%).

Table 3. Classification of Odessa Brown Children's Clinic Active Patients Seen at Seattle Children's Hospital From 2001 to 2007

Clinical Groups	Inpatients No. (%)	ED* Only Patients No. (%)	SCH† Patients No. (%)
Nonchronic	254 (42.2)	1653 (97.1)	1907 (82.7)
Episodic chronic conditions	199 (33.1)	35 (2.1)	234 (10.2)
Lifelong chronic conditions	149 (24.8)	15 (0.9)	164 (7.2)
Total	602 (100)	1703 (100)	2305 (100)

*ED = emergency department.
†SCH = Seattle Children's Hospital.

SEVEN FALSE-POSITIVE PATIENTS

Two children, 2 years old or less at the time of the chart review, were premature at 500 to 900 g, with gastrostomies and suspected developmental delay. One premature child, 750 to 999 g, was hospitalized during the first year of life with bronchopulmonary dysplasia, but at the time of chart review at 4 years of age had only asthma. One child, born during the last year of the study period, had been on a pulmonary ventilator for several weeks for pertussis infection and was doing well with bronchodilators at the time of the review. Two children had traumatic brain injuries, 1 as a result of an accident during the study year and another as nonaccidental trauma in 2005 (shaken baby syndrome). Both had recovered at the time of chart review except for some possible developmental delay. One child had depression and asthma. The CRG software identified this as a 2-system, lifelong condition.

In all false-positive patients, the reviewer confirmed the presence of the chronicity but was uncertain of LLCC designation. Six of the 7 patients required care coordination following discharge from the hospital.

FOURTEEN FALSE-NEGATIVE PATIENTS

Seven children had mental health conditions as the primary chronic condition. Five were admitted to inpatient psychiatry with mental health conditions classified by CRGs as moderate chronic, and 2 hospitalized in the medical unit with comorbid mental health conditions classified as minor chronic. Three children had the following: hearing impairment, Poland's syndrome, and developmental delay (suspected autism). All had been hospitalized only at or before 13 months of age. In all 3, the conditions became apparent after hospitalization.

Two children had craniofacial abnormalities but were hospitalized only once in day surgery for minor procedures. Both were coded to have only cleft lip and palate and not craniofacial abnormalities. One child had congenital heart disease partially corrected in 2001 but was not coded to have a congenital heart disease during subsequent visits to the emergency department. One child had severe asthma and was classified by CRGs as a moderate chronic condition.

In summary, of the 14 false-negative patients, 7 had mental health conditions, 3 had LLCC conditions recognized after hospitalization, 3 may have been miscoded, and 1 represented the severe end of a usually episodic condition.

CONDITION GROUPS OF CRG IDENTIFIED AS LLCC

Table 4 depicts the not blinded clinical assessment of all of the 164 Odessa Brown Children's Clinic children classified with LLCC. Note the groups with the highest prevalence were sickle cell anemia 43 (26.2%), neurological conditions 37 (22.6%), and mental health conditions 22 (13.4%). There were 4 (2.4%) malignancies. All others,

Table 4. Clinical Assessment of Children Classified With Long-Lasting Chronic Conditions (N = 164)*

Body System Group	Primary Condition	Diagnosed, No.	Total in Group No. (%)
Hematological	Sickle cell disease with no comorbid conditions	18	44 (26.8)
	Sickle cell disease with comorbid conditions	25	
	Congenital hemolytic anemia	1	
Neurological	Encephalopathy	3	37 (22.6)
	Cerebral palsy, quadriplegia, brain anomaly, ventricular shunt	24	
	Developmental delay, mental retardation, failure to thrive	7	
	Complex seizures , tuberous sclerosis	3	
Mental health and autism	Eating disorders	2	22 (13.4)
	Impulse control, oppositional defiant, conduct disorders, aggression	7	
	Bipolar, mood, posttraumatic stress disorders	3	
	Schizoid disorder	1	
	Autistic disorder	7	
	Pervasive developmental delay	2	
Endocrine	Diabetes type 1	9	12 (7.3)
	Diabetes type 2 and obesity	2	
	Thyroid disorder	1	
Cardiac	Congenital heart disease	8	10 (6.1)
	Transplant heart, myopathy	2	
Genetic and chromosomal	Down syndrome	3	7 (4.3)
	Other genetic conditions	4	
Gastrointestinal	Inflammatory bowel disease	3	6 (3.7)
	Abdominal wall defect	2	
	Gastrostomy prematurity	1	
Respiratory	Chronic obstructive pulmonary disease	3	5 (3.1)
	Cystic fibrosis	1	
	Chronic pulmonary disease second to pertussis	1	
Malignancies	Leukemia (1), Hodgkin's disease (1), and brain tumor (2)	4	4 (2.4)
Obesity	Morbid obesity (2), obesity with respiratory condition (1), obesity with hip condition (1)	4	4 (2.4)
Musculoskeletal conditions	Osteogenesis imperfecta (1), osteodystrophy of hip (1)	2	2 (1.2)
HIV infection	Pulmonary (1) and brain involvement (1)	2	2 (1.2)
Other systems	Renal (1), craniofacial (1), immune deficiency (1)	3	3 (1.8)
Not chronic	Sickle cell trait miscoded as sickle cell disease (4), congenital heart completely repaired (2)	6	6 (3.7)
Total in the group		164	164 (100)

*Patients were seen at the Odessa Brown Children's Clinic. Clinical risk group analysis of Seattle Children's Hospital data, 2001 to 2007, was used.

