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Development of a Computerized Medical History Profile for Children in Out-of-Home Placement Using Medicaid Data

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Abstract

Children in out-of-home placements (foster children) often undergo multiple placement changes while under the care of child protective services. This instability can result in lack of health care continuity and poor health outcomes. This brief describes the development of a medical history profile, or *passport*, developed from Medicaid administrative data. A purposive sample of 25 youths was provided from a county child protective services agency. The patients were systematically matched with data from the state Medicaid agency. Using Medicaid claims/encounter data we generated health care profiles that provided information on historical use of ambulatory care, diagnoses, providers seen, medications used, and inpatient admissions. Profiles were however limited by missing provider information and non-specific diagnostic coding. Despite these limitations, Medicaid data-based profiles show the potential to be a cost efficient method for improving continuity of care for children in out-of-home placement.

Keywords

Medicaid; foster care; pediatrics; informatics; continuity of care

Children in out-of-home placement, commonly referred to as foster children, often face multiple placement changes during their time in the child protective services system. Among Ohio foster children, the median length of stay in out-of-home care is 14.6 months, and youths experience an average of 2.9 placements.¹ These children also often face both physical and mental health problems^{2–4}. Changes in placement increase discontinuity of health care and fragmentation due to frequently co-occurring changes in health care providers.⁵ The discontinuous care which they receive is associated with poor communication among health providers, lack of adequate record-keeping, increased sub-specialist consultations, and costly laboratory investigations due to lack of previous health history.^{6,7}

Effective coordination and communication of care while in the foster care system can decrease fragmentation of health care.⁸ Web-based health records for foster children offer a possible solution. They can be secure and confidential, they can be updated from multiple sites, and they can travel with foster youth. However, the initiation of such a system presents logistical questions such as how to incorporate prior medical history.

Medicaid has served as a principal source of health care coverage for children in low-income families over the past four decades, and states have traditionally used Medicaid funds to provide services for children in foster care.^{6,8} This paper explores the use of Medicaid claims data to create a medical history profile in this population to help achieve continuity of care. Our goal was to create a medical history profile for foster youth using administrative data currently captured by Medicaid. The success of this pilot was measured using three criteria: 1) completeness of matching individuals identified by child protective services with records in Medicaid data, 2) completeness of provider information, and 3) clinical value of medical information.

Methods

This study used information from the county child protective services (CPS) agency and the state Medicaid agency. All elements of the study were approved by the Nationwide Children's Hospital Institutional Review Board. The population studied was a purposive sample of 25 youths in the CPS Permanent Court Commitment (PCC) program, which includes children who are available for adoption. The PCC program was selected because the county had full custody of these children and could provide consent for their participation. Because the study involved only the use of administrative data, we did not seek assent from the youths involved in the study. The purposive sample was selected to represent a range of ages, genders, and lengths of time in foster care. The subject list provided by CPS included the child's name, date of birth, social security number, and most recent Medicaid number.

This list was sent to the state Medicaid agency where the combination of social security number, date of birth, and most recent Medicaid number were used to query the Medicaid database and identify all past Medicaid numbers. Three databases including all care for the sampled children, across all historical Medicaid numbers, were created by the Medicaid agency. Each database included administrative data for the previous 36 months. The databases were as follows: 1) an admissions database with dates of service, providers of service (physician and hospital), ICD-9 diagnosis codes, ICD-9 procedure codes, and diagnosis related group codes (DRGs) for each hospitalization; 2) a pharmacy database including national drug codes and fill date ranges; 3) and an "episode of care" database including information on all service utilization. In the episodes database, inpatient, outpatient, and pharmacy claims were combined into clinically-related groups that describe a patient's course of care for a single illness or condition, using commercially-available grouper software. Each database was labeled with a unique identifier and with patient demographic data including age at service, date of birth, gender, race, ethnicity, and Zip Code of residence at service. We did not access eligibility data in this analysis because of analytic complexities beyond the scope of this small pilot. These data were used for this project under a project-specific data-use agreement between The Research Institute at Nationwide Children's Hospital and the state Medicaid agency. Utilization data for the study youth were used to create sample medical history profiles using Microsoft Access.

Results

Child Protective Services originally identified 25 children for inclusion in the pilot. One youth from the list was adopted in the delay between receiving the CPS list and being granted access to Medicaid data and was subsequently dropped from the study due to consent issues. The

Medicaid agency was able to match the 24 remaining children from the CPS list with records in the Medicaid data using the combination of social security number, date of birth, and name. Demographic information and dates of service were available for all youths. Twenty-three of the 24 had received some health care in the previous three years and were included in the pilot. Of those 23, three had more than one Medicaid ID in the three year period included in the profiles. Sixteen (70%) were male, and ages ranged from newborn to 17 years (median 12 years). Thirteen (57%) were White and the remaining 10 (43%) were African American.

