Cognitive Appraisal of Pain and "Other" Chronic Stressors in Adults Living With Sickle Cell Disease (SCD): Correlates and Predictors of Emotional and Quality of Life Adjustment Outcomes

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Study Aims
1. Describe salient patient defined ("Other") SCD stressors
   - acute and chronic
   - pain and non-pain

2. Describe how adults appraise their SCD illness experiences.

3. Explore the mediating role of primary and secondary cognitive appraisals in the relationships between SCD pain and non-pain stress and negative mood, and quality of life perceptions in adults living with SCD.
**Background to the Problem**

- Genetic disease (chronic)
  - 1 of 375 live births annually in the United States.
- Multiple Variants
  - Sickle cell anemia (homozygous- most common)
  - Heterozygous variants
  - Sickle Cell Thalassemias
  - Hemoglobin SC disease
- Considerable individual and inter-individual clinical symptom variability
- SCD Vaso-occlusive pain episodes are the hallmark of the disease
  (formally referred to as sickle cell ‘crises’)
- Pervasive
- Unpredictable

**Problem and Significance**

- Frequency of vaso-occlusive pain episodes contributes to increased morbidity and premature mortality.
- Frequency and severity of vaso-occlusive pain episodes contribute to increased healthcare utilization costs.
  - Davies, Roberts, & Gergen 1997; Olney 1999
- Positive correlations between higher use of emotion-focused coping and higher levels of emotional and distress (e.g., anxiety, depression).
- Higher incidence and prevalence of depression and depressive symptoms among adults with SCD than general population and age matched healthy cohorts.
  - Funk & Murdaugh, 2005
- Higher risk for undetected clinical depression and depressive symptoms.

**Literature Review:**

**Stress, Coping, and Emotional Adjustment in SCD**

<table>
<thead>
<tr>
<th>Quantitative Research</th>
<th>Qualitative Research</th>
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<tbody>
<tr>
<td>Investigator Defined Stressors</td>
<td>Patient Defined Stressors</td>
</tr>
<tr>
<td>Poor emotional and functional adjustment outcomes</td>
<td>“Emotional Stress”</td>
</tr>
<tr>
<td>“Psychological Distress” (e.g., Anxiety and Depression)</td>
<td>Health Care Provider Relationships</td>
</tr>
<tr>
<td>Decreased functioning (e.g., work, school, social)</td>
<td>Socioeconomic</td>
</tr>
<tr>
<td>High health care utilization costs</td>
<td>Family Relationships</td>
</tr>
<tr>
<td>“Other” Stressors are measured but not discussed.</td>
<td>Social Relationships</td>
</tr>
<tr>
<td>“Other” Stressors discussed but not measured.</td>
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</table>
Cognitive-Motivational-Relational Theory of Stress and Emotion

1. Stress (Daily Hassles)
   Relational, person-centered, process perspective

2. Cognitive Appraisal
   Primary
   - Personal significance (e.g., 'meaning') of stressful encounters to personal well being
   - Harms/Losses, Threats, Challenges
   Secondary
   - Available internal and external coping resources
   - Controllability of stressful encounter outcomes

3. Adjustment Outcome: Morale
   Short-term: Stress Emotions (Negative Mood)
   Long-term: Quality of Life Perceptions


Non-Pain SCD Stress Questionnaire Pilot Study

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Design</th>
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<tbody>
<tr>
<td>Relevance of items as stressors</td>
<td>Cross sectional</td>
</tr>
<tr>
<td>Clarity of items/questions</td>
<td>Semi-structured Interviews</td>
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<tr>
<td>Variability in responses</td>
<td>Tape Recorded</td>
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<tr>
<td>Sequencing of the intended instruments</td>
<td></td>
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<tr>
<td>Length of time to administer</td>
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<tr>
<td>Participants</td>
<td>Procedure</td>
</tr>
<tr>
<td>Homogeneity</td>
<td>Recruitment</td>
</tr>
<tr>
<td>Receptiveness to the study</td>
<td>Health Care Providers (2)</td>
</tr>
<tr>
<td>Identification of stressor items not listed</td>
<td>Two SCD Adult Support Groups</td>
</tr>
<tr>
<td></td>
<td>Sample</td>
</tr>
<tr>
<td></td>
<td>Adult SCD Participants</td>
</tr>
<tr>
<td></td>
<td>7 Female and 2 Male</td>
</tr>
</tbody>
</table>
Pilot Study: Lessons Learned

