Sickle Cell Disease
Integrated Care Models: Outpatient and Inpatient
National Minority Quality Forum
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Disclosures

- Advisory Board for Pfizer – Council for Change
- Cerus Advisory Board
- Novartis Advisory Board
Children and adults with sickle cell disease, a complex chronic illness with high health care resource utilization, require comprehensive care across the lifespan

- Patients, Families, Providers, Health Systems
  - Pediatric model of care
  - Adult model of care
- Community-based organization
- Private industry
Changes in medical care which may increase life-expectancy in individuals with sickle cell disease

- Infection prevention - penicillin prophylaxis, vaccinations
- Comprehensive care and parental education
- Newborn screening
- Improved complication diagnosis and management
- Transfusion therapy
- Hydroxyurea therapy
- Bone marrow transplantation
Sickle Cell Disease and Pain

- Inconsistent use of nomenclature
- Limited disease severity definitions and predictors
- Limited understanding of underlying pathophysiology
- Limited assessment tools
- Supportive care approach to treatment for acute events
- Limited understanding of chronic pain
- Wide variability in response to therapy
- Complex psychosocial and societal issues

Ellen Weinstein: https://well.blogs.nytimes.com/2014/10/20/sickle-cell-disease-children/?src=twr&_r=0
December 2006

Sickle Cell Disease Patients in U.S. Hospitals, 2004

Claudia A. Steiner, M.D., M.P.H. and Jeffery L. Miller, M.D.

Hospitalizations

- 2004 113,098 (83,149 adults) hospitalizations
- Cost: $488M annually
“For an average patient with SCD reaching age 45, total undiscounted health care costs were estimated to reach $953,640. At a 3% discount rate, the present value of lifetime costs is $460,151. Median lifetime costs were estimated at $392,940 (undiscounted) and $186,406 (discounted).”

Sickle Cell Disease: Cost of Health Care

TABLE III. SCD- and non-SCD-Related Emergency Department and Inpatient Hospitalization Use per Patient-Year, by Age

<table>
<thead>
<tr>
<th>Age at 1st claim</th>
<th>SCD-related</th>
<th>Non-SCD-related</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ED visits</td>
<td>Inpt. stays</td>
</tr>
<tr>
<td>00–09</td>
<td>0.39</td>
<td>0.84</td>
</tr>
<tr>
<td>10–19</td>
<td>0.59</td>
<td>1.36</td>
</tr>
<tr>
<td>20–29</td>
<td>1.37</td>
<td>1.83</td>
</tr>
<tr>
<td>30–39</td>
<td>1.36</td>
<td>2.34</td>
</tr>
<tr>
<td>40–49</td>
<td>1.30</td>
<td>1.88</td>
</tr>
<tr>
<td>50–64</td>
<td>0.55</td>
<td>1.09</td>
</tr>
<tr>
<td>Average</td>
<td>0.92</td>
<td>1.56</td>
</tr>
</tbody>
</table>

SCD, sickle-cell disease; ED, emergency department; Inpt., inpatient.

## Sickle Cell Disease: Care Coordination Needs

<table>
<thead>
<tr>
<th>Health Care Service</th>
<th>Outpatient Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine Hematology</td>
<td>3 – 4 times per year</td>
</tr>
<tr>
<td>Routine Pediatric</td>
<td>1 – 3 times per year</td>
</tr>
<tr>
<td>Radiology for TCDs</td>
<td>1 – 2 times per year</td>
</tr>
<tr>
<td>Immunizations</td>
<td>At least annually</td>
</tr>
<tr>
<td>Dental</td>
<td>At least annually</td>
</tr>
<tr>
<td>Hydroxyurea Monitoring</td>
<td>At least 4 times per year</td>
</tr>
<tr>
<td>Chronic Transfusion Therapy</td>
<td>12 - 24 visits per year</td>
</tr>
<tr>
<td>Pulmonary, Cardiology, Neuro, BH</td>
<td></td>
</tr>
<tr>
<td>URGENT CARE</td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
</tr>
</tbody>
</table>
System Challenges

- High “no show” rates for outpatient visits
- Acute pain management in ED requiring “fast” triage mechanisms and protocols for analgesics and opioid administration
- Unpredictable length of stay for specific complaints
- Relatively high readmission rates
- Difficulty with access to and adherence to outpatient primary and routine hematology care across the lifespan
- Poor transition of care from pediatric- to adult-focused care
Patient / SCD Community Challenges

- Stigma associated with acute and chronic pain management
- Challenges related to opioid prescription tracking
Care Model

- Multidisciplinary, comprehensive care that is accessible, well-coordinated and evidence-based protocol driven
- Integrated behavioral health
- Psychosocial support in all health care settings / home
- Health systems management
- Support for academic and vocational goals
- Integrative health component
- Community-based component
CHOP CSCC Outpatient Team

- Program Director
- Nurse Coordinator, Nurses (2)
- Program Coordinator
- Social workers (3.5)
- Behavioral Health Specialist
- Disease Educator / Education Specialist
- Community Health Worker
- Nurse Practitioners (3)
- Physicians (11 attending physicians)
- Research study coordinator
- General pediatricians, Subspecialists, Surgeons
- Ancillary care services
- Integrative health program
- OVR/MINT Team
- Dental care
SCDAA’s Get Connected
Sickle Cell Disease Registry Initiative

➢ Establish a network to distribute information related to clinical care, research, health services, health policy, and advocacy
  ● Children, adults, and families living with sickle cell disease and sickle cell trait
  ● SCDAA member organizations, and other community-based organizations
  ● Health care providers and other stakeholders

➢ Establish a mechanism to support care coordination

➢ Develop online communities for information sharing and psychosocial support

CDC Public Health Grand Rounds: Improving the Lives of People with Sickle Cell Disease:
Get Connected Activities and Early Results

➢ Identify, educate, and train community health workers
  ● Over 40 community health workers trained
➢ Connect children and adults to services if not connected
➢ Enroll children and adults with sickle cell disease in Get Connected
  ● Over 4,000 children and adults enrolled in 15 states

CDC Public Health Grand Rounds: Improving the Lives of People with Sickle Cell Disease:
Sickle Cell Disease: Solutions

- Integrated models of health care incorporating patient and community focusing on improving health and quality of life outcomes
- Systems to track patients, track health care utilization, identify service gaps
- Effective disease-modifying therapies
- “Universal” cure
- Health policy development reflecting chronic disease population needs
TOGETHER WE WILL BREAK THE SICKLE CYCLE AND FIND A CURE

STAY INVOLVED

Get Connected

Become an Advocate

Technical Training

Find a CBO

STAY CONNECTED