

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

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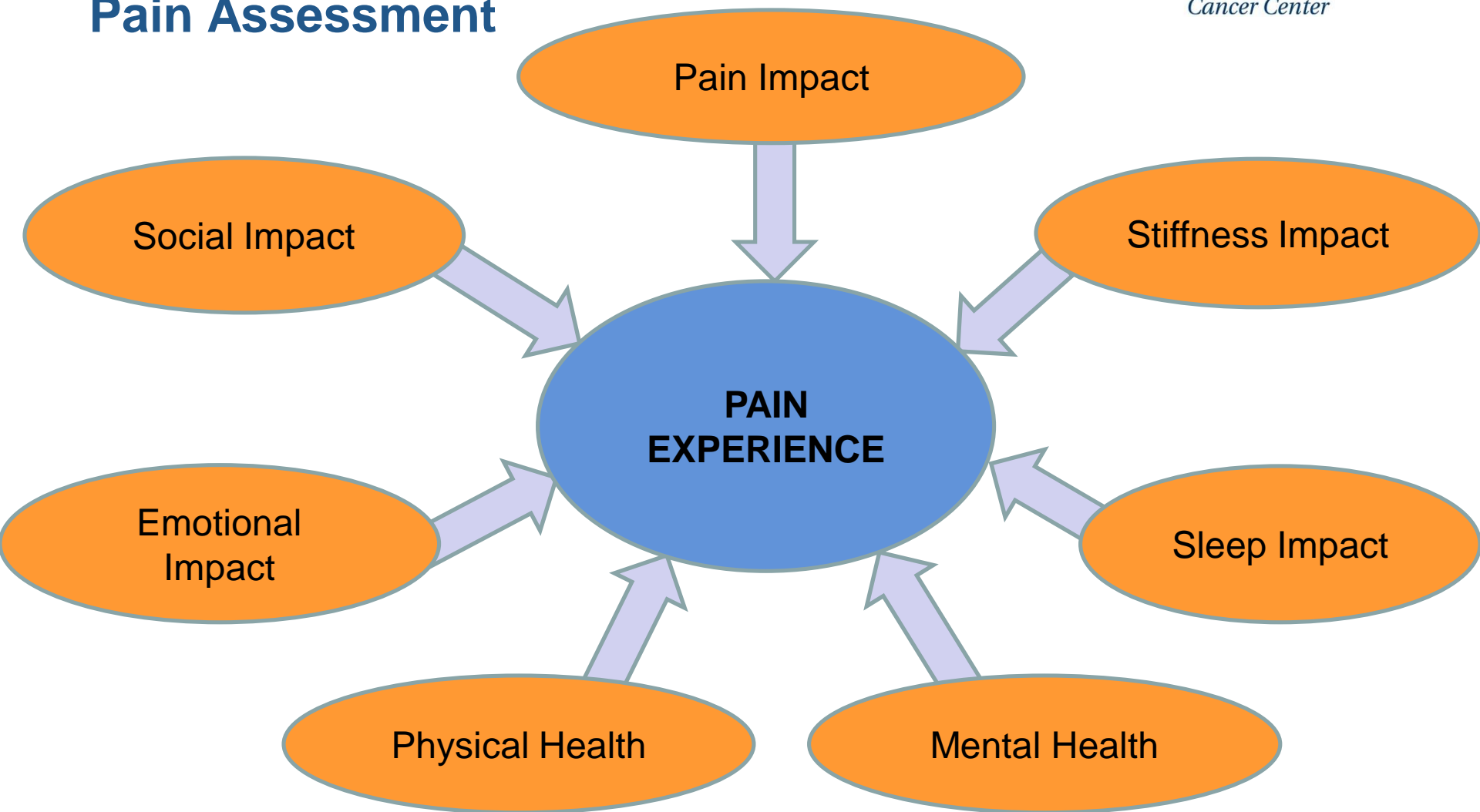
Disclosures