The number of episodes of care for the 23 children ranged from 2 to 28 with a median of 15 episodes. *Preventive health service* was the largest episode category. These were all well-child visits that included vaccinations. Many of the children, also, received treatment for behavioral health concerns including neuroses and depression. Table 1 lists the most frequent episode codes. We note that the episode of care data was somewhat limited because of missing physician information and non-specific episode codes. Episode primary physician was missing in 181 of the 344 encounters generated by the youths profiled (54.7%). While an episode code was present on each encounter, *Other or Not Elsewhere Classified* groups were coded on 42.7 percent of cases, offering limited clinical detail. Physician information was more likely to be missing on episodes with non-specific groups than on other episodes (67.3% vs. 38.5%).

The most commonly prescribed therapeutic drug class was Central Nervous System Agents, including Adderall, Risperdal, and Concerta. The second most common class was Cardiovascular Agents; however, the great majority of prescriptions in this class were for Clonidine, which is commonly used in attention-deficit hyperactivity disorder (ADHD) for insomnia. Other commonly used classes included Hormones and Synthetic Substances (e.g., contraceptives, pituitary hormones, and thyroid hormones), Antihistamines, and Anti-infective Agents. Six of the 23 youth had at least one inpatient admission. Three of the six admissions concerned mental health.

Figure 1 presents a sample of the medical history profiles we were able to generate from the Medicaid data. Please note that the patient and provider identifiers have been modified and some utilization data was deleted from the sample profile to ensure confidentiality. Each profile included four sections: a header with patient name, date of birth, gender, and race; an episodes of care section detailing ambulatory care with episode start date, episode end date, managing physician name and ID, and episode group description; a prescription medication section including therapeutic class, drug name, number of prescriptions, earliest prescription date, and most recent prescription date; and an admissions section including admit and discharge dates, hospital name and ID, attending physician name and ID, principal diagnosis, and DRG. Alternatively, all types of care could be listed together chronologically.

Discussion

The profiles developed in this pilot provided extensive information that highlighted the issues of special health needs and use of multiple medications. They also provided key information on medical providers and clinics that had been visited in the past three years. The profiles allowed for large amounts of data to be summarized into interpretable brief reports that could be used by physicians, social workers, and foster families to manage children's health.

Based on our defined criteria and our goal to create a medical history profile for foster youth using Medicaid claims data, this pilot can be considered a success, with a few notable limitations. Our first criterion was successful matching of data from CPS and Medicaid. We successfully matched all of the youth in the pilot. This is notable because significant problems exist in identifying foster youth within Medicaid data.⁹ In the Rubin study, researchers found that 28% of youths in foster care were incorrectly classified in Medicaid enrollment files.

Correct classification was associated with longer duration in foster care, greater number of placements, and group home placement. These results suggest that building profiles based on Medicaid eligibility codes would systematically exclude some children in foster care. Our project circumvented this problem by identifying the youths to be profiled from the children's services agency rather than the Medicaid data. Identified youths were matched to claims data without respect to their reason for eligibility, increasing the probability that all youths of interest would be matched. This process, while more effective than using Medicaid eligibility data alone, is also more resource intensive because of the requirement of obtaining and matching data from disparate systems.

Limitations were notable in the second and third criteria: *completeness of provider information* and *clinical value of medical information*. Provider was missing on over half of claims (55%). It is likely that, in the majority of these cases, payment was made to a clinic or health center that did not submit an individual physician name or ID. These claims still provide valuable information on diagnoses but do not provide the information required for continuity follow-up with specific clinicians.

Clinical value of medical information is somewhat limited because of lack of specificity in diagnostic coding. Episode group codes were often non-specific with many episodes categorized as *other neuroses*, *other ear, nose, and throat disorders*, *other eye disorders*, or *other bacterial infection*. These catch-all codes do not provide the detail needed for true medical history. Additionally, pharmacy data frequently listed multiple medications in the same class used either serially or simultaneously. Claims data, by its nature, cannot explain whether a medication was discontinued in favor of another and why, nor can they determine with certainty whether multiple clinicians were simultaneously prescribing different treatments for the same condition.

We also note that the transient nature of out-of-home placements, with youths coming and going from households with non-Medicaid insurance coverage or no coverage at all, creates the possibility of significant holes in a Medicaid based profile. Use of eligibility data, which details periods of Medicaid coverage and non-coverage, as part of the profile would have helped document the extent of information gaps, but unfortunately those files could not be used for this pilot. The lack of a documented diagnosis or event, therefore, does not mean that the diagnosis or event has not occurred. Services could have been rendered while a youth was covered under another insurance entity or could have been provided by a provider that does bill Medicaid (e.g., Planned Parenthood). This significant limitation would require that clinicians receive detailed training to ensure that decisions are not made using incomplete information that is believed to be complete. Other more general limitations of administrative claims data, including lack of coding for non-billable activities, have been discussed in detail elsewhere.^{10, 11} While these weaknesses of administrative data may limit the usefulness of these profiles, they do not render the profiles useless. The combination of even limited diagnostic, pharmacy, and provider data is far superior to what is often currently available to clinicians who see youth after a placement change.

