

Understanding and Addressing Stigma Associated with Low Health Literacy

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Health Literacy Across Contexts



YOU DIDN'T KNOW ABOUT FOLIC ACID.

YOU GOT LUCKY

TAKING A MULTI-VITAMIN WITH FOLIC ACID CAN GREATLY IMPROVE YOUR DAUGHTER'S HEALTH.

helps prevent cancer
lower risk of heart disease
helps with memory and retention
may help with depression
reduces risk of birth defects
improves appearance of hair and skin
reduces risk of stroke

Don't wait. Get your daughter started on a multivitamin with Folic Acid to improve her health now and in the future.

Look for a multivitamin that includes the recommended daily amount of folic acid: 400-800 micrograms (400-800mcg or .4- .8mg).

I (we) voluntarily request Dr. Jane Smith as my physician, and such associates, technical assistants and other health care providers as they may deem necessary, to treat my condition which has been explained to me (us) as: Acute Myocardial Infarction or heart attack.

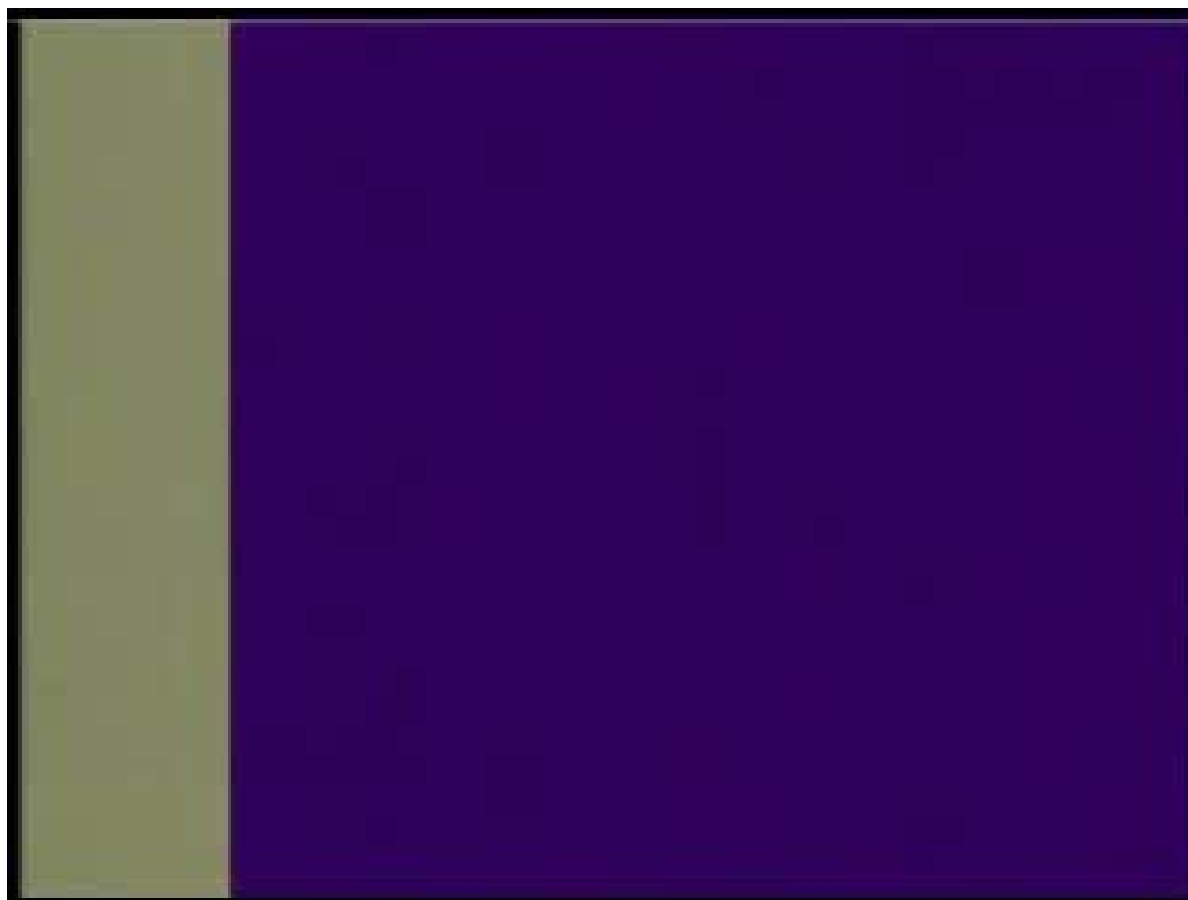
I voluntarily request my physician Dr. Jane Smith, and other medically-necessary health care providers, to treat my condition: Acute Myocardial Infarction, commonly known as a heart attack.