- 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

Need for Comprehensive Pain Assessment



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

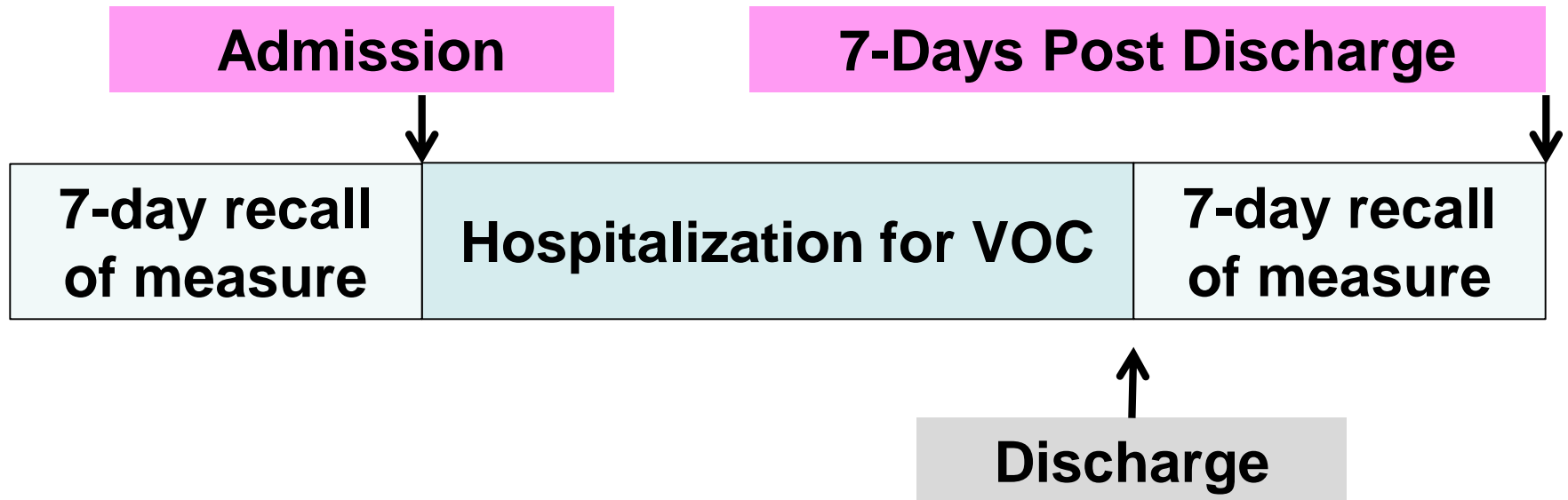
PROMIS Global Health:

- 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

Study Schema



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 \geq 18 years old
- Any Sickle Cell Disease
 - Hb SS, Hb SC,
Hb S β^+ thal, Hb S β^0 thal
- Admitted to Tufts MC inpatient services with painful crisis

