Health-Related Quality of Life among Adults Hospitalized with Sickle Cell Painful Crisis

Kimberly Esham, MD
September 28, 2017
Disclosures

• Nothing to disclose
Pain & Hospitalizations in SCD

• Vaso-Occlusive Crisis (VOC): hallmark of SCD
  – unpredictable, severe
  – dramatic impairment of health-related quality of life (HRQL)

• Hospitalized sickle cell patients
  – highest health utilization & associated cost among the SCD population
  – 5 ED/inpatient encounters per person per year among young adults

• SCD has the highest rate readmission of any chronic condition
  – 41.1% national 30-day readmission rate among young adults

AHRQ HCUP Statistical Brief #153. April 2013.
McClish, Health & QOL Outcomes 2005; 3:50
Need for Comprehensive Pain Assessment

- Pain Impact
- Stiffness Impact
- Sleep Impact
- Physical Health
- Mental Health
- Emotional Impact
- Social Impact

PAIN EXPERIENCE

Panepinto JA. ASH Education vol. 2012 no. 1 284-289
Pain Assessment: Available Tools

- Acquired experience
  - Variable course of individuals
  - Individual preferences while hospitalized

- Pain intensity assessment
  - Numeric Rating Scale (0-10): pain intensity
  - 0 “no pain” - 10 “worst imaginable pain”

- Newer Patient Reported Outcomes Measures (PROs)
  - PROMIS
  - ASCQ-Me

Description of PROMIS Global & ASCQ-Me

PROMIS Global Health:

- Generic measure
  - general population
  - those with chronic conditions
- 10 question measure (physical & mental subscales)
- Time to complete: 1-2 minutes
- Scores: US population mean 50 (SD 10), scale 0-100 points

ASCQ-Me:

- SCD-specific measure
- Developed to complement generic instruments
  - e.g. PROMIS Global Health
- 25 questions (5 per domain)
- Time to complete: ~ 5-6 mins
- Scores: SCD-population mean 50 (SD 10), scale 0-100 points


http://www.ascq-me.org/
Hospitalization for VOC

Study Schema

Admission

7-day recall of measure

Hospitalization for VOC

7-days Post Discharge

7-day recall of measure

Discharge

Tufts Medical Center

Tufts Clinical and Translational Science Institute

Tufts University

Sackler School of Graduate Biomedical Sciences
Study Design Framework

Baseline on Admission

Individual Characteristics
- Demographics
- SES

Disease Characteristics
- ASCQ-Me Pain Episodes
- SCD Genotype

Admission Pain Assessment
- NRS
- PROMIS Global
- ASCQ-Me

Post Discharge Assessment
- NRS
- PROMIS Global
- ASCQ-Me

Healthcare Utilization
- Length of Stay
- 30 Day Readmissions
Inclusion/Exclusion Criteria

**Inclusion Criteria**
- Adults ≥ 18 years old
- Any Sickle Cell Disease
  - Hb SS, Hb SC,
  - Hb Sβ⁺ thal, Hb Sβ⁰ thal
- Admitted to Tufts MC inpatient services with painful crisis

**Exclusion Criteria**
- Inability to provide informed consent
- Non English-speaking
Analysis

- Description of Participant Characteristics
- Baseline ASCQ-Me Pain Episode Measure
  - Descriptive Comparison to Field Test Data
- HRQL Assessment
  - Admission
  - 7-Day Post Discharge
  - Change Scores (Discharge minus Admission scores)
- Validity Analysis
  - Convergent Validity
  - Discriminant Validity
30 Admissions with VOC over 12 months

29 Met Eligibility

28 Enrolled

28 Completed All Assessments on Admission

18 Completed All Assessments 7 Days After Discharge

1 not eligible: non-English speaking

1 declined participation

5 readmitted within 1 week
2 readmitted within 1 month
3 non-respondents
## Baseline Characteristics

<table>
<thead>
<tr>
<th>Hospitalized Cohort</th>
<th>Participants (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in Years, mean (SD)</td>
<td>30.6 (9.6)</td>
</tr>
<tr>
<td>Female, n(%)</td>
<td>16 (57%)</td>
</tr>
<tr>
<td>Hemoglobin SS genotype, n(%)</td>
<td>16 (57%)</td>
</tr>
<tr>
<td>Other sickle cell genotype, n(%)</td>
<td>12 (43%)</td>
</tr>
<tr>
<td>Non-Hispanic Black, n(%)</td>
<td>20 (71%)</td>
</tr>
<tr>
<td>Hispanic, n(%)</td>
<td>8 (29%)</td>
</tr>
</tbody>
</table>
## Baseline SCD Characteristics: More Frequent VOCs

