Acute Care Utilization and Rehospitalization for Children with Inherited Metabolic Diseases Identified through NBS

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Background

- Long-term follow-up activities are essential to assure that high quality medical management is provided and healthcare services are utilized.
- Rehospitalization within a defined time period, such as 30 days, has been used as a clinical indicator of the quality of care for a variety of diseases.
- Currently there are very little existing data on long-term outcomes and health services utilization of the affected children.
- Objective: to examine acute care utilization and re-hospitalization patterns for children with inherited metabolic diseases identified by newborn screening.

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Methods

- **<u>The Cohort</u>**:
  - Children born in **<u>2006 & 2007</u>**
  - Had confirmed Inherited Metabolic Disease (IMD)
  - Identified through the New York State Newborn Screening (NBS) Program

Methods

- **IMDs Included**:
  - Amino acid disorders
  - Fatty acid oxidation disorders
  - Organic acid disorders
  - Urea cycle disorders

Methods

- **Follow-up Period**:
  - Three years after birth

- **Follow-up Method**:
  - Record linkage

Methods

- **Record Linkage**:
  - Matched to birth certificate files to obtain birth and maternal information of the children
  - Matched to Statewide Planning and Research Cooperative System (SPARCS)'s hospital discharge files to obtain healthcare utilization information

Methods

- **Acute Care Encounters**:
  - Treat-and-release at emergency department (ED) visit
  - Inpatient hospital stays including admission via ED
- **Non-Encounters**:
  - children who were not found in hospital discharge data

Methods

- **IMD Related Encounters**:
  - Metabolic disorders
  - Cerebral degenerations
  - Muscular dystrophies and other myopathies
  - Congenital respiratory disorders
  - Gastroenteritis, reflux and other digestive problems
  - Other co-morbidities/conditions

Methods

- **IMD Non-related Encounters**:
  - Routine visits
  - Newborn issue
  - Injuries
  - Viral hepatitis
  - Others (virus or cold causing fever, cough, croup, ear infections, sore throat, etc.)

Results

Table 1. Live births, number of children born in New York State in 2006-2007 and identified with inherited metabolic disorders through newborn screening, and incidence by selected demographics

Characteristics	Total Births N	(Row %)	Total patients N	(Row %)	Incidence rate (per 10,000 birth)
Total	487,716	(100.0)	180	(100.0)	3.69
Child sex					
Male	249,469	(51.2)	98	(54.4)	3.93
Female	238,233	(48.8)	82	(45.6)	3.44
Not stated	14	(0.0)	0	(0.0)	-
Maternal race/ethnicity					
White	239,517	(49.1)	94	(52.2)	3.92
Black	81,053	(16.6)	32	(17.8)	3.95
Hispanic	115,801	(23.7)	23	(12.8)	1.99
Other/unknown	51,345	(10.5)	31	(17.2)	6.04
Maternal age					
< 20 years	35,041	(7.2)	21	(11.7)	5.99
20 - < 35 years	356,524	(73.1)	130	(72.2)	3.65
35+ years	96,143	(19.7)	29	(16.1)	3.02
Unknown	8	(0.0)	0	(0.0)	-
Metabolic disease type					
Amino acid disorders	487,716		35	(19.4)	0.72
Fatty acid oxidation	487,716		61	(33.9)	1.25
Organic acid disorders	487,716		81	(45.0)	1.66
Urea cycle disorders	487,716		3	(1.7)	0.06

Results

Table 2. Acute care encounter status during the first three years of life by patient characteristics among children born in New York State in 2006-2007 and identified with inherited metabolic disorders (IMDs) through newborn screening

