DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 1: History of SCDC, SCDC Goal Setting, and Existing Infrastructure in Participating States

November 7, 2019
CDC’s Sickle Cell Disease Surveillance History

The Centers for Disease Control and Prevention (CDC) and participating states began sickle cell disease (SCD) surveillance (monitoring) in 2010. SCD surveillance involves collecting information on diagnosis, treatment, and healthcare access for people with SCD in the United States. CDC and participating states developed many educational materials based on this information.

CDC coordinated these efforts as part of the three projects outlined below. All three used similar data sources, but each had a different funding source and amount. These differences influenced the number of participating states.

- https://www.cdc.gov/ncbddd/hemoglobinopathies/surveillance-history.html
- https://www.cdc.gov/ncbddd/hemoglobinopathies/rush.html
- https://www.cdc.gov/ncbddd/hemoglobinopathies/phresh.html
- https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html
Where do people with SCD live and receive their health care?
What can we better understand about the transition from pediatric to adult care?
Are there unique characteristics of Hispanic populations with SCD?
What happens to people with SCD as they age?
How, where, why, and when do people with SCD utilize healthcare services?
Goals and Objectives for SCD Surveillance

- Georgia’s and California’s Experience
  - Planned Outcomes
  - Unplanned Outcomes
- Developing Goals and Objectives
GA and CA Planned Outcomes

- RuSH (2010-2012)
  - Incidence
  - Prevalence
  - Healthcare utilization
  - Feasibility of surveillance (thalassemia and SCD)
  - Publications
GA and CA Unplanned Outcomes (1)

- Statewide collaboration with clinical providers/centers
  - Data collection
  - Analyses and publications
  - Grant proposals
- Collaboration and connection with state agencies
  - Data stewards
  - Medicaid
  - Newborn screening
  - Departments of Public Health
GA and CA Unplanned Outcomes (2)

- Improved infrastructure and access to care (CBOs, clinical care)
  - Grants to increase capacity, transportation, etc.
  - Attention to problems (with data)
  - Data to support new clinical sites (both states)
- State and Federal policy support and changes
  - CA AB 1105
  - Public Health Law 115-327 (SCD and Other Heritable Blood Disorders ... Act of 2018)
  - Increased funding from other agencies
GA and CA Unplanned Outcomes (3)

- Health education
  - Capacity/resources to produce social media, webinars, training modules, Project ECHO implementation for clinicians
  - Videos for those living with SCD and clinicians
  - Outreach materials for distribution by CBOs and online
  - Patient resource tools and websites

- Publications and analyses
  - In collaboration with non-SCD, external researchers
  - Internal or multi-state
Input into Goals and Objectives

- Begin by collecting expertise and opinions
  - (But also begin by collecting data!)
- Broad-based expertise – People with knowledge about:
  - SCD (clinical, lived experience, CBOs)
  - Public health surveillance
  - Data stewards (what’s feasible?)
  - Other disease areas with success (e.g., hemophilia, cystic fibrosis)
  - State agencies (what’s already being done, e.g., newborn screening)
Building from Current Infrastructure

- Starting with What’s in Place
  - Newborn screening
  - State registry system
  - Clinical registries
  - CBO registries or systems
  - Surveillance for other diseases (Reportable? Cancer registry?)
California Surveillance Infrastructure

- 10 years of hemoglobinopathy surveillance
- Developed in Newborn Screening Program
- Data from multiple supportive state agencies
  - Administrative data (hospital discharge, ED)
  - Claims data (Medicaid)
  - Vital records (deaths)
  - Newborn screening (births w/SCD)
  - Clinical records (11 sites)
- Consistent staff/expertise over time
- Part of a larger team (Tracking California)
  - Within state department of public health
(Some) Collaboration Within State

- **Community based organizations**
  - SCDFC
  - Cayenne Wellness
  - Sickle Cell Advisory Council of Northern California
  - Sickle Cell Anemia Awareness of San Francisco

- **Clinical collaborators**
  - UCSF Benioff Children’s Hospital Oakland
  - UCSF Zuckerberg General Hospital San Francisco
  - UCSD Rady Children’s Hospital San Diego
  - UC Davis Medical Center
  - Children’s Hospital Orange County
  - Loma Linda University Hospital
  - Children’s Hospital Los Angeles
  - Center for Inherited Blood Disorders (Orange)
  - Stanford/Lucille Packard (Palo Alto)
  - Martin Luther King Jr. Medical Center (Los Angeles)
  - Valley Children’s Hospital (Fresno)
Use of SCD Surveillance Data and Resources

- Expand SCD surveillance in California
  - New analyses and patient resources
  - Gather more data (Kaiser, Medicare)

- Improve access to care
  - New clinics based on data (with state funding)
  - Funded clinical grants based on pilot data
  - Identifying primary care givers w/SCD populations
  - Support CBOs in outreach and funding

- Health education
  - Materials for those with the disease and others
  - Transition videos
  - Annual reports
  - Webinar series
  - Social media
Use of SCD Surveillance Data and Resources

- Analyses and publications
  - Methodology
  - Mortality
  - Emergency department utilization
  - Maternal mortality
  - Cancer incidence
  - Periods of frequent emergency department utilization
  - End of life acute care utilization
  - Medicaid expansion impact for SCD (submitted)
  - Weather and VOC (in process)
  - Pediatric quality of care indicators (in process)
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DATA SOURCES

• **GA Department of Public Health (DUA, BAA)**
  – Newborn screening
  – Death records
  – Hospital and Emergency Department discharge data (Ga. Hospital Association via GDPH)

• **GA Department of Community Health (DUA)**
  – Medicaid/PeachCare claims
  – State Health Benefit Plan claims

• **Clinical case reports (under public health authority)**
  – Grady Comprehensive Sickle Cell Program
  – Children’s Healthcare of Atlanta Comprehensive Sickle Cell Program

• **Clinical case reports (under DSA)**
  – Augusta University Medical Center Comprehensive Sickle Cell Program
  – Memorial Children’s Hospital Sickle Cell Program
## Cases Identified by Dataset

<table>
<thead>
<tr>
<th>Data Set</th>
<th>Confirmed Cases</th>
<th>Probable Cases</th>
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<tbody>
<tr>
<td>Newborn Screening</td>
<td>730</td>
<td>98</td>
</tr>
<tr>
<td>Augusta University (clinical)</td>
<td>1,218</td>
<td>14</td>
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<tr>
<td>Grady (clinical)</td>
<td>1,661</td>
<td>2</td>
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<tr>
<td>CHOA (clinical)</td>
<td>1,908</td>
<td>242</td>
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<tr>
<td>Medicaid/CHIP</td>
<td>2,986</td>
<td>1,993</td>
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<tr>
<td>State Health Benefit Plan</td>
<td>209</td>
<td>215</td>
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<tr>
<td>Hospital administrative data</td>
<td>3,339</td>
<td>2,147</td>
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<tr>
<td>De-duplicated Total</td>
<td>4,288</td>
<td>3,011</td>
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PAST & CURRENT USES

**Validation Studies**
- Case definition for SCD
- Accuracy of mortality data for SCD identification
- Best sources of data to monitor preventive services
- Identifying transfusions and transfusion reactions
- Multi-site transfusions & complication risk

**Quality of Care/Outcomes**
- Mortality
- Prescriptions filled for hydroxyurea
- Up-to-date immunizations
- Initiation of TCD screening
- Iron overload
- Use of iron chelators
- Comorbidities
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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.