Medicaid-based medical profiles can serve as part of a comprehensive program supporting continuity of care for foster children. For example, Medicaid agencies could develop Internet-based interfaces that would allow a clinician to download a report for a foster youth seen in his or her office. This report, which could be added to the medical record, could be used to document prescription history and past providers and diagnoses. On a larger scale, these data could be used to populate sections of a more comprehensive medical passport that would augment the claims data with information from youth, biological parent, and foster parent interviews, clinical health assessments, and school records. The costs for such a system would lie in human and computer resources required for programming the data extraction, matching,

and reporting, and for generating reports or updates on a regular basis. The cost of data acquisition, however, is limited because the system would rely on data already captured in the billing and administrative process.

This pilot demonstrates that Medicaid data can serve as a good starting point for patient-level personal health records for youth in the foster care systems. The data are already collected with the provision of care so there is no additional cost for acquisition. Data are as timely as the Medicaid systems process allow and are likely to be considerably timelier than information collected in periodic assessments, especially for prescription medications. Profiles generated and updated regularly could be an important tool to help foster parents, social workers, and child protective services agencies maximize the health of children during a potentially turbulent time.

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Medicaid Medical Use Profile

Patient ID 123456
Name: Doe, Jane
Date of Birth 9/xx/19xx
Gender Female
Race WHITE

Episodes of Care

Start Date	End Date	Managing Phys ID and Name	Episode Group
12/1/2005	12/1/2005	000000000375xxxx JOHN SMITH MD	Other Disorders of Female Genital System
11/21/2005	11/21/2005	~ ~Missing	Other General Signs, Symptoms, and Conditions
11/17/2005	11/17/2005	000000000237xxxx MARY SMITH MD	Oth Inflam and Infect of Skin and Subcutaneous Tis
11/14/2005	11/14/2005	~ ~Missing	Other Eye Disorders
11/13/2005	3/17/2006	~ ~Missing	Other Neuroses
11/9/2005	11/9/2005	00000000036xxxx JOHN JONES MD	Other Circulatory Disorders
8/14/2005	8/14/2005	~ ~Missing	Injury, Open Wound, or Blunt Trauma: Lower Extr
6/29/2005	6/29/2005	00000000066xxxx MARY JONES MD	Other Arthropathies, Bone and Joint Disorders

Prescription Medications

Most Recent	Earliest	Therapeutic Class	Drug Name	# Scripts
12/16/2005	11/17/2005	Antibiot, Tetracyclines	DOXYCYCLINE HYCLATE	4
12/27/2005	11/18/2004	Anticonvulsant, Benzodiazepine	CLONAZEPAM	23
1/11/2004	12/15/2005	Anticonvulsants, Misc	LAMICTAL	27
12/15/2005	10/28/2005	Antihistamines & Comb, NEC	LORATADINE	3
9/12/2005	2/2/2005	Antihistamines & Comb, NEC	ALAVERT	7
12/28/2005	11/17/2005	Antiinf S/MM, Antiinf Loc Misc	BREVOXYL-4	3
8/30/2005	2/28/2005	Antiinf S/MM, Antiinf Loc Misc	BENZOYL PEROXIDE LOTION	10
12/2/2005	12/2/2005	Antiinf S/MM,Antifungal & Comb	TERAZOL 3	1
11/17/2005	11/17/2005	Cell Stim/Proliferant S/MM	NECRETIN-A MICRO (AGES 0-23 Only)	1
12/22/2005	12/14/2005	Psychother,Tranq/Antipsychotic	ABILIFY	3
10/20/2005	9/8/2005	Psychother,Tranq/Antipsychotic	RISPERDAL	7
11/14/2004	10/22/2004	Psychother,Tranq/Antipsychotic	SEROQUEL	2
12/15/2005	2/9/2005	Unclassified Agents, NEC	SINGULAIR	14

Admissions

Discharge: 7/xx/2005 **Admit:** 7/xx/2005 **Facility** 000000000999999 Anywhere CHILDRENS HOSPITAL
Attending Physician ID and Name 000000009xx1x15 ~Missing
Principal Diagnosis 78039 Convulsions NEC

Figure 1.
 Sample Profile (de-identified and incomplete)

Table 1

Top Ten Episode Groups

Episode Group	% of Episodes	% of Pts
	N=344	N=24
Encounter for preventive health services	51 (14.8%)	21 (91%)
Other eye disorders	38 (11.0%)	14 (61%)
Other Neuroses	36 (10.5%)	12 (52%)
Otitis media	18 (5.2%)	7 (31%)
Other Bacterial Infections	15 (4.3%)	8 (35%)
Croup	12 (3.4%)	5 (22%)
Antisocial Personality Disorder	11 (3.2%)	8 (35%)
Encounter for other Administrative Reason	11 (3.2%)	8 (35%)
General signs, symptoms, and other conditions	10 (2.9%)	6 (26%)
Depression	9 (2.6%)	8 (35%)