**Sickle cell disease (SCD)** is a genetic disorder in which hypoxia produces polymerisation of sickle hemoglobin (HbS). This triggers multiple downstream effects of red cell distortion (sickling), hemolysis, occlusion of blood flow, and inflammation leading to significant end-organ damage and ischemic tissue injury that accumulates over a patient’s lifetime.

Fatigue, pain (vaso-occlusive crisis, acute chest syndrome) and other clinical complications are under-recognized, undertreated and associated with early death. To mitigate these complications and reduce mortality, treatment with hydroxycurea is recommended.

Prior research has demonstrated that the pediatric SCD population is more likely to have access to quality care (hematologists and other specialized care) while the adult SCD population has notable barriers to access of quality care that includes varying insurance coverage and specialist availability.

Previous literature has shown the challenges faced by SCD patients in their transition from pediatric to adult care, but did not describe key treatments or services surrounding this critical transition.

**OBJECTIVE**

- To describe the outpatient and inpatient healthcare resource utilization patterns in a large cohort of SCD patients in the US.

**METHODS**

**Study Design and Data Sources**

- This is a retrospective administrative claims database analysis among a sample of Commercially- and Medicaid-insured populations in the US.
- These databases provide detailed outcomes measures including outpatient pharmacy claims, resource utilization and associated costs for healthcare services delivered in both inpatient and outpatient settings for over 41 million individuals.
- For this study, de-identified US administrative claims data from January 1, 2009 through December 31, 2014 were extracted from the Truven Health MarketScan® Commercial Claims Database and Medicaid Database.

**Patient Selection**

- For each year (2009-2014), the following inclusion/exclusion criteria were applied:
  - Inclusion: Patients with SCD
  - Either 1 inpatient or 2 outpatient (different days) non-diagnostic claims for SCD (ICD-9 code 282.41, 282.42 or 282.6x).
  - Continuous enrollment in medical and pharmacy benefits for year of SCD identification
  - 1 year of continuous enrollment in medical and pharmacy benefits prior to SCD identification

**Outcomes**

- Utilization of the following healthcare services was measured in the year prior to SCD identification:
  - Inpatient [IP] admissions
  - Emergency department (ED) visits
  - Specialist visits (hematologist/oncologist, primary care)
  - Primary care includes internal medicine, medical doctor, osteopathic, family practice, genetic, preventative and pediatrics
  - Oncologists were included with hemato-oncologists as they generally have expertise as a secondary specialty, which is not able to be captured in this database.

- Hydroxycurea (HU) use

- Any use
- Adherence as determined by the medication possession ratio (MPR), and those with 30 days of continuous use based off days supplied in outpatient pharmacy claims
- Averages across all years were reported to provide a comprehensive overview of resource utilization across all age groups.

- All results were reported by age group (<6, 6-11, 12-17, 18-30, 31-44, ≥45), and payer (commercial, Medicaid).

- Medication data indicate drugs administered in a physician’s office or filled by a pharmacy, and do not include drugs used in an outpatient setting.

- These data highlight the importance of ongoing initiatives, such as those lead by the ASH SCD Coalition, to increase access to SCD care, across all patients in the US. The need for Medicaid programs focused on SCD is also highlighted by the data.

**LIMITATIONS**

- The MarketScan® Research Databases represent a sample of individuals with employer- and Medicaid sponsored health insurance. Thus, findings from this study may not be generalizable to populations with other forms of insurance or the uninsured.

- Data and identification of a diagnosis utilized ICD-9-CM codes diagnoses only reflect the claims submitted by the physicians for reimbursement.

- Potential of underestimating the proportion of patients who visited a hematologist/oncologist is present as we were unable to identify nurse practitioners working in those settings who billed separately for their services. The proportion of claims with a missing/unspecified provider greatly varied between payers (20% for Medicaid and 3% for Commercial). Therefore, the proportion of patients who visited a hematologist/oncologist was likely underestimated.

- The need for Medicaid programs focused on SCD is also highlighted by the data.

**RESULTS**

**Table 1. Annual Cohorts**

<table>
<thead>
<tr>
<th>Year</th>
<th>Commercial</th>
<th>Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>2,619</td>
<td>4,807</td>
</tr>
<tr>
<td>2010</td>
<td>2,748</td>
<td>5,055</td>
</tr>
<tr>
<td>2011</td>
<td>2,929</td>
<td>4,963</td>
</tr>
<tr>
<td>2012</td>
<td>3,285</td>
<td>5,189</td>
</tr>
<tr>
<td>2013</td>
<td>2,752</td>
<td>6,649</td>
</tr>
<tr>
<td>2014</td>
<td>2,969</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Commercial</th>
<th>Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>2,619</td>
<td>4,807</td>
</tr>
<tr>
<td>2010</td>
<td>2,748</td>
<td>5,055</td>
</tr>
<tr>
<td>2011</td>
<td>2,929</td>
<td>4,963</td>
</tr>
<tr>
<td>2012</td>
<td>3,285</td>
<td>5,189</td>
</tr>
<tr>
<td>2013</td>
<td>2,752</td>
<td>6,649</td>
</tr>
<tr>
<td>2014</td>
<td>2,969</td>
<td></td>
</tr>
</tbody>
</table>

- Medication data indicate drugs administered in a physician’s office or filled by a pharmacy, and do not include drugs used in an outpatient setting.

- A marked increase in the proportion of patients with ≥3 ED visits compared to Commercial patients and this trend was observed across age groups but was more marked in patients ≥30 years.

- A marked increase in the proportion of patients with ≥3 ED visits was observed at age 18-30 years in both payer populations.

- Medication data indicate drugs administered in a physician’s office or filled by a pharmacy, and do not include drugs used in an outpatient setting.

- A marked increase in the proportion of patients with ≥3 ED visits compared to Commercial patients and this trend was observed across age groups but was more marked in patients ≥30 years.

- A marked increase in the proportion of patients with ≥3 ED visits was observed at age 18-30 years in both payer populations.

- Under 40% of patients (all genotypes) had a claim for HU across payers and age groups and under 10% had 90 days of continuous HU use across payers and most age groups.

- The proportion of patients with any HU used peaked at ages 18-30 years in both payer populations; however, patients in this age group were least likely to use HU continuously for at least 90 days.

- In all age groups, Commercial patients were also more adherent (determined by MPR) to HU treatment compared with Medicaid patients.

**CONCLUSIONS**

- Claims for hematologist/oncologist visits were strikingly low among Medicaid patients. Further research is needed to determine if this represents differential access or if this is related to different clinic structures or billing practices.

- Access to specialty care is the poorest during the transition from pediatric to adult (18-30 age group) care for both Commercial and Medicaid patients.

- Higher ED and IP utilization in conjunction with HU compliance may indicate greater disease severity and/or unmet needs among adult (≥18 age group) Medicaid SCD patients.

- These data highlight the importance of ongoing initiatives, such as those lead by the ASH SCD Coalition, to increase access to SCD care, across all patients in the US. The need for Medicaid programs focused on SCD is also highlighted by the data.

- The Medicaid population consistently had a larger proportion of patients with an inpatient admission and higher number of IP admissions compared with the Commercial population with the difference more marked in adults (≥30).

- Compared with patients in Medicaid, a markedly larger proportion of Commercial patients had a hematologist/oncologist visit, with the same finding observed across all age groups.

- A marked drop in the proportion of patients with a hematologist/oncologist visit observed in Commercial patients at age 18-30 years.