Sickle Cell Disease in South Carolina
Stakeholder and Advocacy Meeting
January 28, 2016

Julie Kanter, MD
Director of Sickle Cell Disease Research
Assistant Professor
Medical University of South Carolina
Agenda

• What is happening now in South Carolina?
• Current plans to develop a comprehensive state (SC) sickle cell disease plan
• How can we improve the development of a coordinated case management state plan?
• Time Line for year 1
• Initiate plans for a bundled/shared savings program for patients and partners of the SC network
What is Sickle Cell Disease?

• Sickle Cell Disease (SCD) is the most common inherited blood disorder in the United States
• Affects approximately 100,000 individuals
• More than 98% of affected persons in the US are African-American, African or Black American
• Highest cause of 30-day readmission in many hospitals in South Carolina
Why is Sickle Cell Disease hard?

• Patients are living longer with SCD
• Adults are highly underserved and often live in rural areas where they do not have access to specialized care
• There are not enough physicians trained to care for persons with SCD
• The majority of primary care and emergency department physicians have not received education in SCD management.
• PCPs are often unwilling or uncomfortable with SCD patients
• As a result of these systemic issues, adults with SCD are often forced to rely on urgent care treatment, which is not disease or patient-focused.
What is happening in South Carolina?

• Sickle Cell Disease is highly prevalent in SC  
  --Recent data estimate up to 4500 persons with SCD
• Very few providers willing/able to take patients with SCD >18
• Lack of care coordination for all patients with sickle cell disease (of all ages)
• Limited post-acute care services, follow-up for patients of all ages
• Lack of quality improvement in SCD
• Lack of statewide protocols
• Pharmacy/Prescription ordering is poorly coordinated and often works against the patient to improve care
• Care coordinators/Case Managers are not coordinated and likely underutilized
Where are SCD patients receiving acute care?

<table>
<thead>
<tr>
<th>Region</th>
<th>Patients, No.</th>
<th>Encounters per Patient, No. (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>ED</td>
</tr>
<tr>
<td>Total</td>
<td>2313</td>
<td>2.90 (2.63-3.17)</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-9</td>
<td>473</td>
<td>1.08 (0.97-1.18)</td>
</tr>
<tr>
<td>10-17</td>
<td>272</td>
<td>1.31 (1.12-1.50)</td>
</tr>
<tr>
<td>18-30</td>
<td>713</td>
<td>4.92 (4.24-5.60)</td>
</tr>
<tr>
<td>31-45</td>
<td>478</td>
<td>3.77 (3.05-4.84)</td>
</tr>
<tr>
<td>46-64</td>
<td>290</td>
<td>1.75 (1.33-2.17)</td>
</tr>
<tr>
<td>≥65</td>
<td>87</td>
<td>0.30 (0.19-0.41)</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowcountry</td>
<td>808</td>
<td>3.83 (3.23-4.44)</td>
</tr>
<tr>
<td>Midlands</td>
<td>613</td>
<td>2.44 (2.08-2.80)</td>
</tr>
<tr>
<td>Pee Dee</td>
<td>541</td>
<td>2.74 (2.20-3.28)</td>
</tr>
<tr>
<td>Upstate</td>
<td>351</td>
<td>1.80 (1.39-2.21)</td>
</tr>
<tr>
<td>Expected payer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>1057</td>
<td>2.84 (2.46-3.22)</td>
</tr>
<tr>
<td>Medicare</td>
<td>559</td>
<td>4.57 (3.77-5.36)</td>
</tr>
<tr>
<td>Private</td>
<td>486</td>
<td>1.62 (1.30-1.94)</td>
</tr>
<tr>
<td>Self-pay/uninsured</td>
<td>211</td>
<td>1.74 (1.44-2.05)</td>
</tr>
</tbody>
</table>

Schlenz et al, Needs Assessment of Sickle Cell Disease in South Carolina, Public Health Reports, in press
Are patients in South Carolina getting appropriate post-acute follow up?
Are patients in South Carolina getting appropriate post-acute follow up?
Current improvement process plans

• National Maternal and Child Health Workforce Development Grant
  • CO-Leads: Dr. Kanter and Jessica Drennan MSW
• SC2 Pilot funding (Duke Endowment)
  • PI: Dr. Julie Kanter
  • Project Coordinator: Katherine Williams
• State Sickle Cell Disease Study Committee
  • Representative John King, Co-Chairman
National MCH Workforce Development Grant

