Measuring Health Literacy Across Diverse Populations

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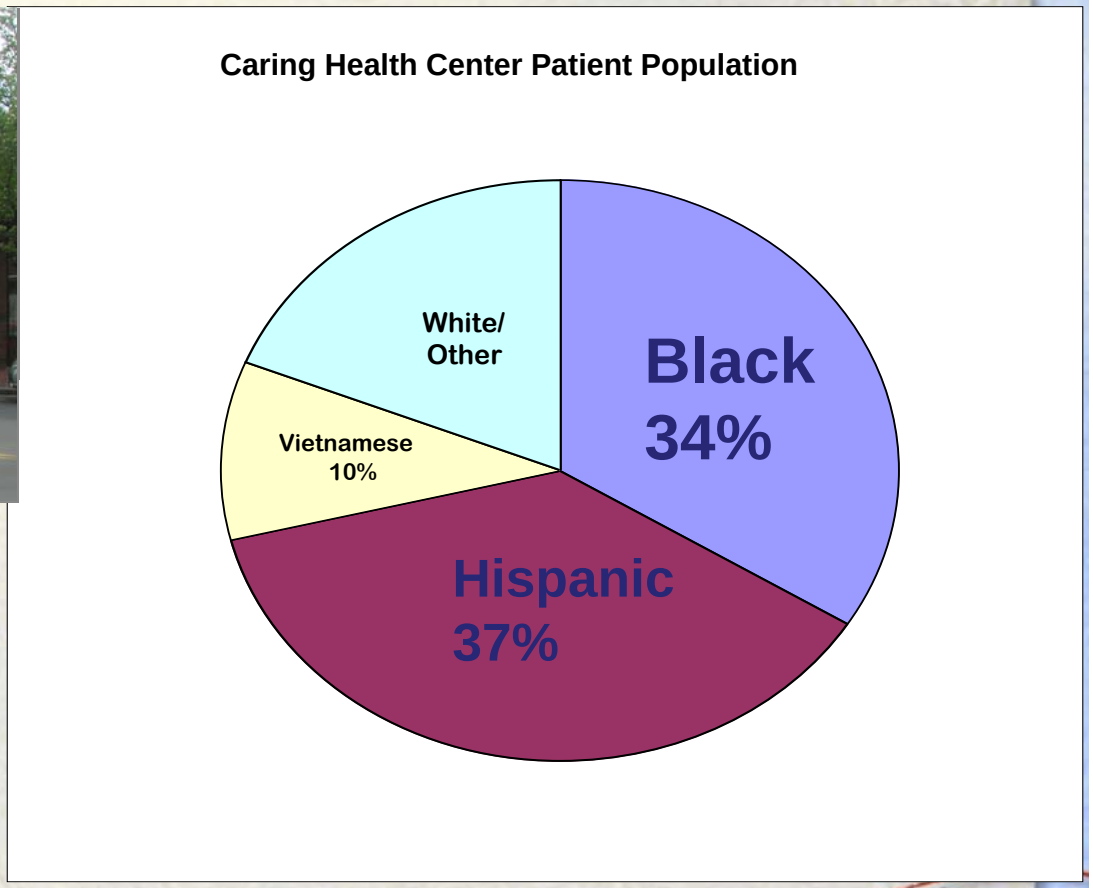
Research site: Caring Health Center, Springfield, MA

- Section 330 community health center
- Medically underserved, refugee resettlement area
- >50% of CHC's adult patients require translation services