Characteristics	Total patients	IMD-related encounters N (Col. %)	Unrelated encounters N (Col. %)	No encounter N (Col. %)
Total	180	73 (40.6)	75 (41.7)	32 (17.8)
Child sex				
Male	98	34 (34.7)	47 (48.0)	17 (17.3)
Female	82	39 (47.6)	28 (34.1)	15 (18.3)
Maternal race/ethnicity				
White	94	37 (39.4)	39 (41.5)	18 (19.1)
Black	32	15 (46.9)	13 (40.6)	4 (12.5)
Hispanic	23	9 (39.1)	10 (43.5)	4 (17.4)
Other	31	12 (38.7)	13 (41.9)	6 (19.4)
Maternal age				
< 20 years	21	11 (52.4)	9 (42.9)	1 (4.8)
20 - < 35 years	130	52 (40.0)	53 (40.8)	25 (19.2)
35+ years	29	10 (34.5)	13 (44.8)	6 (20.7)
Payment type				
Private/commercial	62	25 (40.3)	37 (59.7)	0 (0.0)
Public/Medicaid	71	37 (52.1)	34 (47.9)	0 (0.0)
Self-pay, other,	47	11 (23.4)	4 (8.5)	32 (68.1)
Metabolic disease type				
Amino acid disorders	35	13 (37.1)	12 (34.3)	10 (28.6)
Fatty acid oxidation	61	27 (44.3)	27 (44.3)	7 (11.5)
Organic acid disorders	81	32 (39.5)	35 (43.2)	14 (17.3)
Urea cycle disorders	3	1 (33.3)	1 (33.3)	1 (33.3)

Results

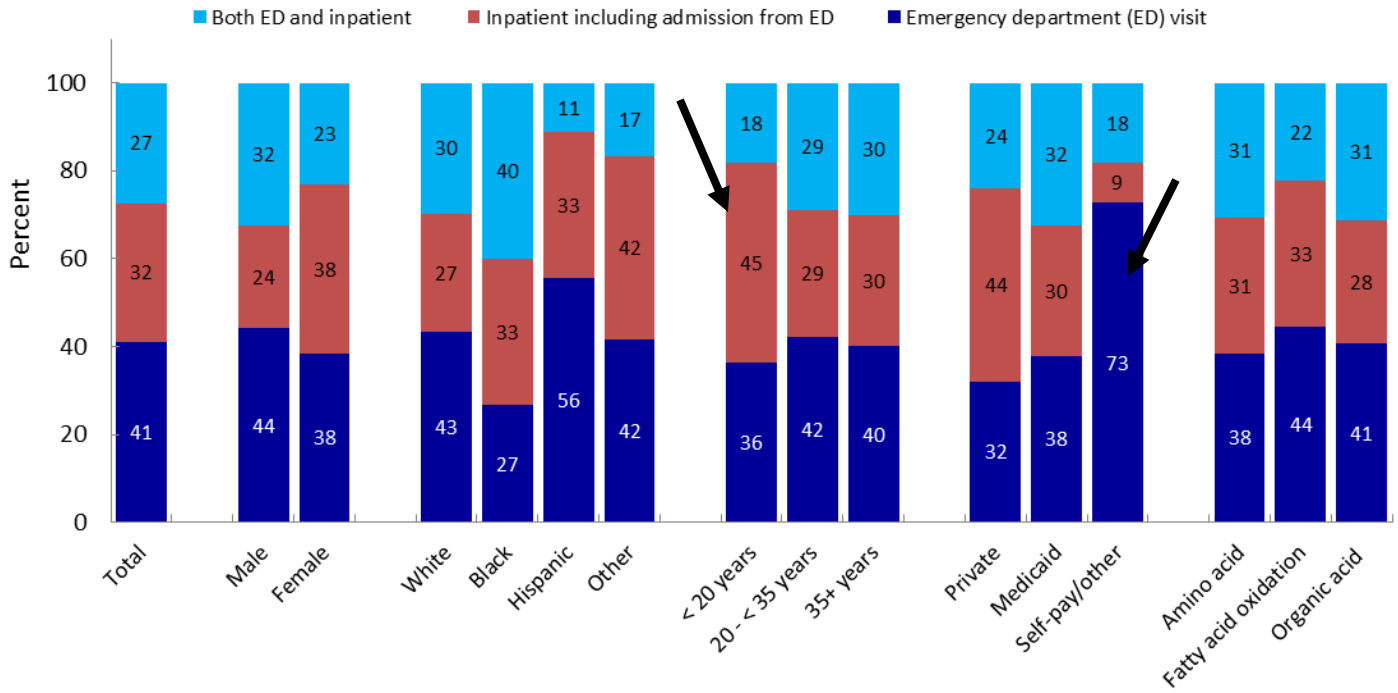

Figure 1. Inherited metabolic disorder (IMD)-related acute care encounter type during the first three years of life by patient characteristics among children born in New York State in 2006-2007 and identified with IMDs through newborn screening

