Structural and Cultural Factors in Chronic Disease Self-Management in a Low-income Population

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Methods

- Community-based research
- Multi-method research design
- Longitudinal survey with 291 patients from 4 ethnic groups
  - African-American, Latino, Vietnamese, white
  - Administered orally by bilingual/bicultural interviewers
- Medical Chart Abstraction at baseline and 12 months

Qualitative Data Collection

1. Formative Focus groups (n=9)
2. In-depth Interviews (n=35)
3. Chronic Disease Daily Diaries (n=15)
4. Home Observations (Food shopping, meal preparation, access to safe space for physical activity) (n=10)

Today's Aims

- Cultural beliefs affect health knowledge and behaviors
- Health beliefs and explanatory models among people with adequate and inadequate health literacy
- Motivations for adherence
- Barriers to adherence
- Recommendations

What are Explanatory Models?

- EMs explain cause, treatment, effects of illnesses
- EMs can compete, overlap, extend, or contradict one another
- Multiple EMs may exist for one condition

Kleinman's 8 questions

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. What do you think your sickness does to you?
4. How severe is your sickness? Do you think it will last a long time, or will it be better soon in your opinion?
5. What are the chief problems your sickness has caused for you?
6. What do you fear most about your sickness?
7. What kind of treatment would you like to have?
8. What are the most important results you hope to get from treatment?

Explanatory model: Hypertension

- Vietnamese female: “I notice that I would have a headache, and my face is very warm”
- Latino male: “People with hypertension can’t eat a lot because you start getting short of breath. And another thing is that when you get scared or something, my pressure goes up and I get headaches too…. One of the biggest problems with high pressure with me is the- No, well, it’s my temper, if I get angry with anything, a discussion, it’s like anxiety.”

Explanatory model: Hypertension

In my understanding, hypertension is that the heart is pumping the blood very fast. The flow of the blood is very fast. Faster than normal. And that, well, since it's not normal in the system of the human body, it can bring on complications... and heart problems because the heart is going to be very agitated, um, if it has, like in my case, where I already have high cholesterol, that means the veins are obstructed, they're--since they have too much fat, the blood is passing through there but like very pressurized. When you have high blood pressure and pumping faster it can get blocked.

Explanatory Model: Diabetes

- Vietnamese male: “I don’t know much about diabetes or what it does, I just follow my doctor’s recommendations. But I think the years I spent in prison in Vietnam, and overwork, and bad food can cause diabetes.”
- Latino male: “What worries me is that it [my blood sugar] goes up the same way it comes down. … So sometimes when the diabetes goes up, my blood pressure rises too.”

Explanatory Model: Diabetes

- Vietnamese male: “The cause is the high intake of sugar versus how much your body can use. So in old age my body works less and needs less of the sugar. But if I eat a lot of sugar, like the sweetcake… that’s not to say – our body does need sugar, it just doesn’t need as much any more at this age. So I used the sugar in the food and the vegetables instead of the other kind of sugar.”

Conflating multiple conditions: An opportunity?

Sodium + blood pressure + cholesterol = “salturated fat”:

“Soups are, if you ever read the back of them, they’re high in cholesterol. Not, not so much high in chole— they got, high in cholesterol plus they’re high in blood pressure, they’re high in salt. … I gotta eat low sodium, … I gotta eat less than 6m—no, no, I gotta eat 6mg of salt... a day. Salturated fat a day. Salt.”

Motivations for adherence: Family relationships

“I’m only 41 years old and it’s been 11 years since I’ve seen my mom. She’s in Puerto Rico, and I really felt scared that I would have a heart attack or something. And that motivates me to take my medicines daily, because I want to see my mom. I don’t want to die over here without seeing my mom. So I have taken this very seriously. I know that I have this illness, and the only thing that can help me is to follow the doctor’s instructions and that’s why in the whole morning, the first thing I do is take my medications. They are really important to me.”

Motivation for adherence: social support

“In my house we got used to eating a lot of salad, because since the doctor and some other people as well have told me that salad is really healthy for when you have cholesterol since it doesn’t have any fat. So, in between meals, if I get hungry, I eat a salad. [Q: Who else said that to you besides your doctor?] A: People who are also waiting to get called up in the clinic. I have talked to them about my situation. … so they have told me, ‘look the same thing happened to me and my cholesterol went down because I had a diet that was this way,’ so, I have done it because of that.”

Barriers to self-management: co-pays

A: …last month I had to wait for the prescription for almost 2 weeks because I didn't have the money, they were $9, they were three medication, so it was $9. I had to wait 2 weeks [for my next disability payment], collect so then I could pay the $9 and get my prescriptions.

Q: So in these 2 weeks...

A: I was left without medications.

Barriers to self-management: Health insurance coverage

"There's another medication [Nexium] that I used to take but MassHealth also stopped that. That was for my stomach, intestine. It's hurting, but the medication isn't covered, and there were no more samples for me. … The doctor has prescribed other pills since MassHealth has stopped that but those don't work as well."

Barriers to self-management: Health insurance coverage

- Low health literacy may compound constraints imposed by limited health insurance coverage:
  - A: MassHealth stopped covering [Zetia], so this is left over, and I'm saving it for, as needed.
  - Q: How do you know you need it, when to take it?
  - A: When I feel uncomfortable.
  - Q: And how does that feel?
  - A: For example, when I have my blood pressure taken when I go see the doctor, if I am told that it's high then I take it.

Recommendations for Clinicians

- Build on low literacy patients' strengths in social support, and cultural values
- Recognize elements of patients’ explanatory models that incorporate biomedical concepts
- Build on culturally congruent conceptions of health and illness to help patients' abilities to successfully manage their chronic illnesses

Recommendations for researchers

- Broaden our understanding of health literacy to include:
  - Explanatory models of disease
  - Self-care abilities
- Might the conflation of chronic diseases described by participants provide data, rather than noise?

For more information

- Contact shaws@email.arizona.edu or visit http://anthropology.arizona.edu/culturehealth literacy/

Adherence without comprehension?

- I take my medication as soon as I wake up. I take a vitamin pill, I'm on Vitamin D now, too. I take one 500mg and I take one that's 1000mg of D. [Q: Why do you take vit D?] A: (pause) *That* you gotta ask my doctor.
- I know the medicine helps. I don't know how but I feel better when I takes it so I follow the doctor's orders.
- I must remember every morning. When I take my coffee that's when I take the medicine, because the doctor says so, because I have hypertension I must take medicine. When the doctor orders we must follow.