Sample Overview

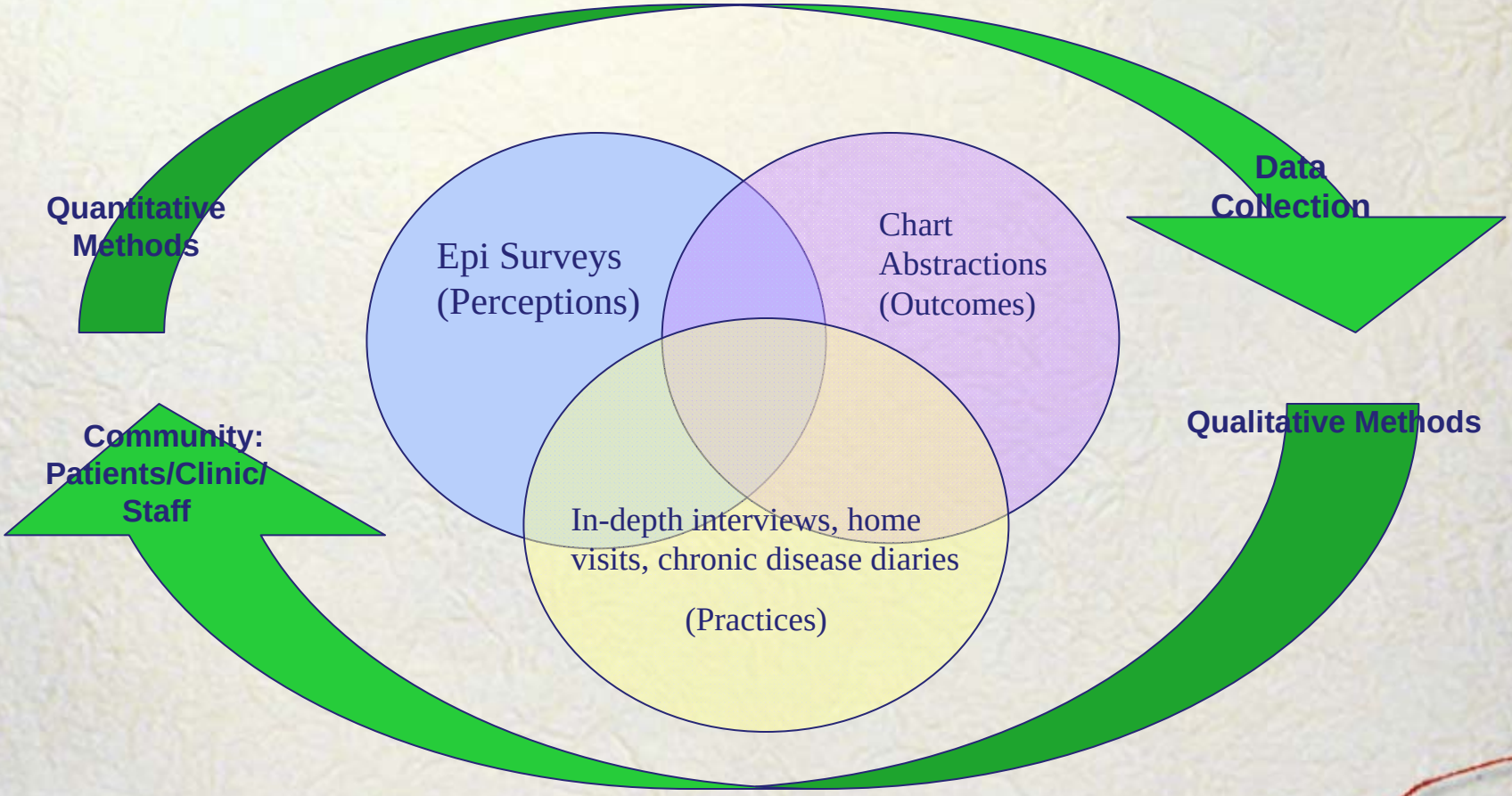
- 83% of Latino (PR) participants speak Spanish at home
- 100% of Vietnamese participants speak Vietnamese or other southeast Asian languages at home
- 34% of all participants had ≤8th grade education
- 67% rated their health as fair to poor
- 59% are disabled
- 74% estimate their **household** income to be less than $1,200/mo

N=291	white	African-American	Vietna-mese	Latino
Male	25	34	40	49
Female	15	30	47	51
Total	40	64	87	100

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
- Formative focus groups for instrument development
- In-depth interviews (n=30)
- Home visits (n=6)
- Chronic disease diaries (n=9)

Methods


Quantitative Methods
Data Collection
Epi Surveys (Perceptions)
Chart Abstractions (Outcomes)
Community: Patients/Clinic/ Staff
Qualitative Methods
In-depth interviews, home visits, chronic disease diaries
(Practices)

Qualitative Data Collection

1. Formative Focus groups (n=9)
2. In-depth Interviews (n=30)
3. Chronic Disease Daily Diaries (n=5)
4. Home Observations (Food shopping, meal preparation, access to safe space for physical activity) (n=5)

Instrument Development

- Adapted existing health literacy and acculturation scales for use in four ethnic groups (African-American, white, Latino, and Vietnamese) by:
  - translating TOFHLA into Vietnamese and pre-testing w/ members of target population
  - Formative focus groups to develop examples/prompts for acculturation scale

Instrument Development, cont.

- We matched health literacy scales to participants' language of choice:
  - Wave 1: **All** participants completed the TOFHLA (Test of Functional Health Literacy in Adults) numeracy scale, and:
    - Latinos completed the SAHLSA (Short Assessment of Health Literacy for Spanish-speaking Adults)
    - English-speakers (White and Black) completed the REALM (Rapid Estimate of Adult Literacy in Medicine)
  - Wave 2: We added the complete TOFHLA reading comprehension scale, translating it into Vietnamese and administering English, Spanish and Vietnamese versions of the entire TOFHLA short form. (We did not repeat the SAHLSA and REALM.)
- NB: The TOFHLA has not been normed or validated for Vietnamese-speakers