Results

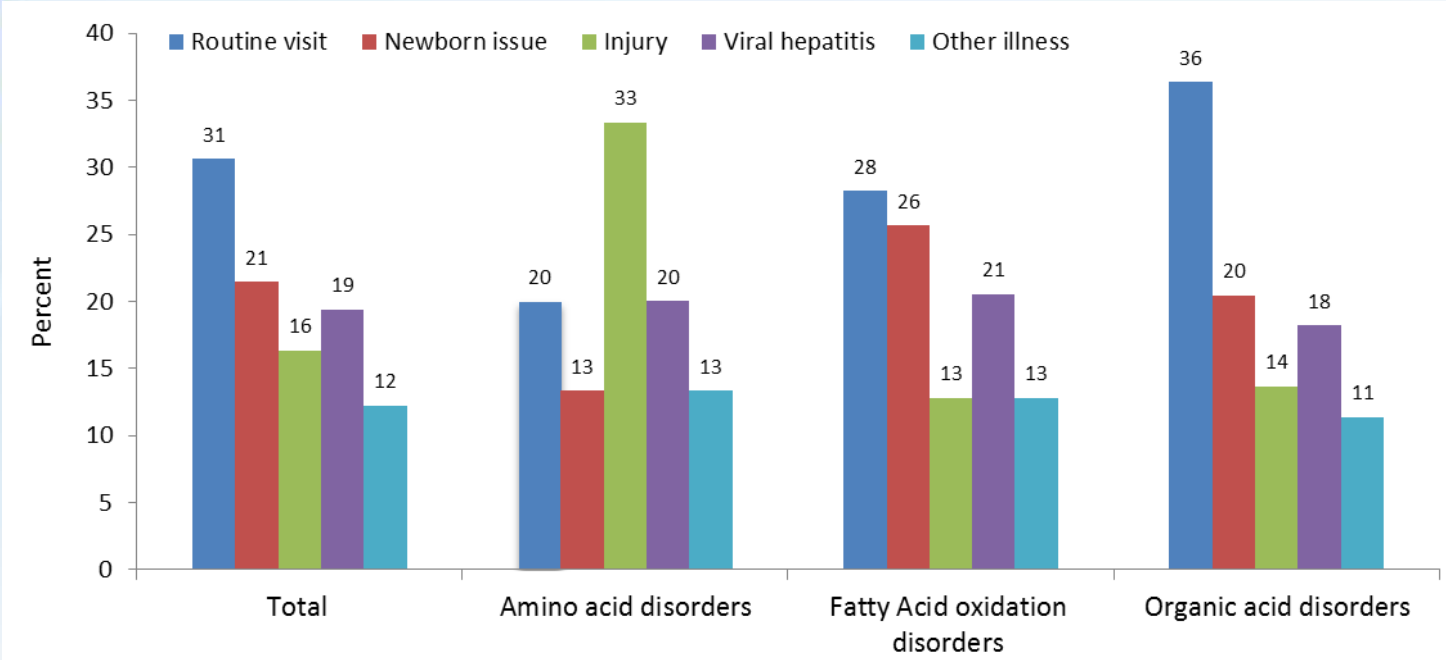

Figure 2. Unrelated conditions by IMD category among children with IMD-unrelated acute care encounters during the first three years of life among children born in New York State in 2006-2007 and identified with IMDs through newborn screening