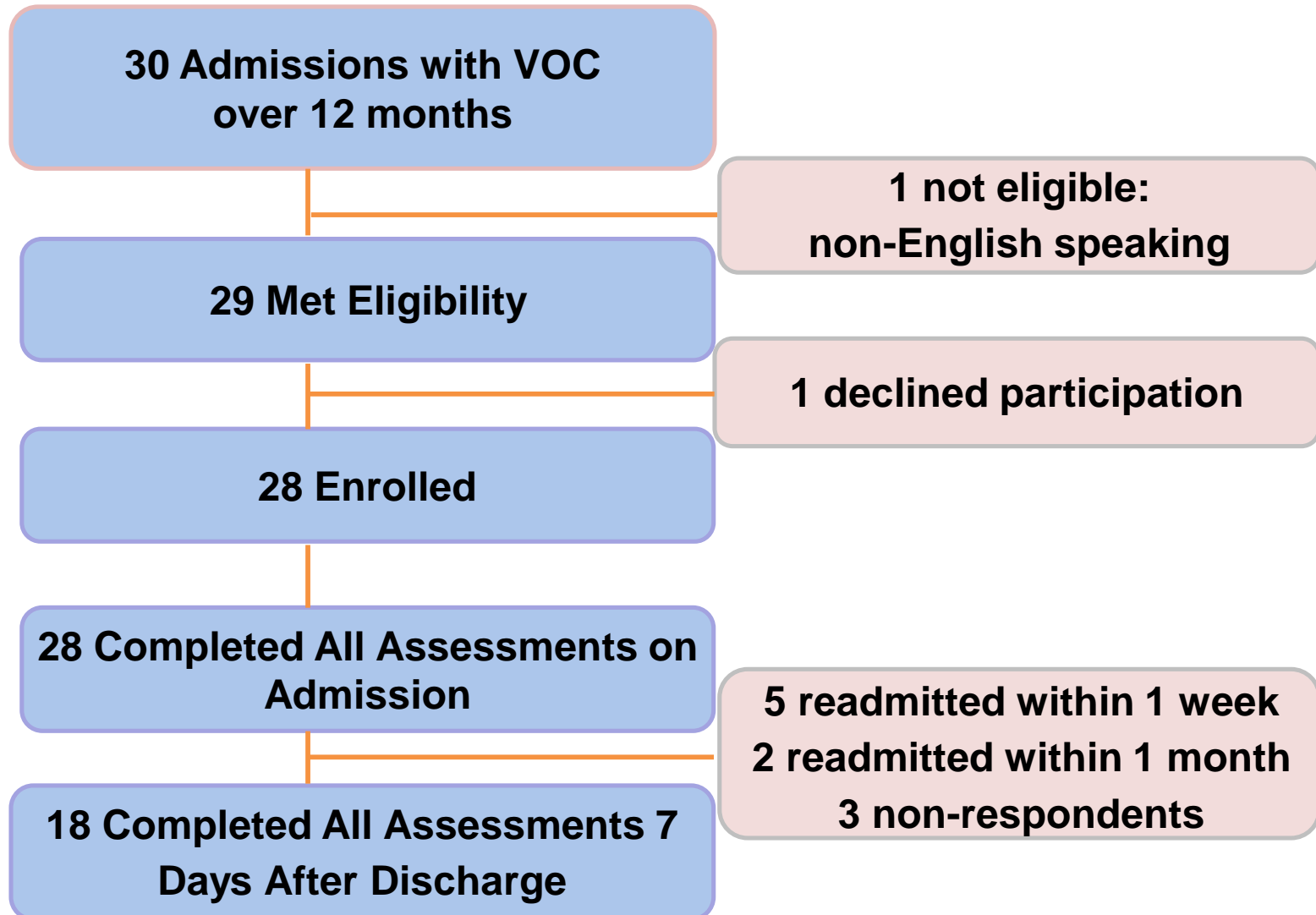
Exclusion Criteria

- 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

Consort Diagram



Baseline Characteristics

Hospitalized Cohort	Participants (n=28)
Age in Years, mean (SD)	30.6 (9.6)
Female, n(%)	16 (57%)
Hemoglobin SS genotype, n(%)	16 (57%)
Other sickle cell genotype, n(%)	12 (43%)
Non-Hispanic Black, n(%)	20 (71%)
Hispanic, n(%)	8 (29%)

Baseline SCD Characteristics: More Frequent VOCs

Measure	ASCQ-Me Field Test (n=561)	Hospitalized Cohort (n=28)
Pain Episode Frequency, mean (SD)	8.5 (2.7)	9.3 (2.1)

- *Possible Frequency Score Range 0-11*
- *Higher scores reflect more frequent VOC over the past 12 months*

Baseline SCD Characteristics: More Frequent VOCs

Measure	ASCQ-Me Field Test (n=561)	Hospitalized Cohort (n=28)
Pain Episode Frequency, mean (SD)	8.5 (2.7)	9.3 (2.1)

- Possible Frequency Score Range 0-11
- Higher scores reflect more frequent VOC over the past 12 months

Pain Episode	ASCQ-Me Field Test (n=561)	Hospitalized Cohort (n=28)
Frequency ≥ 2 VOCs in the past 12 months	20%	90%

Baseline SCD Characteristics: More Severe VOCs

Pain Episode Severity Measure	ASCQ-Me Field Test (n=561)	Hospitalized Cohort (n=28)
Severity of pain during last crisis (0-10)	Mean 7.8 (SD 2.3)	Mean 8.9 (SD 1.4)