1. Feasibility
2. Difficult to recruit participants
3. Latent Variable: SCD Pain
   SCD Stress Questionnaire
4. Talked a lot about the Health Care Provider Relationship
5. Frequency of stressor occurrence is not related to the (appraised) severity of the stressor experience

SCD Stress Questionnaire Subscales

<table>
<thead>
<tr>
<th>SCD Illness Symptoms (&quot;Other&quot;)</th>
<th>Family/ Social Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unpredictability</td>
<td>Disrupted family routines</td>
</tr>
<tr>
<td>Weather Effects</td>
<td>Inability to care for family</td>
</tr>
<tr>
<td>Addiction concerns</td>
<td>Inability to have children</td>
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<tr>
<td>Medication efficacy</td>
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<table>
<thead>
<tr>
<th>Socio-Economic</th>
<th>Health Care Provider Relationships</th>
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<tr>
<td>Neighborhood pharmacy</td>
<td>Lack of SCD knowledge</td>
</tr>
<tr>
<td>Employment</td>
<td>Refusal to believe pain severity</td>
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<tr>
<td>Lack of adequate income</td>
<td>Discrimination</td>
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<td></td>
<td>Lack of emotional support</td>
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Theoretical Constructs

**Daily Hassles** (e.g., Chronic Stress)

"...the ongoing experiences and conditions of daily life that are appraised as harmful or threatening to and individual's personal wellbeing that characterize everyday transactions with the environment."

SCD Pain Related and Non-Pain Related (e.g., "Other")
Theoretical Constructs continued

**Cognitive Appraisal**
"... the deliberate, conscious efforts that individuals use to
categorize person-environment relationships significance for personal well being."

**Primary Threat Appraisal**
"... harms and/or losses that have not yet taken place but are anticipated; ... the extent
that humans can anticipate the future, they can plan for it and work through some
of the difficulties in advance..."

**Secondary Control Appraisal**
"... Complex evaluative process that takes into account which coping options are
available, the likelihood that a given coping option will accomplish what it is
supposed to, and the likelihood that one can apply a particular strategy of set of
strategies effectively."

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Study Design

- Cross sectional
- Descriptive and correlational

**Measures**
- Sickle Cell Disease Stress Questionnaire*
- Brief Pain Inventory (Cleeland et al 1991)
- Pain Appraisal Inventory (Unruh 1998).
- Profile of Mood States (Negative Mood) (Lorr & McNair, 1992).
- Quality of Life Index-Sickle Cell Disease (Ferrans, 2005).

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Sample

**Inclusion Criteria**
- Male and female
- 18 years and over
- African American, African, Caribbean, Latino ethnicity.
- Pregnant Women
- Confirmed sickle cell disease diagnosis (Hb SS, Hb C, Hb thalassemia)
- English is primary language

**Exclusion Criteria**
- Children
- Prisoners
- Mentally Challenged
- Sickle cell trait diagnoses
- Free from cognitive deficits (e.g., related to cerebral vascular
  accident)
- Can not speak/understand English
Power Analysis

N = 103 Adults

Hypotheses Testing: Hierarchial Multiple Regression Analyses
  3 demographic (control)variables
  age, gender, and genotype
  4 independent (predictor)variables
  stress (pain and non-pain),
  appraisal (control and decrease)

Two tailed level, Alpha 0.05

Power level of .80

Medium effect of .15 (Cohen, 1992)

Recruitment Strategies

✓ Academic University Hospital HCP's
✓ Private Practices
✓ Snowball- Network Recruitment
✓ Community Organizations
✓ Recruitment Flyers
✓ Public Service Announcements

Procedures

✓ Structured interviews.
✓ Estimated 1-2 hours in length*.
✓ Conducted in participant’s home or a mutually agreed upon location.
✓ Tape recorded (with participant’s consent) for future studies.
✓ Neutral, nondirective probes to participant’s response for clarity of situational and contextual factors.
Study Challenges

Sample size
Participants with less severe SCD may be difficult to locate.
Males historically smaller proportions in general, SCD specifically.
Lack of an accurate epidemiological SCD data base.

Recruitment of minority participants

Unpredictability of SCD clinical symptoms

SCDSQ is not a validated instrument

Time Constraints

Lack of funding****

Unanticipated increase in gas prices

Questions and Reference List

• Please send email request to:

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