Findings: Health Literacy

Ethnic Group	REALM Mean n.s.	TOFLHA Mean* p<.001
White	52.0	79.77
Black	53.8	79.61
Vietnamese	N/A	51.04
Latino	52.7*	60.21
	*14 Latinos completed REALM	*Wave 2, n=151 p<.0001

Findings:
In/adequate Health Literacy

Health Literacy scores	White (n=40)	African-American (n=64)	Vietnamese (n=86)	Latino (n=100)	Significance
TOFHLA	79.77 a N=13	13.70 a 33	9.77 b 46	10.17 b N=56	p<.0001
adequate	76.9%	81.8%	23.9%	53.6%	p<.0001
marginal	7.7%	9.1%	19.6%	10.7%	
inadequate	15.4%	9.1%	56.5%	35.7%	
REALM	52.0	53.8	N/A	52.71 (n=14)	n.s.
adequate	72.5%	82.8%		78.6%	n.s.
inadequate	27.5%	17.2%		21.4%	
SAHLSA	N/A	N/A	N/A	35.34	
adequate				66.3%	
inadequate				33.7%	

Income, Education and Health Literacy

TOFHLA score is positively, but not consistently, correlated with:

- Fluency in English
- Education level
- Income

Consider self fluent in English		
	Yes	No
Numeracy X	11.57	9.33
Inadequate	15.4%	52.9%
Marginal	3.8%	20.0%
Adequate	80.8%	27.1%

Income and TOFHLA		
Monthly HH inc	Inadequate	Adequate
<$800/mo.	60%	40%
$800+	40%	58%

Measuring Health Literacy: Qualitative Findings

Patients tend to substitute personal experience in place of abstract examples in TOFHLA:

Interviewer (in Spanish): So, this is a card that says, “the normal blood glucose level is between 60-150.”

Participant 3 (in English): That’s incorrect.

Interviewer (in Spanish): And below it says, “today your level is 160.”

P3: That’s incorrect.

Interviewer: If this was your result, would it be within the normal range?

P1: No… incorrect.

Interviewer: And why?

P1: Because as I understand it is from 80 to 120.

P3 (interrupting P1): It’s up to 132.

P1: And here it says 160 which is too much. If someone has 160 they need to inject a little bit of insulin. At least 1mg or 2.

P3: Or take a pill.

~From a Latino focus group

Qualitative Findings, cont.

Q:...So this first one...you see the card there, card one? It says, 'if your blood sugar today is 160 would your blood sugar be normal today? ....

P1: I'd say, No! My, my blood sugar usually don't be 150 and you know... It be under that, 120, or something, uh, 138... So it can go up and down,

Q: It's usually about what, you said?

P1: One-, one-no higher than 138.

Q: Okay.

P2: Me, I probably would be normal and I got high blood sugar, so I... have a problem with that.

Q: So what would your answer be to this one, you were saying?

P2: I'd put say um... It would be normal.

Q: It would be normal. And your reasoning behind that you said, was because your…

P2: Yeah, I uh, I have high blood sugar and when I first went to caring health, I started going there in '95, and the doctor there told me, well actually mine was around 80, 90 to 170....That's always been kinda normal for me, ever since I had it's been, high and, high and low, like this morning I woke up and took my blood sugar, Ooh, it's 220. That was at 9 o'clock this morning!

~From an African-American Focus Group

Cloze Procedure in TOFHLA Is Not Universally Known

- For example, one participant kept saying “I’m too old” and “I don’t know.” The patient seemed willing to try but seemed upset when she was unable to understand the question. The patient seemed to feel uneasy.
- Another participant, confronted with the TOFHLA reading comprehension, reported that she doesn’t want to read. When the interviewer explained the process the patient was reluctant to go get her eyeglasses. She state she doesn’t remember having to do this the previous year (when only TOFHLA numeracy section was administered in Vietnamese).

-From fieldnotes, TOFHLA survey

Cultural beliefs affect health literacy and health behaviors

- Cultural health beliefs are part of internally consistent ethno-medical systems
  - That may/not incorporate biomedical information
  - Pluralistic medical systems: hierarchies of resort are often informed by experience
- e.g., hot/cold “humoral” theories of illness causation
- e.g., Russian patients lack a concept of “chronic disease” based on their experiences with Soviet health care
  - may be more likely to discontinue diabetes or hypertension meds once they feel better

Recommendations

- Couple instrument development with focus groups/formative research
- Simple translation may not be adequate for diverse groups: Follow SAHLSA instrument development procedure to develop Vietnamese/other health literacy scales

Conclusions

- Patients tend to substitute personal experience in place of abstract examples in TOFHLA
- Cloze procedure in TOFHLA is not universally known
- Cultural beliefs affect health knowledge and behaviors in ways that may or may not incorporate biomedical information

For more information

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