<table>
<thead>
<tr>
<th>Measure</th>
<th>ASCQ-Me Field Test (n=561)</th>
<th>Hospitalized Cohort (n=28)</th>
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<tbody>
<tr>
<td>Pain Episode Frequency, mean (SD)</td>
<td>8.5 (2.7)</td>
<td>9.3 (2.1)</td>
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- Possible Frequency Score Range 0-11
- Higher scores reflect more frequent VOC over the past 12 months
Baseline SCD Characteristics: More Frequent VOCs

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- Possible Frequency Score Range 0-11
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<table>
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<tr>
<th>Pain Episode</th>
<th>ASCQ-Me Field Test (n=561)</th>
<th>Hospitalized Cohort (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency ≥ 2 VOCs in the past 12 months</td>
<td>20%</td>
<td>90%</td>
</tr>
</tbody>
</table>

## Baseline SCD Characteristics: More Severe VOCs

<table>
<thead>
<tr>
<th>Pain Episode Severity Measure</th>
<th>ASCQ-Me Field Test (n=561)</th>
<th>Hospitalized Cohort (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of pain during last crisis (0-10)</td>
<td>Mean 7.8 (SD 2.3)</td>
<td>Mean 8.9 (SD 1.4)</td>
</tr>
</tbody>
</table>
## Baseline SCD Characteristics: More Severe VOCs

### Pain Episode Severity Measure

<table>
<thead>
<tr>
<th>How much did your last pain crisis interfere with your life?</th>
<th>ASCQ-Me Field Test (n=561)</th>
<th>Hospitalized Cohort (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’ve never had a crisis</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>Not at all, I did everything I usually do</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>I had to cut down on some things…</td>
<td>21%</td>
<td>32%</td>
</tr>
<tr>
<td>I could not do most things…</td>
<td>30%</td>
<td>14.3%</td>
</tr>
<tr>
<td>I could not take care of myself…needed some help…</td>
<td>18%</td>
<td>21%</td>
</tr>
<tr>
<td>I …needed constant care…</td>
<td>19%</td>
<td>21%</td>
</tr>
</tbody>
</table>

### About how long did your most recent pain attack (crisis) last?

<table>
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<th>ASCQ-Me Field Test (n=561)</th>
<th>Hospitalized Cohort (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’ve never had a crisis</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>Less than 1 hour</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>1-12 hours</td>
<td>18%</td>
<td>4%</td>
</tr>
<tr>
<td>13-24 hours</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>1-3 days</td>
<td>22%</td>
<td>18%</td>
</tr>
<tr>
<td>4-6 days</td>
<td>25%</td>
<td>18%</td>
</tr>
<tr>
<td>1-2 weeks</td>
<td>14%</td>
<td>32%</td>
</tr>
<tr>
<td>More than 2 weeks</td>
<td>7%</td>
<td>29%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measure/Domain</th>
<th>Population Reference</th>
<th>Admission, mean(SD) n=28</th>
<th>Discharge+7, mean(SD) n=18</th>
<th>Change, mean(SD) n=18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Intensity</td>
<td>NRS 0-10</td>
<td>8.3 (2.1)</td>
<td>5.1 (2.5)</td>
<td>- 3.3 (3.0)</td>
</tr>
<tr>
<td>PROMIS-Global Physical Health</td>
<td>Mean 50 (SD 10)</td>
<td>37.0 (6.7)</td>
<td>40.3 (9.2)</td>
<td>4.5 (8.5)</td>
</tr>
<tr>
<td>PROMIS-Global Mental Health</td>
<td>Mean 50 (SD 10)</td>
<td>44.5 (8.0)</td>
<td>44.2 (7.5)</td>
<td>2.0 (6.3)</td>
</tr>
</tbody>
</table>
## ASCQ-Me
### Admission and 7-Days Post Discharge

<table>
<thead>
<tr>
<th>ASCQ-Me Domain</th>
<th>Population Mean (SD)</th>
<th>Admission, mean(SD) n=28</th>
<th>Discharge+7 mean(SD) n=18</th>
<th>Change, mean(SD) n=18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Impact</td>
<td>50 (10)</td>
<td>44.9 (7.2)</td>
<td>46.4 (7.9)</td>
<td><strong>3.6 (6.5)</strong></td>
</tr>
<tr>
<td>Social Functioning</td>
<td></td>
<td>46.2 (6.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain Impact</td>
<td></td>
<td>42.2 (6.4)</td>
<td>44.9 (8.4)</td>
<td><strong>3.2 (9.0)</strong></td>
</tr>
<tr>
<td>Stiffness Impact</td>
<td></td>
<td>48.9 (7.5)</td>
<td>46.2 (8.5)</td>
<td><strong>-1.7 (7.4)</strong></td>
</tr>
<tr>
<td>Sleep Impact</td>
<td></td>
<td>45.1 (9.0)</td>
<td>44.9 (5.8)</td>
<td><strong>3.8 (7.5)</strong></td>
</tr>
</tbody>
</table>
Evidence of Convergent Validity at Admission

