Sickle Cell Disease: An Issue of Health Equity?

2017 NMQF Leadership Summit on Health Disparities and Spring Health Braintrust
Sickle Cell Disease Symposium
April 25, 2017

Mary Hulihan, DrPH
Centers for Disease Control and Prevention/Division of Blood Disorders
Inspired by the recognition of healthcare disparity—both in the clinical care of persons with SCD and in the research efforts directed toward understanding and treating this condition.

Despite the substantial advances in the treatment of SCD which have occurred in the last 30 years, there is a lack of equity in the quality of clinical care provided to patients with SCD as evidenced by a failure to apply knowledge obtained from research to much of the at-risk population.

Hassell, 2008
## Funding

<table>
<thead>
<tr>
<th>Variable</th>
<th>SCD</th>
<th>Cystic Fibrosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>US prevalence&lt;sup&gt;a&lt;/sup&gt;</td>
<td>80 000</td>
<td>30 000</td>
</tr>
<tr>
<td>Federal support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NIH fiscal-year 2004 funding, in millions of dollars&lt;sup&gt;b&lt;/sup&gt;</td>
<td>90</td>
<td>128</td>
</tr>
<tr>
<td>NIH funding per person with disease, $</td>
<td>1125</td>
<td>4267</td>
</tr>
<tr>
<td>No. of federal grants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of grants funded in 1968&lt;sup&gt;c&lt;/sup&gt;</td>
<td>22</td>
<td>65</td>
</tr>
<tr>
<td>No. of grants funded in 1972, after Sickle Cell Anemia Control Act&lt;sup&gt;d&lt;/sup&gt;</td>
<td>215</td>
<td>80</td>
</tr>
<tr>
<td>No. of grants funded in 2004</td>
<td>331</td>
<td>459</td>
</tr>
<tr>
<td>Private philanthropic support, $</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cystic Fibrosis Foundation 2003 annual revenue&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
<td>152 231 000</td>
</tr>
<tr>
<td>Sickle Cell Disease Association of America 2003 annual revenue&lt;sup&gt;f&lt;/sup&gt;</td>
<td>498 577</td>
<td></td>
</tr>
<tr>
<td>Revenue per person affected with disease</td>
<td>6</td>
<td>5074</td>
</tr>
<tr>
<td>Total NIH and private support, in millions, $</td>
<td>90.4</td>
<td>280.2</td>
</tr>
<tr>
<td>Total support per person affected with disease, $</td>
<td>1130</td>
<td>9340</td>
</tr>
</tbody>
</table>

<sup>a</sup> Adjusted for laypeople and health professionals (census-adjusted).

<sup>b</sup> National Institutes of Health (NIH).

<sup>c</sup> Number of public service grants.

<sup>d</sup> National Institutes of Health (NIH).

<sup>e</sup> Cystic Fibrosis Foundation.

<sup>f</sup> Sickle Cell Disease Association of America.
Table 2. All-cause 30-day readmissions ranked by conditions with the highest readmission rates,*
U.S. hospitals, 2010

<table>
<thead>
<tr>
<th>Rank</th>
<th>Principal diagnosis for index hospital stay **</th>
<th>Number of index stays</th>
<th>30-day all-cause readmissions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Number of readmissions</td>
</tr>
<tr>
<td>1</td>
<td>Sickle cell anemia</td>
<td>87,326</td>
<td>27,837</td>
</tr>
<tr>
<td>2</td>
<td>Gangrene</td>
<td>33,786</td>
<td>10,693</td>
</tr>
<tr>
<td>3</td>
<td>Hepatitis</td>
<td>37,480</td>
<td>11,593</td>
</tr>
<tr>
<td>4</td>
<td>Disease of white blood cells</td>
<td>54,861</td>
<td>16,771</td>
</tr>
<tr>
<td>5</td>
<td>Chronic renal failure</td>
<td>17,394</td>
<td>4,766</td>
</tr>
<tr>
<td>6</td>
<td>Systemic lupus erythematosus and connective tissue disorders</td>
<td>18,850</td>
<td>5,123</td>
</tr>
<tr>
<td>7</td>
<td>Mycoses</td>
<td>23,026</td>
<td>6,222</td>
</tr>
<tr>
<td>8</td>
<td>HIV infection</td>
<td>34,958</td>
<td>9,230</td>
</tr>
<tr>
<td>9</td>
<td>Screening and history of mental health and substance abuse</td>
<td>60,417</td>
<td>15,695</td>
</tr>
<tr>
<td>10</td>
<td>Peritonitis and intestinal abscess</td>
<td>25,219</td>
<td>6,315</td>
</tr>
</tbody>
</table>

Elixhauser, 2013
Figure 1. All-cause mortality rates for the sickle cell disease population identified through population-based surveillance (2004 through 2008), the African American population (2008),* and all populations (2008)* California and Georgia

*Paulukonis, 2016
Other examples

- 50% of the SCD caregivers reported a yearly household income of $20,000 or less
- ~50-70% are Medicaid beneficiaries
- For similar surgical procedures:
  - Younger age
  - Higher risk of complications
  - Longer lengths of stay
  - Higher costs
- Discrepancies in monitoring transfusion outcomes
- Longer ED wait times for analgesic administration and care from a provider

Why is there still uncertainty about whether or not SCD is an issue of health equity?

- Conversations about race and social constructs
- Clinical quality measures and coordinated process for adoption
- Data
  - National registry
  - CDC’s Sickle Cell Data Collection project

Tanabe, 2012; Smith, 2006
Collect, synthesize and disseminate multi-source, population-based, longitudinal data for people with sickle cell disease (SCD)

1. Establish a health profile of the SCD population
2. Track changes in SCD outcomes over time
3. Ensure credible, scientifically sound information to inform standards of care
4. Inform policy and health care practices

Improve quality of life, life expectancy, and health among those living with SCD

www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html
SCDC Infrastructure

Newborn Screening Data 2004–2014
Hospital Discharge Data 2004–2014
Medicaid Claims Data 2004–2014
Emergency Department Data 2004–2014
Vital Records Data 2004–2014
Clinic Case Reports
INDEX
Case File
Of the 615 people with SCD who lived in California and Georgia, nearly half did not have SCD listed as a cause of death on their death certificate.
SCDC Next Steps

- Disseminate findings
  - Peer-reviewed publications, scientific presentations, social media, policy briefs
  - Maternal mortality, high ED utilization, causes of mortality, personal stories, transition from pediatric to adult care

- Include additional states
  - Establish training institute to help other states develop population-based surveillance system for sickle cell disease

- Secure additional sustained support and funding
Thank you!

ibx5@cdc.gov

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
Telephone, 1-800-CDC-INF0 (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov Web: www.cdc.gov