52 (31.7%), were conditions of low prevalence. Six (3.7%) were excluded because they did not have a chronic condition: 4 coding errors and 2 with repaired heart defect.

DISCUSSION

Children with LLCC require a disproportionate share of resources in children's hospitals and in health plans. We have demonstrated a method of identifying children with LLCC with a high specificity and moderate sensitivity by using hospital discharge data. To our knowledge, this is the first time hospital discharge data, processed through specific software coding algorithms, has been used to identify individual patients for collaborative care management according to chronic disease categories. At Seattle Children's Hospital, these children represented 41.1% of the total patients and 71.4% of patient days. In an analysis of approximately 460,000 children <19 years enrolled in New York State Medicaid Managed Care Programs in 2006 using the CRGs methodology described in this paper, 2.6% of children had LLCC and accounted for 17.3% of children's charges.[30] This comparison suggests a low prevalence of LLCC, high proportion of costs in a Medicaid population, and a high concentration of these children with high service use in a children's hospital. This group of children, when measured over several years, is likely to accrue a high percentage of health care costs. There has not been a focus on identifying LLCC for care coordination, in part because of the lack of consistent methodologies to do so.

This methodology has strengths and limitations. It appears to be highly specific in identifying LLCC. In another study evaluating all chronic CRG designations for identifying children with chronic conditions in a managed care setting, there was 66% to 73% chart review agreement for the presence of a chronic condition status.[31] This poor to moderate agreement was driven by children with mild to moderate chronic conditions that dominated this study sample. In the same study, the CRG status groups 6, 8, and 9, which are dominated by children with LLCC, had a chart review agreement of 12 of 13 (92.3%). In our study, by concentrating on children with LLCC and with uniform coding standards, the specificity is 95%.

A significant limitation is that this method is not as sensitive as it is specific. This is most apparent for

children with mental health conditions, who in the chart review accounted for 7 of 14 patients missed. The methodology may need to be improved for more sensitivity for mental health conditions. It will not identify infants hospitalized before their condition is clinically evident (3 of 14 patients). It will not identify children miscoded (3 of 14 patients), or children at the severe end of an episodic chronic condition such as asthma (1 of 14 patients). It will not identify LLCC hospitalized elsewhere because of the fragmented nature of information systems and health care in the United States.

A limitation to this study is that there was only 1 reviewer and no gold standard for potentially lifelong mental health illnesses or those at the very severe end of common conditions such as asthma. Conditions such as chromosomal abnormalities, hemoglobinopathies, and static encephalopathy are clearly lifelong. The selection of cases in this study may favor the latter and not the former groups that are more difficult to designate as lifelong. In the final analysis, note the long-lasting nature of the conditions in the complete list of positively identified patients of the Odessa Brown Children's Clinic (Table 4).

A limitation for the generalizability of this study is that the clinic and Seattle Children's Hospital use common medical record numbers and other systems may not. This can be mitigated if hospitals link patients to specific providers or clinics by other methods of identification. In this study, there was not a further aggregation of the LLCC group into additional severity groups: those with single chronic conditions, those with complex or multisystem chronic conditions, and malignancies. This is possible by using other CRG aggregations. The method we have demonstrated provides a core set of children with LLCC for care coordination in a medical home.

After using this method to identify children with LLCC, there may be some unidentified children who benefit from care coordination. Practices can create additional patient lists or add to this one. This might include the following: 1) at risk newborns, 2) those with mental health conditions, 3) other children with LLCC not hospitalized or hospitalized elsewhere, 4) children identified through developmental screens, 5) those with common non-LLCC chronic conditions such as asthma and attention-deficit/hyperactivity disorders, and 6) families with social concerns, and possible others.[32]

There are limited, well-controlled outcome studies and reimbursement strategies for the care of LLCC in medical homes, partly because of lack of reproducible identification methods.[11] This paper describes a methodology that children's hospitals can use to identify a group of children with LLCC. Children with LLCC represent a small percentage of the childhood population yet represent a large percentage of children cared for at children's hospitals. They consume considerable resources and place large responsibility of care on health care providers and family. Children's hospitals, with their expertise in caring for children with LLCC, could take a lead role in identifying these children and in coordinating their care with medical homes.

CONCLUSION

It is possible to use hospital-coded data run through a software algorithm to identify a group of children with LLCC for care coordination. Future work is needed to enhance identification of children with serious and long-lasting mental health conditions.

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