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From Evidence to Practice

- **BENCH**: Can we invent a solution to a health problem?
- **BEDSIDE**: Could the invention work in humans?
- **PATIENTS**: Does it benefit patients?
- **PRACTICE**: Can it be delivered reliably in practice?
- **PUBLIC HEALTH**: Does it improve public health?

SCD Age Related Disparities

Lanzkron, Haywood *Blood* 2010;116:736

Paulukonis et al *Pediatr Blood Cancer* 2017; 64
First NHLBI research program to use Implementation Science to identify and address barriers to quality care in sickle cell disease

Multi-modal, multi-sector strategies promote adoption of research findings into healthcare, to address healthcare disparities

Goals
- Conduct needs based community assessment of barriers to care
- Design studies to address barriers
- Develop SCD Registry
Needs Assessment Basic Survey

- Demographics
- SCD Genotype
- Sickle Cell Disease Self-Efficacy
- Pain Interference

ASCQ-Me

- Pain Episode Frequency
- Pain Episode Severity
- Quality of Care
  - Provider Communication
  - Emergency Department Care
  - Access to routine and
## Individuals with Sickle Cell Disease (N = 440)

<table>
<thead>
<tr>
<th></th>
<th>Female</th>
<th>Male</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td>245 (56)</td>
<td>193 (44)</td>
<td></td>
</tr>
<tr>
<td><strong>Age, n (%)</strong></td>
<td>92 (21)</td>
<td>176 (40)</td>
<td>172 (39)</td>
</tr>
<tr>
<td>15 - 18 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 - 30 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31 - 50 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Race, n (%)(^a)</strong></td>
<td>428 (97.5)</td>
<td>8 (2)</td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hispanic ethnicity, n (%)(^a)</strong></td>
<td>414 (95)</td>
<td>22 (5)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Percentages do not always add up to 100 due to non-responders
### Individuals with Sickle Cell Disease (N = 440)

<table>
<thead>
<tr>
<th></th>
<th>High school graduate or less</th>
<th>Some college/AA</th>
<th>College degree or higher</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head of Household</td>
<td>142 (36)</td>
<td>142 (36)</td>
<td>91 (23)</td>
</tr>
<tr>
<td>educational attainment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation, n (%)</td>
<td>116 (27)</td>
<td>131 (30)</td>
<td>104 (24)</td>
</tr>
<tr>
<td></td>
<td>Working now</td>
<td>Disability Income</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Student</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Annual income, n (%)</td>
<td>268 (66)</td>
<td>108 (27)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&lt; $30,000</td>
<td>&gt; $30,000</td>
<td></td>
</tr>
</tbody>
</table>

*aPercentages do not always add up to 100 due to non-responders*
<table>
<thead>
<tr>
<th>Insurance, n (%)</th>
<th>Medicaid</th>
<th>Medicare</th>
<th>Private</th>
<th>Other</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>166 (39)</td>
<td>129 (30)</td>
<td>70 (16.5)</td>
<td>21 (5)</td>
<td>9 (2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hemoglobin type, n (%)</th>
<th>Hgb SS/ Hgb Sβ zero thalassemia</th>
<th>Hgb SC</th>
<th>Hgb S beta + thalassemia</th>
<th>Other</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>306 (70)</td>
<td>18 (4)</td>
<td>2 (0.5)</td>
<td>21 (5)</td>
<td></td>
</tr>
</tbody>
</table>

bMultiple insurances could be selected
Psychometric Properties

- **Reliability (Cronbach’s alpha)**
  - Pain Interference = 0.95
  - Self-Efficacy = 0.87
  - ASCQ-Me QoC = 0.73

- **Construct Validity (CFA)**
  - Pain Interference – all items loaded to one factor with factor loadings > 0.71
  - Self-Efficacy – all items loaded to one factor with factor loadings > 0.56
Psychometrics (cont’d)

- Construct Validity (CFA)
  - ASCQ-Me QoC – items loaded to two factors (Provider Communication and ED Care), excluding item asking about access to outpatient appointments
  - RMSEA = 0.07; Bentler CFI = 0.94
Factors Associated with Pain Interference and Self-Efficacy

- In linear regression models, increased pain interference associated with female gender, older age, lower income, disabled status, public or no insurance, increased frequency and severity of pain episodes, higher ED and inpatient utilization, severe pain with no healthcare.

- Decreased self-efficacy associated with older age, lower income, disabled status, increased frequency of pain episodes, higher ED and inpatient utilization, severe pain with no healthcare.
67% of 379 respondents reported delayed or avoided going to the ED when they thought they needed care in the past 12 months.
83% of 361 respondents reported they have a usual care provider who generally treats “a lot of patients with SCD”
Known Groups

Pain severity/frequency impacted satisfaction with non-acute care; limited demographics associated with satisfaction with ED care
Summary

- SCDIC needs assessment provided opportunity to contribute additional information about the validity and reliability of ASCQ-Me and PROMIS measures with a geographically diverse SCD sample
- Measures appear reliable for our sample, with good construct, face validity
- ASCQ-Me QoC demonstrated different factor structure compared with field test
Summary

- Findings highlight pervasive disparities in outcomes and access to resources for the population, underscoring the importance of the work of the consortium.
SCDIC Proposed Interventions

- IS aims focus not only on evaluating clinical effectiveness of interventions but focus on understanding the context of the interventions
- IS outcomes include focus on acceptability and feasibility of interventions, as well as barriers and facilitators to implementation
- Example:
  - ED Care protocol will intervene at the level of the patient (improve access to, and motivation to use, individualized medication prescribing and monitoring protocol (IPP)) and provider (knowledge barriers to pain management and access to IPP) and will consider differences in contexts across sites

Baumann, King et al  *BMC Health Serv Res* 2018; 18: 500.
SCDIC Registry - Data Elements

- phenX Toolkit
  - Sickle Cell Disease Core Tier 1 and Core Tier 2 demographics
- PROMIS
  - Pain Quality
  - Emotional Distress - Depression
  - Fatigue
- Neuro-QOL
  - Cognitive Function
- ASCQ-Me
  - Pain Episode Frequency
  - Pain Episode Severity
  - SCD Medical History Checklist
  - Emotional Impact
  - Pain Impact
  - Sleep Impact
  - Social Functioning Impact