I (we) authorize my physician, and such associates, technical assistants and other health care providers to perform such other procedures which are advisable in their professional judgment.

I authorize my physician, and any other necessary health care providers, to use their professional judgment to perform the additional procedures that they believe are needed.



A Personal Story



Public Perceptions of Health Literacy

- *The problem is with the idiots that take 1000mg and then cant wait for it to work so they take another 2-4 in an hour or so. The people that are stupid and dont read the bottle that says “DO NOT TAKE MORE THAN XXX in a 24 hour period.” It’s clear as day on the fricking bottle. So we ban something because the average person is too stupid to read the bottle?*
- *Bottom line: READ THE DAMN LABEL. Make sure you're not taking too much. Check with your doctor if you're not sure. A lot of medications will screw you up if you take too much. Equip yourself with knowledge and you'll be fine.*

Public Perceptions of Health Literacy

- *I don't know about the pharmacy you use, but all of our labels are clearly marked. For example if a patient receives some Norco 5, their label will read: Hydrocodone/APAP 5-325. The first number (5) is the hydrocodone and the second number (325) is the tylenol.*
- *In this case, assuming suitable labeling, "stupidity" implies possession of fairly low cognitive capacity (for label cross checking) and/or memory (for tracking pills taken over time). Sounds an awful lot like, for instance, the sicker, more arthritic old people who, as a population, probably suck down painkillers and anti-inflammatory drugs like nobody's business.*

Stigma

- Stigma is defined as an attribute of a person that is deeply discrediting
- Stigma can be enacted when “normal” individuals discriminate against those with a stigmatized attribute
- Stigma can be felt when one perceives they are experiencing discrimination based on a stigmatized attribute

Stigma and Health Literacy

- Low health literate patients try to hide their challenges from healthcare providers
- Training manuals for healthcare providers highlight ways that low health literate patients might try to hide their problem
 - “Forgetting” their glasses
 - Always needing to show someone else documents and information



If we knew what it was we were doing, it would not be called research,
would it?

-Albert Einstein

A STUDY OF HEALTH LITERACY AND STIGMA

Research Questions

- **RQ1:** How does participants' self-reported health literacy compare to their measured health literacy?
- **RQ2:** What factors – age, ethnicity, insurance status, etc. – affect participants' perceptions of an individual's struggles with health information?

Methods

- Nationally representative sample (N=4,974)
- Measures
 - Objective and subjective assessment of health literacy
 - Vignettes which varied gender, ethnicity, and insurance status
 - Attitudes toward people who struggle with health information

Vignette 1

- *Mr. S. is a 33-year old **White** father of one. He has health insurance through **Medicaid**. His daughter had an ear infection. When he picked up her medicine from the pharmacy, he was told to give her one tablespoon twice a day. The pharmacist asked him if he had any questions, and he did not. He thought this was easy and didn't feel like he should have any questions. When he got home, he poured one tablespoon of medicine into her ear – leading to a trip to the emergency room. The doctor at the emergency room could not believe Mr. S. poured medicine into his daughter's ear, but Mr. S. explains that he thought medicine should go where the problem was.*

Vignette 2

- *Ms. S. is a 72-year old **Hispanic** woman. She has health insurance through **Medicare**. She is on several medications to manage these conditions, but she does not always take her medicine correctly. Sometimes she takes too many pills in a day, sometimes she forgets to take them at all. She always feels fine, though, so she does not think there is any kind of problem. At her annual check-up, Ms. S.'s doctor explains that her high blood pressure and high cholesterol are getting worse - putting her at risk for a heart attack, a stroke, or even death. They discuss how Ms. S. is taking her medicine, and when asked Ms. S. assures the doctor she knows how she is supposed to take her medicine. Ms. S. feels like taking her medication should be simple, and she shouldn't have any questions.*

RQ1: How does participants' self-reported health literacy compare to their measured health literacy?

- Objective health literacy:
 - Average NVS = 4.9 (SD=1.4)
 - 16% of participants scored 3 or less
- Subjective health literacy:
 - 7% indicate lack of confidence filling out medical forms
 - 5% report problems learning about medical conditions
 - 6% have someone help them read health materials

RQ1: How does participants' self-reported health literacy compare to their measured health literacy?

- Of the 16% of the sample that screens as having low health literacy...
 - 68% express confidence filling out medical forms
 - 59% never or rarely have problems learning about medical conditions
 - 68% never or rarely have someone help them read health materials

RQ2: What factors – age, ethnicity, insurance status, etc. – affect participants’ perceptions of an individual’s struggles with health information?