<table>
<thead>
<tr>
<th>PROMIS Scale</th>
<th>ASCQ-Me Scale</th>
<th>Correlation Hypothesis</th>
<th>Correlation Coefficient (r)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROMIS Global Physical Health</td>
<td>ASCQ-Me Pain Impact</td>
<td>Moderate</td>
<td>0.34 (p=0.03)</td>
</tr>
<tr>
<td>PROMIS Global Mental Health</td>
<td>ASCQ-Me Emotional Impact</td>
<td>Strong</td>
<td>0.42 (p=0.03)</td>
</tr>
</tbody>
</table>

**Recall Correlation Coefficients:**

- 0.2: weak
- 0.4: moderate
- 0.6: strong
# Evidence of Convergent Validity at 7-Day Post Discharge

<table>
<thead>
<tr>
<th>PROMIS Scale</th>
<th>ASCQ-Me Scale</th>
<th>Correlation Hypothesis</th>
<th>Correlation Coefficient (r)</th>
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</thead>
<tbody>
<tr>
<td>PROMIS Global Physical Health</td>
<td>ASCQ-Me Pain Impact</td>
<td>Moderate</td>
<td>0.62 (p&lt;0.01)</td>
</tr>
<tr>
<td>PROMIS Global Mental Health</td>
<td>ASCQ-Me Emotional Impact</td>
<td>Strong</td>
<td>0.72 (p&lt;0.01)</td>
</tr>
</tbody>
</table>

**Recall Correlation Coefficients:**
- 0.2: weak
- 0.4: moderate
- 0.6: strong
<table>
<thead>
<tr>
<th>Measure/Domain at Admission</th>
<th>High VOC Frequency, mean(SD)</th>
<th>Low VOC Frequency, mean(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NRS (0-10)</td>
<td>8.8 (1.0)</td>
<td>7.5 (2.9)</td>
</tr>
<tr>
<td>PROMIS-Global Physical</td>
<td>36.1 (6.6)</td>
<td>38.4 (6.9)</td>
</tr>
<tr>
<td>PROMIS-Global Mental</td>
<td>43.4 (8.8)</td>
<td>46.2 (6.7)</td>
</tr>
<tr>
<td>ASCQ-Me Emotional Impact</td>
<td>44.1 (8.1)</td>
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<td>45.5 (6.4)</td>
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</tr>
<tr>
<td>ASCQ-Me Pain Impact</td>
<td>41.2 (4.6)</td>
<td>43.7 (8.5)</td>
</tr>
<tr>
<td>ASCQ-Me Stiffness Impact</td>
<td>47.2 (6.7)</td>
<td>51.7 (8.1)</td>
</tr>
<tr>
<td>ASCQ-Me Sleep Impact</td>
<td>46.1 (7.4)</td>
<td>43.4 (11.2)</td>
</tr>
</tbody>
</table>
Conclusions

• Administering patient-reported measures at point-of-care among hospitalized SCD patients is feasible and informative.

• Despite the intensity of the patients’ condition, high:
  – 97% enrollment
  – 100% data collection on admission

• Retention: 64% complete data at 7-days post discharge
  – in most cases due to hospital readmission
Conclusions

• Baseline ASCQ-Me Pain Episode scores
  – Reflect recurrent & prolonged painful VOC episodes over prior year

• PROMIS Global & ASCQ-Me scores
  – Profile pain experience of adults admitted with VOC
  – All scores were below population norms
  – Indicative of substantial suffering from VOC pain experience both upon admission & following discharge
Lessons Learned

• Pain Episode Frequency and Severity:
  – Sobering: In our sample,
  – 60% ≥ 4 painful crises/year
  – 40% unable to care for themselves during a VOC episode

• Relevance of some ASCQ-Me domains more apparent
  – Surprising information gleaned: e.g. impact of stiffness
Questions?
Acknowledgements

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Additional Thanks
Hem/Onc Program Directors
Hem/Onc Faculty
Hem/Onc Co-Fellows
ICRHP & CTS Colleagues

Thank You
### Supplement: Healthcare Utilization Compared to Nationwide Sample

<table>
<thead>
<tr>
<th>Healthcare Utilization</th>
<th>Nationwide Inpatient SCD Sample</th>
<th>Summary Statistic (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Length of Stay</td>
<td>6 days</td>
<td><strong>10.5 days (SD 9.5)</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(range 2-45 days)</td>
</tr>
<tr>
<td>30-day Readmission Rate</td>
<td>41.1%</td>
<td><strong>39.3%</strong></td>
</tr>
</tbody>
</table>

Brousseau, JAMA. 2010;303(13):1288-1294