Ethno-Cultural Barriers to Health Literacy and Disease Management Among African-Americans (AAs) in South Carolina

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Project DIABETES
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Population: (2014 Census)
4.832 Million
- 63% Non-Hispanic White
- 27.8% African American
- 5.4% Hispanic/Latino

Diabetes: 43 counties have Diabetes rate above 7% and 3 have rates of 13%

Obesity Rate: 32.1%

Statewide Adult Literacy Rate: 14.5%
Graduated from High School: 84.5%
Percent Below Poverty 18.1%
Diabetes

- Currently affects over 28 million adults in US \(^6,7\),

- In South Carolina, 1 in 8 African Americans (AAs) have T2DM\(^6\),

- Managed through complex medication regime, physical activity, diet & lifestyle changes, that often exclude family members,

- Adherence may be linked to culture, illness perception and low Health Literacy (HL)\(^5\).
Background
Definition of Health Literacy

• The degree to which individuals have the capacity to obtain, process, understand and act on health information and services needed to make appropriate health decisions\(^1\),

• Influenced by cognitive skills, extended families, multiple systems, culture and social determinants of health\(^2\),

• Encompasses access to health information, capacity to use it, critical to empowerment and improving health outcomes\(^3\).
Why Health Literacy Matters

• People with low HL and chronic diseases, especially diabetes, self-report their health to be poorer than do those with higher HL levels\(^3\),

• 90 million (47%) US adults cannot accurately and consistently locate, match, and integrate information from newspaper, advertisement or forms\(^9\),

• 52% of SC residents cannot accurately and consistently integrate information from newspaper, \(^9\)
Importance of our Study

• Few studies have incorporated a cross-cultural approach, to address poor/low health literacy and chronic diseases across heterogeneous racial/ethnic populations,

• Fewer seek to explore cultural variation among AAs from other geographical regions, for their trusted sources and preferred format for seeking health information,

• Utilize a cross-cultural approach to identify contextual meanings and interpretations of diabetes as an illness among 4 distinct geographical regions within SC,
AIMS:
Explore the effect of beliefs and culture on health literacy and self-management of diabetes (SMDM) among AAs from 4 regions in SC,

To develop a reliable, valid, and generalizable survey tool with items that represent cultural beliefs, spirituality, diabetes experiences, and preference for receiving health information,
Research Design

• Non-experimental, mixed-method design divided into 3 phases

• **Phase One/Qualitative:** 14 focus groups to explore illness perceptions, cultural habits and beliefs, trusted information source, style, and preferred format for health information, and inform design of survey,

• **Phase Two/Quantitative:** Instrument Development
  Cognitive Interviews (CI) (11), Pre-test Instrument to 20 people,

• **Phase Three/Quantitative:** Administer the survey to 200 individuals (50 from each region),

Our Approach
Community Engagement

• Most AAs in SC reside in 9 counties known as the Low Country

We propose to study 4 specific areas in SC known as:

1. Blue Ridge Mountains (BRM) (Greenville, Edgefield)

2. Upper Piedmont Central Midlands/Lower Piedmont, (UP/LP) (Richland, Fairfield)

3. Coastal Plain (Outer, Inner) (OI) (Allendale, Jasper)

4. Pee Dee /Sand hill (SH) (Dillion, Orangeburg)
Conceptual Framework

- Guided by two models: Airhihenbuwa, PEN-3-Cultural model\textsuperscript{12} and the Social Ecological Model (SEM) model.\textsuperscript{11}
PEN-3 Model (Airhihenbuwa, 1995)

Person
Extended Family
Neighborhood

Focus of
Intervention

Perceptions
Enablers
Nurtures

Key influences on
HEALTH

Cultural
Identity

Cultural
Empowerment

Positive
Exotic
Negative

Impact of behavior
on health

Relationships
&
Expectations

MUSC
COLLEGE of NURSING
The sample included 14 focus groups with a combined total of 117 participants. 94% of these were living with diabetes/or had a family history of diabetes.