• CO-Leads: Dr. Kanter and Jessica Drennon DHEC
• Goals:
  • Improving access to care,
  • Using quality improvement tools to drive health transformation,
  • Fostering systems integration and harmonization within public health and across organizational boundaries
  • Furthering effective change management, collective action and individual leadership skills that will lead to health improvement of specific populations.
South Carolina Sickle Cell Disease Access to Care Pilot Program (SC²): Building a statewide program though collective impact

• The SC² program is designed to increase access to care for all persons with SCD in South Carolina
• SC² includes both specialty and primary care
• Uses a hub-and-spokes care delivery model using a collective impact approach.
  • In-person clinics
  • Telehealth clinics
• This approach will both harness the resources of the state to approach SCD and will also use a technology-based approach to increase education of providers
Sickle Cell Disease State Committee

• Sickle Cell Disease State Committee: created and charged with better serving adults with sickle cell disease (SCD), health care providers, and the public about State care and treatment.

• The committee is to examine existing services and resources available to children with the disease as well as adults with the disease.

• Additionally, the committee is to establish partnerships with institutions, and communities, a statewide network of service providers for adults with the disease; a comprehensive education and treatment program for adults, as well as establish standardized treatment and emergency room protocols.
designed to connect the dots and fill in the gaps in care
Concrete Plans:

• 1. Develop a statewide sickle cell disease protocol for treatment based on the national NHLBI sickle cell disease care guidelines

• 2. Work with our CMS partners to obtain approval for this protocol
  - What does this mean?
  - How can we make this happen?

• 3. Discuss how we can improve and coordinate a case management program
  - MCO
  - Foundations
  - Hospitals

• 4. Discuss how we can build a shared savings program

• 5. Develop/utilize a sickle cell disease registry for individualized care plans for patients seeking acute care (scdcare.com)
Methods:

People:
- SC² program coordinator to lead patient navigation, outreach clinic scheduling, coordinate meetings and educational symposiums
- SC² social worker to identify resources, provide social service support, insurance management, and address disease specific concerns.
- MD will Initiate weekly outreach clinics at identified sites to increase patient access to specialized SCD specific care and develop individualized education and treatment plans for affected patients

Information Technology
- Utilize an SC² SCD registry to enhance access to patient-specific individualized treatment plans for providers throughout the state
- Data assessment for quality improvement (Care Coordination Institute)
- Use telehealth for acute care needs at the individual medical homes
- ECHO program for educational conferences
Methods:

Education

• Initiate monthly teleconferences based on the ECHO model to bring the interdisciplinary expertise of specialists to the local providers DHEC-funded quarterly symposiums for statewide provider education
• Quality Assessment with feedback

YEAR 1:

• Hire personnel and Initiate work in 2 outside sites (already in process)
• Initiate stakeholder/advocacy meetings
• Begin to develop and register patients with individualized plans
• Continue symposiums
• Quality tracking
• Website
• Begin monthly education conferences in June using ECHO model
Measurable Outcomes:

• **Hydroxyurea:** Enhanced access to disease modifying medications: Hydroxyurea (HU) is currently the only FDA-approved disease-modifying drug for SCD.
  • Recent data demonstrates that we can expect an annual decrease in cost of $6,000/patient who take the medication.

• **Improving transfusion utilization:**
  • Stroke is one of the biggest complications seen in SCD. Blood transfusions are indicated for stroke prevention in those at-risk with SCD or for acute treatment of severe organ dysfunction
  • Providers without SCD training/knowledge often transfuse unnecessarily
  • Unnecessary transfusions cause complications and unnecessary expense.
  • Each unit not transfused saves up to $500 per event and decreasing the risk of blood exposure

• Decreasing hospitalizations and ER visits
SC$^2$ Sustainability

- Work with the centers for CMS and the state MCOs to develop a sustainable, reimbursable model for care in SCD
- Utilize the current payment structure to demonstrate that the SC$^2$ clinical program will generate sufficient revenue at individual outreach clinic locations and save on urgent care costs -- sufficient to support the continued efforts of the program
- Education of local providers
  - Previous programs have demonstrated that situated learning and practice are supported by collaborative learning, coaching, and mentoring which will be part of SC$^2$
  - The ECHO initiative also showed that disease specific education can be accomplished through iterative practice, feedback, modeling, and mentoring and consultation with interdisciplinary experts and peers.
- Improvement in care of patients with SCD will also lead to the success and sustainability of the project