Results

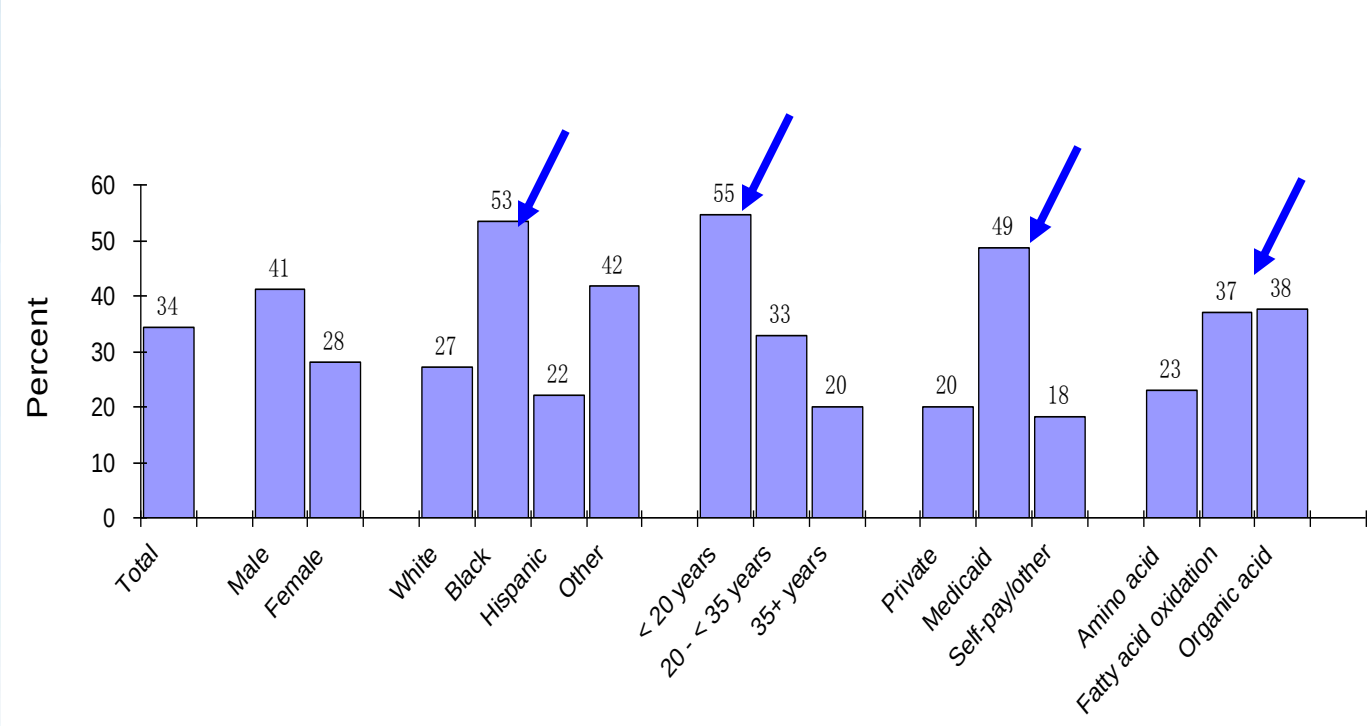

Figure 3. The percent of inherited metabolic disorder (IMD)-related re-hospitalization during the first three years of life by patient characteristics among children born in New York State in 2006-2007 and identified with IMDs through newborn screening

