Cultural Health Beliefs and Practices that Shape Health Literacy and Chronic Illness Outcomes in Four Populations: Preliminary Findings

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Background:

- Health literacy is an important factor in patient compliance and chronic disease outcomes.

- Often those with greatest health burdens (immigrant and refugee groups, low income, ethnic minority populations) have limited access to health information and limited ability to process that information.
Background:

- Previous research has focused on traditional definitions of health literacy.
- Little work has placed health literacy in the broader context of socioeconomic and cultural differences between patients and providers.
- NCI-funded 4 year project “The Impact of Culture on Health Literacy and Chronic Illness Outcomes” to explore cultural factors associated with health literacy and health outcomes.
Background: What is Health Literacy?

1. **Working Definition**: The ability to understand and act on a doctor/health provider’s instructions

2. **Traditional Definitions**: Related to and determined by patient literacy; often a marker for patient’s educational level and a proxy of patient’s SES
How does culture influence health literacy?

- Cultural health beliefs and practices influence patient/provider perceptions of:
  - Causes of illness
  - Appropriate treatments
  - Compliance/adherence practices
  - Self-care and disease prevention
  - How the body and mind work
  - Symptoms
  - Appropriate doctor/patient conduct and communication
Why study health literacy?

- If, in fact, health literacy is a factor in disparate health outcomes across cultural groups, then health literacy becomes a target for change aimed at “closing the gap”

- Health Literacy is changeable. It can be improved.

- Therefore, health literacy becomes a target for public health interventions to reduce and eliminate health disparities among ethnic minorities.

- Recommendations/suggestions to providers on how to improve the patient/provider communication and improve patients’ health literacy
Theoretical Model

Health Literacy

Culture

Adherence

Health Outcomes
Study Site:
Caring Health Center, Springfield, MA

- Section 330 federally qualified health center
- Main Street & Forest Park
- Medically Underserved Area
- CHC serves low to no income, uninsured or underinsured, immigrants and ethnic minority groups
Community Served

- 70% non-White
  - 49% Latino
  - 15% African American/Black
  - 6% Asian/Pacific Islander

- Increasing numbers of refugees from Somalia, Sudan, Liberia, Turkey, the former Soviet Union and Eastern Europe

- Many face cultural and linguistic barriers to accessing health care
Community Served: Pilot Study “Closing the Gap”

African American and Latino CHC patients with diabetes (N=122)

- Latino participants (n=77): 89% Puerto Rican
- 55% speak Spanish at home
- Educational Level: 89% have not completed high school
- Employment: 64% are unemployed
- 89% rate their health as fair to poor
- 54% describe themselves as disabled
Community Served: Pilot Study “Closing the Gap”

- Blood sugar control:
  - 53% 1 to 3 days of high blood sugar reaction in the last month
  - 32% up to 6 days of high blood sugar reaction in the last month
  - Only 11% had not experienced any high blood sugar days in the last month.

- 95% test blood sugar
- 57% keep a record of results
- 60% share results with their doctor
- 18% told by doctor that diabetes had affected their eyes or that they have retinopathy
Community Served: Pilot Study “Closing the Gap”

- **Diabetes Knowledge**
  - Scored fairly low
  - 81.7% could not name the food that was highest in carbohydrates of 4 choices
  - 72% thought Hemoglobin A1C measured average blood glucose over last 6 months
  - 90% thought unsweetened fruit juice had no effect on blood sugar
  - 83% thought best way to care for feet was to buy shoes a size larger than usual
Methods

- Multi-method design combining qualitative and quantitative approaches to data collection
  - Epidemiological Survey (Baseline, 18 months)
  - Medical Chart Abstraction (Baseline, 12, 24 months)
  - Formative focus groups, In-depth interviews, Chronic Disease Diaries, Home Observations
Methods:

- Triangulation of qualitative data with survey data and chart abstraction data to identify cultural factors associated with low health literacy and poor adherence
## Overall Design:
*(N = 400)*

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th>African - American</th>
<th>Latino</th>
<th>Vietnamese</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diabetes</strong></td>
<td>(n=50)</td>
<td>(n=50)</td>
<td>(n=50)</td>
<td>(n=50)</td>
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<tr>
<td><strong>Hypertension</strong></td>
<td>(n=50)</td>
<td>(n=50)</td>
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</tbody>
</table>
Core Variables in the Study:

- Culture/ Ethnicity
- Chronic Disease (Diabetes/Hypertension)
- Health Literacy
- Adherence
- Health Outcomes
- Cancer Screening Utilization
Epidemiological Survey: Baseline & 18 Months

- (Demographics)
- **Acculturation** (Latino/Hispanics, Vietnamese, African American)
- **Health Status**
  - Mindfulness skills
  - Tobacco Use
  - Physical Activity
  - Diet/Nutrition
  - Health Care Access
  - Specialist Care
- **Disease Specific Questions** (Diabetes & Hypertension)
- **Treatment Adherence**
- **Cancer Screening**
- **Health Literacy** (TOFHLA, REALM, SAHLSA)
- Patient Perceptions of Care
Survey Design: Process

- Compiled one seamless survey from a variety of existing instruments
- Consulted with providers
- Piloted survey with staff for timing, flow, and understanding
Survey Design: Process