Baseline SCD Characteristics: More Severe VOCs

Pain Episode Severity Measure	ASCQ-Me Field Test (n=561)	Hospitalized Cohort (n=28)
How much did your last pain crisis interfere with your life?		
<input type="checkbox"/> I've never had a crisis	2%	0%
<input type="checkbox"/> Not at all, I did everything I usually do	10%	10%
<input type="checkbox"/> I had to cut down on some things...	21%	32%
<input type="checkbox"/> I could not do most things...	30%	14.3%
<input type="checkbox"/> I could not take care of myself...needed some help...	18%	21%
<input type="checkbox"/> I ...needed constant care...	19%	21%
About how long did your most recent pain attack (crisis) last?		
<input type="checkbox"/> I've never had a crisis	2%	0%
<input type="checkbox"/> Less than 1 hour	4%	0%
<input type="checkbox"/> 1-12 hours	18%	4%
<input type="checkbox"/> 13-24 hours	8%	0%
<input type="checkbox"/> 1-3 days	22%	18%
<input type="checkbox"/> 4-6 days	25%	18%
<input type="checkbox"/> 1-2 weeks	14%	32%
<input type="checkbox"/> More than 2 weeks	7%	29%

PROMIS-Global Admission and 7-Days Post Discharge

Measure/ Domain	Population Reference	Admission, mean(SD) n=28	Discharge+7, mean(SD) n=18	Change, mean(SD) n=18
Pain Intensity	NRS 0-10	8.3 (2.1)	5.1 (2.5)	- 3.3 (3.0)
PROMIS-Global Physical Health	Mean 50 (SD 10)	37.0 (6.7)	40.3 (9.2)	4.5 (8.5)
PROMIS-Global Mental Health	Mean 50 (SD 10)	44.5 (8.0)	44.2 (7.5)	2.0 (6.3)

ASCQ-Me Admission and 7-Days Post Discharge

ASCQ-Me Domain	Population Mean (SD)	Admission, mean(SD) n=28	Discharge+7 mean(SD) n=18	Change, mean(SD) n=18
Emotional Impact	50 (10)	44.9 (7.2)	46.4 (7.9)	3.6 (6.5)
Social Functioning		46.2 (6.8)		
Pain Impact		42.2 (6.4)	44.9 (8.4)	3.2 (9.0)
Stiffness Impact		48.9 (7.5)	46.2 (8.5)	-1.7 (7.4)
Sleep Impact		45.1 (9.0)	44.9 (5.8)	3.8 (7.5)

Evidence of Convergent Validity at Admission

PROMIS Scale	ASCQ-Me Scale	Correlation Hypothesis	Correlation Coefficient (r)
PROMIS Global Physical Health	ASCQ-Me Pain Impact	Moderate	0.34 (p=0.03)
PROMIS Global Mental Health	ASCQ-Me Emotional Impact	Strong	0.42 (p=0.03)

Recall Correlation Coefficients:

0.2: weak

0.4: moderate

0.6: strong

Evidence of Convergent Validity at 7-Day Post Discharge

PROMIS Scale	ASCQ-Me Scale	Correlation Hypothesis	Correlation Coefficient (r)
PROMIS Global Physical Health	ASCQ-Me Pain Impact	Moderate	0.62 (p<0.01)
PROMIS Global Mental Health	ASCQ-Me Emotional Impact	Strong	0.72 (p<0.01)

Recall Correlation Coefficients:

0.2: weak

0.4: moderate

0.6: strong

Evaluation of Discriminant Validity at Admission

Measure/Domain at Admission	High VOC Frequency, mean(SD) n=17	Low VOC Frequency, mean(SD) n=11
NRS (0-10)	8.8 (1.0)	7.5 (2.9)
PROMIS-Global Physical	36.1 (6.6)	38.4 (6.9)
PROMIS-Global Mental	43.4 (8.8)	46.2 (6.7)
ASCQ-Me Emotional Impact	44.1 (8.1)	46.0 (5.7)
ASCQ-Me Social Functioning	45.5 (6.4)	47.2 (7.5)
ASCQ-Me Pain Impact	41.2 (4.6)	43.7 (8.5)
ASCQ-Me Stiffness Impact	47.2 (6.7)	51.7 (8.1)
ASCQ-Me Sleep Impact	46.1 (7.4)	43.4 (11.2)

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% \geq 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?



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Supplement: Healthcare Utilization Compared to Nationwide Sample

Healthcare Utilization	Nationwide Inpatient SCD Sample	Summary Statistic (n=28)
Average Length of Stay	6 days	10.5 days (SD 9.5) (range 2-45 days)
30-day Readmission Rate	41.1%	39.3%