

**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.
Houston et al 2000; Platt et al 1994.
- ✓ Frequency and severity of vaso-occlusive pain episodes contribute to increased health care 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).
Gil, et al 1989; 2004.
- ✓ 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
Grant, Gil, Floyd, et al 2000.

Literature Review: Stress, Coping, and Emotional Adjustment in SCD

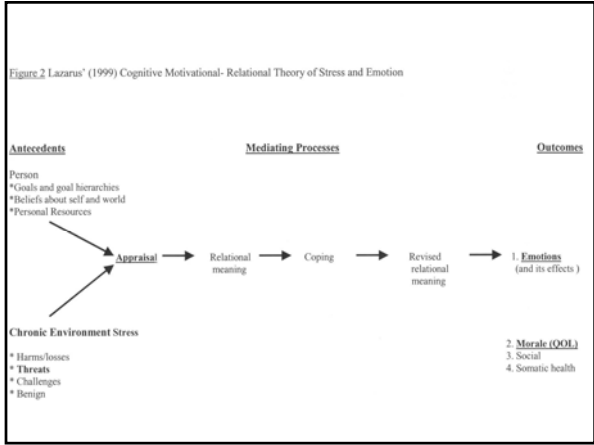
- | <u>Quantitative Research</u> | <u>Qualitative Research</u> |
|--|---|
| ✓ Investigator Defined Stressors | ✓ Patient Defined Stressors |
| ✓ Poor emotional and functional adjustment outcomes | ✓ "Emotional Stress" |
| ✓ "Psychological Distress"
(e.g., Anxiety and Depression) | ✓ Health Care Provider Relationships |
| ✓ Decreased functioning
(e.g., work, school, social) | ✓ Socioeconomic |
| ✓ High health care utilization costs | ✓ Family Relationships |
| ✓ "Other" Stressors are measured but not discussed. | ✓ Social Relationships |
| | ✓ "Other" Stressors discussed but not measured. |

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
- Lazarus, R. S. (1999). 7



Non-Pain SCD Stress Questionnaire Pilot Study

<p>Questionnaire</p> <ul style="list-style-type: none"> Relevance of items as stressors Clarity of items/questions Variability in responses Sequencing of the intended instruments Length of time to administer <p>Participants</p> <ul style="list-style-type: none"> Homogeneity Receptiveness to the study Identification of stressor items not listed 	<p>Design</p> <ul style="list-style-type: none"> Cross sectional Semi-structured Interviews Tape Recorded <p>Procedure</p> <ul style="list-style-type: none"> Recruitment <ul style="list-style-type: none"> Health Care Providers (2) Two SCD Adult Support Groups <p>Sample</p> <ul style="list-style-type: none"> Adult SCD Participants 7 Female and 2 Male
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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

SCD Illness Symptoms ("Other")

Unpredictability
Weather Effects
Addiction concerns
Medication efficacy

Family/Social Relationships

Disrupted family routines
Inability to care for family
Inability to have children

Socio-Economic

Neighborhood
pharmacy
Employment
Lack of adequate
income

Health Care Provider Relationships

Lack of SCD knowledge
Refusal to believe pain severity
Discrimination
Lack of emotional support

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."

Lazarus 1999, p 33-35.

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Study Design

❖ Cross sectional

❖ Descriptive and correlational

❖ Measures

- ✓ Sickle Cell Disease Stress Questionnaire*
- ✓ Cognitive Appraisal of Health Scale-SCD (Kessler, 1998).
- ✓ 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).

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: Hierarchical 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)

Power Analysis and Sample Size
(PASS) Hintze, 2000

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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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