- Ran formative focus groups with each ethnic group to explore certain topics
- Modified survey based on focus group results
- Piloted English survey with sample of English-speaking Latino, Vietnamese, African American, and White patients
- Professionally translated into Spanish and Vietnamese
Survey Design: Challenges

- Ensuring cultural relevance

- Health literacy instruments have limited applicability across cultural/ethnic groups and across languages
Survey Design: Challenges with TOFHLA

- **TOFHLA Reading Comprehension:**
  - Dropped reading comprehension section. “Test” format not suitable for patient population.
  - Replaced TOFHLA reading comprehension with REALM

- **TOFHLA Numeracy:**
  - Prescription bottle labels translated into each language. Scores need to be interpreted with caution because prescription labels are often only printed in English
Survey Design: TOFHLA Numeracy

If you take your first tablet at 7:00 a.m., when should you take your next one?

1 Correct
0 Incorrect
Survey Design: Challenges with REALM

- For Spanish-speaking participants, replaced REALM with SAHLSA (Short Assessment of Health Literacy in Spanish-speaking Adults).

- For the Vietnamese survey, currently exploring, researching, consulting to figure out how best to measure health literacy.
REALM: Rapid Estimate of Adult Literacy in Medicine

List 1-3 Sample:

**List 1**
- Fat
- Flu
- Pill
- Dose
- Eye
- Stress

**List 2**
- Prescription
- Notify
- Gallbladder
- Calories
- Depression
- Miscarriage

**List 3**
- Diagnosis
- Potassium
- Anemia
- Obesity
- Osteoporosis
- Impetigo
SAHLSA: Short Assessment of Health Literacy in Spanish-speaking Adults

próstata  ictericia
Glándula  circulación
amarillo  blanco
Qualitative Data Collection:

1. Formative Focus groups
2. In-depth Interviews
3. Chronic Disease Daily Diaries
4. Home Observations (Food shopping, meal preparation, access to safe space for physical activity)
Latino Focus Group:

- **Home remedies:**
  - Black coffee for eye infection, coffee grinds wrapped in a bandana for a headache, potato peels on the bottom of feet for fever
  - Savila, hoja de tomate, ajo, parcha, yerba bruja
  - Now easier to access doctor and rely on medical treatment than to grow, access, and use home remedies of Puerto Rico
Latino Focus Group:

- **Diet/Nutrition**: “Hay que comer la comida!” Economically, it is difficult to cook separate meals for family members.

- **Fast food defined**: Time it takes to cook thoroughly, time it takes to eat completely, where it is eaten, what it is eaten in combination with, and how long it has been sitting out

- **Physical Activity**: Stretches in the bed and/or against the wall; yoga ball while watching T.V.; walking with children in the park, caring for small children/grandchildren
African American Focus Group:

- **Diet/Adherence**: Reason for noncompliance with recommended diet is because food is not good. Eat what you are served. Family (wife) tends to give large portion.

- **Mindfulness**: Pay a lot of attention to the body and how it feels. If something feels wrong, take a couple of days to observe it. If not resolved, go to the doctor. Notices changes in the body when does not take medication. Body lets him know that he should be taking the pills.

- **Social Support**: Important to consult with wife, pastor, friends, and family about health
Vietnamese Focus Group:

- **Acculturation**: Acculturation and impact on adherence and use of home remedies; traditional healing versus seeing the doctor, “join them” attitude.

- **Home Remedies**: Receive things from Vietnam from family members. Choose to follow doctors orders rather than use home remedies.

- **Diet/Nutrition**: Has different impact on health in Vietnam versus in U.S. Sedentary lifestyle/environmental factors impact daily physical activity. Diet becomes more significant factor in health in the absence of enough movement.
Vietnamese Focus Group

- **Physical Activity**: Walking in neighborhood and Forest park; Combine physical activity with religion (e.g. sweep and pray); listening to doctor and taking medications is not enough, have to also do physical activity.

- **Mindfulness**: Body reacts to what is in the mind. Stressful thoughts present as neck pain or rise in blood pressure. Main reason for not feeling well, usually, is in the mind—stress. Need to sing, listen to music, garden, dance, laugh, to distress.
Barriers to Care

- Transportation
- Health Insurance
- Lack of social support system (particularly regarding chronic illness)
- Depression
- Lack of information
- Childcare
- Poverty
- Homelessness
- Language Barrier
Preliminary Recommendations:
Health literacy research with low-income/ethnic minority populations

- Stigma associated with (il)literacy makes rapport even more essential
- CBPR ensures greater acceptability of instrument to diverse participant groups
- Qualitative methods collect linguistically & culturally relevant concepts & terms
Preliminary Recommendations: Health care providers caring for diverse, low literate populations

- **Express** respect for patients’ health practices and beliefs
- Explore reasons for non-adherence
- Recognize diverse health beliefs as a critical aspect of health *literacy* (e.g., What is fast food?)
Preliminary Recommendations: Health care providers, cont.

- Provide education materials (videos & handouts) for lower literacy
- Practice **active listening**: Check back in w/ patient re: patient’s understanding of instructions
- Ensure availability of trained medical interpreters