Results

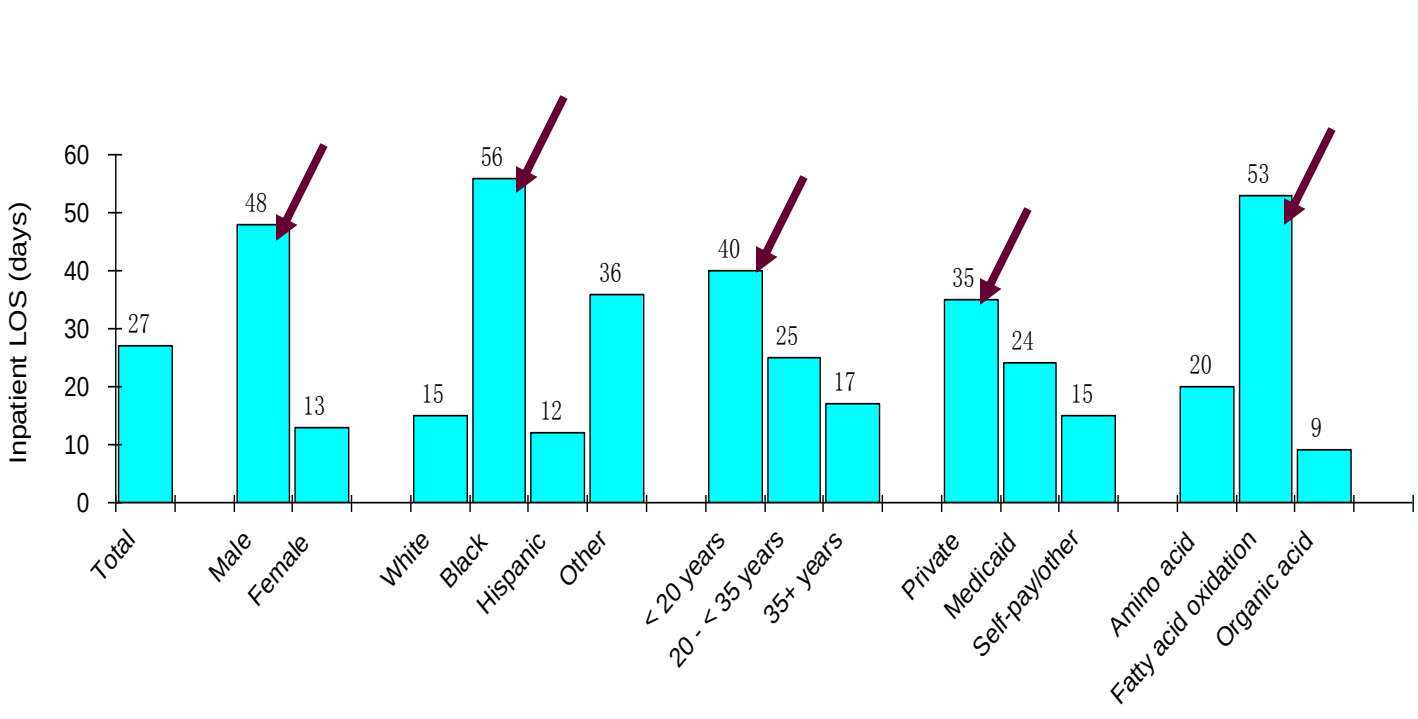

Figure 4. Average inpatient length of stay for the inherited metabolic disorder (IMD)-related hospitalizations during the first three years of life by patient characteristics among children born in New York State in 2006-2007 and identified with IMDs through newborn screening

Results

Table 3. Inherited metabolic disorder (IMD)-related emergency department (ED) revisits or re-hospitalization during the first three years of life by patient characteristics among children born in New York State in 2006-2007 and identified with IMDs through newborn screening

Characteristics	Total patients (2+ encounters) N (Row %)	Revisits within 30 days N (Col. %)	Revisits > 30 days N (Col. %)
Total	25 (100.0)	7 (28.0)	18 (72.0)
Maternal race/ethnicity			
White	10 (40.0)	2 (20.0)	8 (80.0)
Black	8 (32.0)	3 (37.5)	5 (62.5)
Other	7 (28.0)	2 (28.6)	5 (71.4)
Maternal age			
< 20 years	6 (24.0)	2 (33.3)	4 (66.7)
>=20 years	19 (76.0)	5 (26.3)	14 (73.7)
Payment type			
Public/Medicaid	18 (72.0)	5 (27.8)	13 (72.2)
Other	7 (28.0)	2 (28.6)	5 (71.4)
Metabolic disease type			
Amino acid disorders	3 (12.0)	0 (0.0)	3 (100.0)
Fatty acid oxidation disorders	10 (40.0)	3 (30.0)	7 (70.0)
Organic acid disorders	12 (48.0)	4 (33.3)	8 (66.7)

Summary

- Administrative databases (NBS and hospital discharge data) were used to estimate health services utilization through data linkage.
- Among 2006 & 2007 New York birth cohort, 180 children were identified having confirmed inherited metabolic disease (IMD) with an annual incidence rate of 3.69 per 10,000 births.
- 82% utilized healthcare facilities; 50% encounters were IMD related, 34% had 2 or more IMD related encounters during the 3-year follow-up period.
- Acute care encounters were more frequent and re-hospitalization rates were higher for children of younger mothers or non-Hispanic Black mothers, Medicaid recipients, or children with fatty acid oxidation disorders..
- Children of non-Hispanic black mothers or younger mothers were more likely to have multiple encounters within 30 days compared to children of mothers of other races/ethnicity groups or older mothers, respectively.

Limitations

- Unavailability of patient names in hospital discharge data might result in incorrect matches or non-matches and thus, lead to misclassification of the healthcare encounters
- Lost to Follow-up
- Small numbers in stratified analysis due to the rareness of the disorders

Collaborators/Key Players

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