Hospital Admissions, Mortality and Comorbidities Among New York State Sickle Cell Patients, 2005-2013

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Abstract: Analyses of administrative and large data sources in Sickle Cell Disease (SCD) can answer questions not suitable for prospective study but have been hampered by lack of validated methods to adjust for individual comorbidities and lack of baseline utilization data over time. We sought to develop a database to characterize inpatient SCD care across New York State and generate a re-weighted sickle-cell specific Charlson Comorbidity index (S-CCI) for use in future large data SCD research. We identified 18,541 individual SCD patients admitted to New York State hospitals between 2005 and 2013 from the SPARCS database. We present data from both a randomly selected derivation cohort, used to develop the S-CCI and a validation cohort, The S-CCI resulted in small improvements in model fit and discrimination while using fewer covariates, allowing a more parsimonious model. Despite being the most common comorbidity, chronic pulmonary disease was not predictive of mortality. Mortality per hospitalization was 0.61%. Many patients (32%) were admitted only once during the nine year period. However, the majority was admitted more frequently with over 15% of patients being admitted more than once per year.

Keywords: Sickle cell disease■Hospital admission■Mortality■SPARCS■Charlson comorbidity index

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INTRODUCTION

Despite being amongst the most common genetic disorders in the world, mortality, morbidity and hospital admissions remain poorly characterized for sickle cell disease (SCD) patients. SCD is a genetic, autosomal recessive hematological disorder caused by mutations on the β globin chain. In the United States, 72,000 to 98,000 individuals have SCD.[1] Affected individuals' red blood cells are repetitively damaged by polymerization of hemoglobin under de-oxygenated conditions.[2] The result is chronic hemolysis, vaso-occlusion and progressive organ injury. Many medical problems are more common in patients with SCD than the general population including infection at higher rates and severity than in the general population, stroke and cognitive impairment, and premature organ failure. Many patients with SCD also suffer from pain crises that can lead to frequent hospitalizations. Studies have shown that sickle cell patients have longer hospital stays and are at higher risk of complicated outcomes, mortality,[3] and higher cost of care in inpatient hospital settings than general hospital populations.[4] SCD is known to confer shorter life expectancy and a history of complications such as acute chest syndrome and renal failure predict early death.[5]

One contributing factor to our lack of understanding of SCD is the paucity of databases and statistical methods to study this population. A recent analysis of California emergency department visits showed that highest utilization group accounted for nearly half of visits, identifying a potential target for intervention.[6] However, models specific to episodes of acute illness requiring hospital admissions their outcomes are lacking.

Administrative datasets are powerful because they provide large, representative sample sizes at a relatively low cost, though they are limitations posed by disease status misclassification, linking patient encounters across insurance providers, states and territories, and lack of clinical and sociodemographic indicators.[7] The New York State Department of Health's Statewide Planning and Research Cooperative System (SPARCS) Limited dataset is a comprehensive all payer data reporting system established in 1979 that collects administrative data on patients seen within New York State (NYS). We utilized SPARCS data from 2005 to 2013 to provide insight in to SCD morbidity and hospitalization patterns.

Adjustment for individual comorbidities is an essential step when using administrative datasets to describe patterns of health service utilization and draw causal inferences between exposures and outcomes of interest. The Charlson Comorbidity Index (CCI) is a weighted method of stratifying patients' risk of death based on comorbid conditions. Originally developed in 1984 to predict 1, 5 and 10 year mortality among breast cancer patients,[8] the CCI and subsequent modifications are used widely today to risk-adjust patients' likelihood of mortality (inpatient, 30-day, and 1-year), re-admission, and cost of care. Charlson et al. assigned patients scores based on the presence of certain pre-existing comorbid conditions as

Table 1. Visit-specific derivation and validation cohort characteristics for sickle cell patients' inpatient visits in New York State Hospitals (2005-13).

	Derivation cohort 9270 patients 67,293 visits		Validation cohort 9271 patients 65,524 visits		Full NYS cohort 18,541 patients 132,817 visits	
	N	%	N	%	N	%
Male	31,288	46.50	30,902	47.16	62,190	46.82
Median age (Median, IQR)	27	19, 40	27	18, 39	27	18,40
Visits per patient over 9 years						
1	2967	32.01	3027	32.65	5994	32.33
2 - 5	3608	38.92	3567	38.47	7175	38.70
6 - 10	1278	13.79	1224	13.20	2502	13.49
11 - 15	485	5.23	522	5.63	1007	5.43
16 - 25	419	4.52	451	4.86	870	4.69
> 25	535	5.77	480	5.18	1015	5.47
Charlson comorbidities						
Myocardial infarction	873	1.30	1034	1.58	1907	1.44
Congestive heart failure	2950	4.38	3126	4.77	6076	4.57
Peripheral vascular disease	633	0.94	515	0.79	1148	0.86
Cerebrovascular disease	1809	2.69	1724	2.63	3533	2.66
Dementia	177	0.26	199	0.30	376	0.28
Chronic pulmonary disease	12,225	18.17	12,503	19.08	24,728	18.62
Connective tissue disease	790	1.17	955	1.46	1745	1.31
Peptic ulcer disease	411	0.61	372	0.57	783	0.59
Mild liver disease	1911	2.84	1822	2.78	3733	2.81
Diabetes without complications	4050	6.02	3615	5.52	7665	5.77
Diabetes with complications	710	1.06	623	0.95	1333	1.00
Paraplegia and hemiplegia	369	0.55	384	0.59	753	0.57
Renal disease	3727	5.54	4030	6.15	7757	5.84
Cancer	1055	1.57	1019	1.56	2074	1.56
Moderate/severe liver disease	414	0.62	378	0.58	792	0.60
Metastatic carcinoma	338	0.50	357	0.54	695	0.52
HIV/AIDS[a]	N/A	N/A	N/A	N/A	N/A	N/A
Quan Charlson Comorbidity Index (Q-CCI)						
0	48,111	71.49	46,026	70.24	94,137	70.88
1	12,245	18.2	12,182	18.59	24,427	18.39
≥ 2	6937	10.31	7316	11.17	14,253	10.73
Inpatient mortality	386	0.57	421	0.64	807	0.61

[a]*Data on patients' HIV/AIDS status was not available in this dataset.*

indicated by diagnosis codes documented in their medical record at each hospital visit. In the original CCI, each of several comorbidities (see Table 1) was weighted based on the strength of its association with mortality.[8] Patients' CCI score is calculated by summing the weights for each of their comorbidities. In 2011, the CCI was refined and re-weighted by Quan et al. to better reflect how advances in disease treatment and management changed the

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