Stigma in Sickle Cell Disease
Scale Development: A pilot study in adults and family/caregivers in the US and Nigeria

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Sickle Cell Disease

- Sickle Cell Disease (SCD) is an inherited blood disorder

- SCD affects millions of people throughout the world
  - Parts of Africa
  - Mediterranean countries
  - Spanish-speaking areas such as South America, Cuba and Central America, & USA.

- The sickle cells travel through the blood stream where they tend to get stuck and cut off blood flow, causing excruciating pain & organ disease.
Stigma

- Goffman (1963) defined stigma as “people’s attitudes towards someone who is discredited by physical or personality deformity or association with a group”

- Goffman described three types: physical, character blemishes, tribal stigma

- Butt (2008) commented that stigma “constitutes a substantial burden of disease”

- Significant public (world) health problem
Stigma studies

- Epilepsy (Austin, MacLeod, Dunn, Shen & Perkins (2004))
- HIV/ AIDS (Berger, Ferrans, & Lashley, 2001; Emlet, 2005)
- Mental health
- Tuberculosis, leprosy, Hepatitis
Stigma and SCD

- Often stigmatized as drug seekers (Odesina, et al., 2010)
- “Culture of silence” (Burnes, Antle, Williams, Cook, 2008)
- Inhibits mothers from talking openly about SCD in the community (Burnes, et al.)
Significance of tool development

- Scarcity in the international literature regarding cultural implications, health beliefs, and issues of stigma in SCD and trait status

- Testimonies, case examples, qualitative studies highlight attitudes, beliefs and stigmatization, noting that:
  - Universal barrier effecting care and quality of life
  - Unique attributes and obstacles from different countries and cultures
  - Experienced across environments of care
Tool Development

- Items were matched across 4 sub-groups with minor language changes
- Appraisal of instrument items for face validity from 6 nurses with expertise in SCD from the US and Nigeria
- Tested with individuals who experienced SCD for cultural competency and content validity
- Received exempt status through University of Connecticut IRB and CBO/NGO in Nigeria
Community Based Participatory Research

- University Partners with Community Based Organizations

- CQSCC, Citizens for Quality Sickle Cell Care, New Britain, CT

- FFFDP, Faith Foundation for Disease Prevention, Osogbo, Nigeria
Participants

- Adults, over the age of 18
- Sickle Cell Disease
- Live in the US or Nigeria
- Identified family caregivers
- English speaking
- Convenience sample of 42
# Stigma in Sickle Cell Disease: Pilot sample demographics, N=42

<table>
<thead>
<tr>
<th></th>
<th>USA</th>
<th>Nigeria</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult living with SCD</td>
<td>7 (16.6)</td>
<td>9 (21.4)</td>
<td>16 (38.1)</td>
</tr>
<tr>
<td>Family Member</td>
<td>16 (38.1)</td>
<td>10 (23.8)</td>
<td>26 (61.9)</td>
</tr>
<tr>
<td></td>
<td>23 (54.7)</td>
<td>19 (45.2)</td>
<td>42 (100%)</td>
</tr>
</tbody>
</table>
Scale Development and Psychometric Evaluation

- Statistical analysis on pilot sample of 42 participants included self-report of ease of use and understanding of terminology

- A chronbach’s alpha reliability coefficient to evaluate the internal consistency of the 40 item *Stigma in SCD Scale* for the pilot was determined to be alpha = .858

- Minor editing was suggested and was incorporated into the revised measure
Results

- 42 adults living with SCD and family/caregivers participated
- Total score for the combined data set, Mean = 40.6, SD = 20.9, Range = 4 - 86 out of a possible 120 points
- Nigerians as a group reported higher stigma, \( r = .59, p < .01 \)
Item Analysis

- Item analyses were conducted for Mean, SD, & Range to identify high areas of stigma and compared across participant and country groups.

- The only item that US respondents reported higher stigma than Nigerians was: “Service providers do not believe people with SCD have disabilities” ($r = .57$, $p < .01$).

- Adults from both countries “fear their significant other would reject ‘me’ if they learn more about my illness” ($r = .44$, $p < .01$) more than their family/caregivers felt they would be rejected.
## Highest Reported Stigma: Item Analysis

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>People believe that a person with SCD is a drug seeker (F)</td>
<td>1.90</td>
<td>0.96</td>
</tr>
<tr>
<td>… believe a person with SCD is lying about their pain (F)</td>
<td>1.71</td>
<td>1.16</td>
</tr>
<tr>
<td>People with SCD are treated like outcasts (F)</td>
<td>1.60</td>
<td>0.98</td>
</tr>
<tr>
<td>People who know I have SCD treat me as if I am fragile (A)</td>
<td>1.55</td>
<td>1.09</td>
</tr>
<tr>
<td>People believe a person with SCD is lazy (F/A)</td>
<td>1.55</td>
<td>1.35</td>
</tr>
<tr>
<td>People are uncomfortable around someone with SCD (F)</td>
<td>1.45</td>
<td>1.13</td>
</tr>
<tr>
<td>I feel that I am a burden to my family (A)</td>
<td>1.45</td>
<td>1.15</td>
</tr>
</tbody>
</table>
## Factor Analysis

<table>
<thead>
<tr>
<th>Component: Factor Analysis</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Societal impact regarding the disease and isolation</td>
<td>.887</td>
<td>-.328</td>
<td>.146</td>
<td>.291</td>
</tr>
<tr>
<td>2. Personal feelings of shame, rejection, guilt, etc.</td>
<td>.249</td>
<td>.839</td>
<td>-.332</td>
<td>.352</td>
</tr>
<tr>
<td>3. Treatment when in pain and concerns for the future</td>
<td>.163</td>
<td>.433</td>
<td>.789</td>
<td>-.404</td>
</tr>
<tr>
<td>4. Sense of burden and needing assistance</td>
<td>-.354</td>
<td>-.032</td>
<td>.496</td>
<td>.792</td>
</tr>
</tbody>
</table>
Discussion

- SCD stigma reduces availability of social support
- Delay in diagnosis, treatment, & comprehensive care
- Affects marriage, relationships, mobility, employment, attendance at social events
- Quality of Life and self-esteem can be affected
Implications

- Pilot begins to describe the challenges that adults & family caregivers face in communities, health care providers/systems, employment

- Stigma may be linked to both adherence to treatment regimens and health-related quality of life outcomes

- Content is needed in consumer and provider education programs to address stigma impact on families, community, and health care
Thank you!
References