The focus groups took place from August to November of 2012 at locations that included the following...
Focus Group Demographics

- Gender – 78% Female, 22% Male
- Age – Mean **Average 54** Years Old
- Less than half 22% Married
- Employed – 25% or had
- Insurance – 26%
DATA ANALYSIS

Qualitative Constructivist Grounded Theory Approach

• A **codebook** was developed defining general themes identified in the focus group interview script. Sub-themes emerged from the data analysis and were added to the codebook as they emerged,

• Transcribed textual data from the focus groups were reviewed through a **continuous comparing of data segments**, looking for similarities, differences and themes,
Results from Focus Group
“A cry for help”

• The burden of living with diabetes

• Causation

• Location of resources
Phase Two: Instrument Development
Title: Development of an Instrument to Measure Diabetes Management, Spirituality, Cultural Beliefs & Health Literacy
Phase Three/Administration of Survey Relationships & Expectations

**Perceptions**
- Diabetes is the same as Sugar and Older folks prefer “Sugar”
- Trust doctors the most for Health information
- Fear associated with loss of limbs and eyesight
- Eating small portion is hard
- **Develop a partnership with God to help manage diabetes**
- Need help with medical instructions
- Hardest part about managing diabetes is eating right, portion control, changing diet, and reading labels

**Enablers**
- Group Sessions/classes or videos with family members or classes to learn more about Diabetes prevention and management
- Culturally sensitive pamphlets with clear diagrams and words

**Nurturers**
- Want family members to be part of the learning process as well
- Providers with same culture
- Humility
- Location of resources
Phase Three/Administration of Survey & Results & Cultural Empowerment

Positive

Learning how to improve diet is most important for what they want to learn
Willingness to learn

Exotic

At home remedies:
- Cinnamon
- Tea
- Ginger
- Vinegar & water
- Orange juice

Negative

- Have fears of amputations, blurred vision/blindness and death
- Want to eat what they want no matter the consequences
- Can’t afford medicines, eating healthy, or joining a gym
- No concept of what they need to know or want to know to manage diabetes better
- Lack of trust in healthcare system
## Survey Demographics

200 persons completed the surveys

<table>
<thead>
<tr>
<th></th>
<th>With Diabetes</th>
<th>Without Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Age</strong></td>
<td>60 years old</td>
<td>51 years old</td>
</tr>
<tr>
<td><strong>Married</strong></td>
<td>35%</td>
<td>35%</td>
</tr>
<tr>
<td><strong>Insurance</strong></td>
<td>91% have insurance</td>
<td>78% have insurance</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>73% women</td>
<td>81% women</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>8% college degree, 30% HS diploma</td>
<td>18% college degree, 23% HS Diploma</td>
</tr>
</tbody>
</table>
Other Survey Results

Most Preferred Ways of Receiving Education

• **Group sessions** so I can hear about different peoples’ situations,

• **Classes** to include family members,

• **Eye-catching, engaging pamphlets/flyers,**

Fears Related to Diabetes

44% percent of the sample acknowledged explicitly that diabetes was a serious condition,

**Bringing with it fears of amputation (25%), blindness (21%), and death (17%),**

“By not controlling it I mean, you can die from it. That’s something serious,”
Other Survey Results Cont.

Perceived Causes

36% believed diabetes is inherited,

38% said it is caused by carbohydrates, sweet foods/drinks,

Perceptions about Diabetes

More participants (33%) preferred to call the illness “diabetes” rather than “sugar”

26% voiced that there was no stigma attached to having diabetes,
Dissemination Phase

- **Four Free Community Forums**: Simpson United Methodist Church Allendale County

- **Four Stakeholders Meetings**: Fairfield County : St Luke Baptist Church, Fairfield County
Project DIABETES receives Award from Congressman Clyburn, 2015


Questions
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