- People react more negatively to a younger individual struggling with health information
 - Feel the younger individual is more personally responsible
 - Have more anger towards the younger individual
 - More pity for the younger individual
- People who self-report struggling with health information more likely to express pity toward those who struggle with health information

RQ2: What factors – age, ethnicity, insurance status, etc. – affect participants’ perceptions of an individual’s struggles with health information?

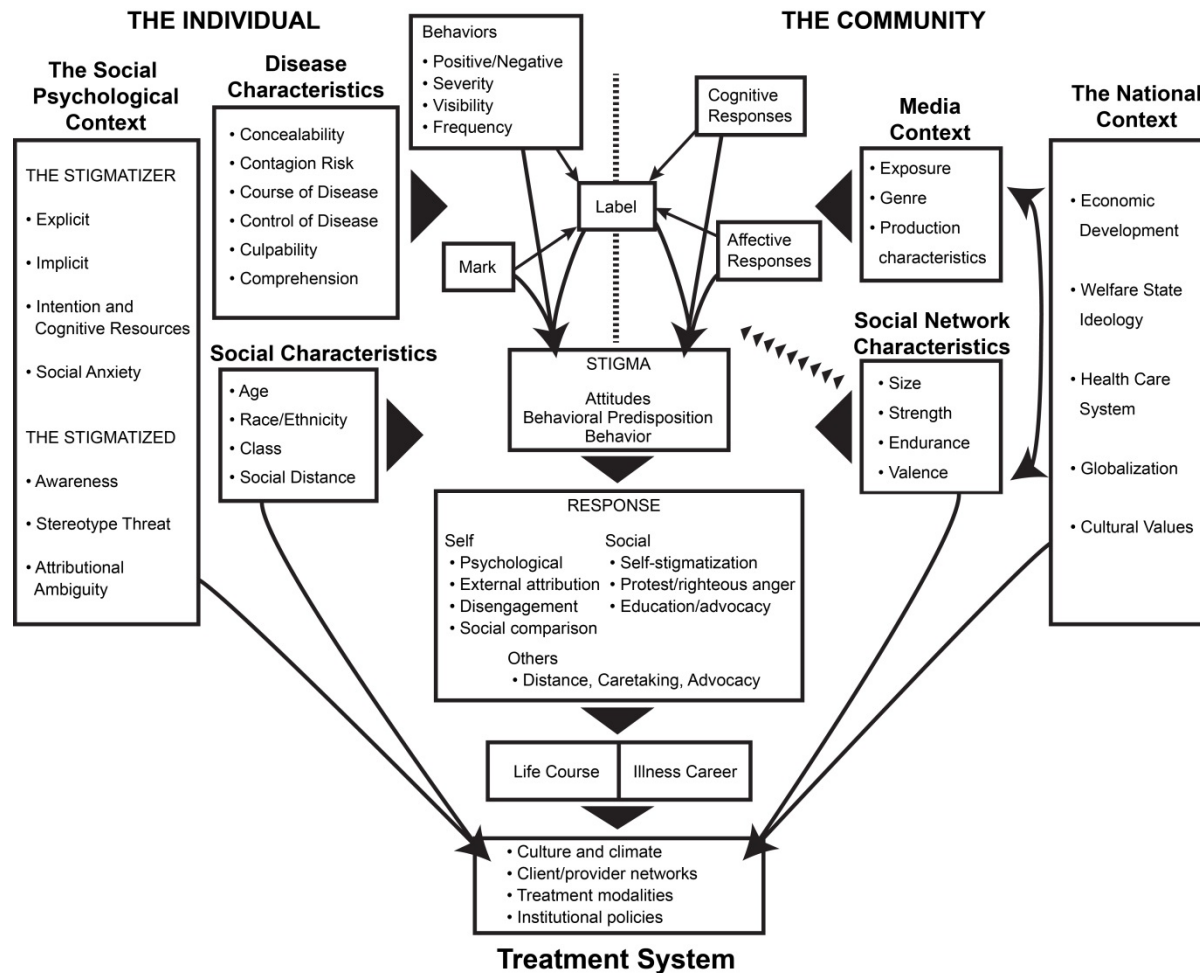
- Healthcare providers less likely to be angry and more likely to have pity for lower health literate patients
- Ethnicity/race, gender, and insurance status don’t matter

It usually takes me more than three weeks to prepare a good impromptu speech.

-Mark Twain

SO WHAT DO WE DO?

What Causes Stigma?



Advancing Research and Practice

- **Micro-Level Factors (Individuals)**
 - Interpersonal interactions with healthcare providers of all kinds
- **Meso-Level Factors (Organizations and Groups)**
 - Informed consent
 - How healthcare systems care for people with physical disabilities (e.g., visual and hearing impairments) which may compromise health literacy
 - Social networks and contact with people with low health literacy
- **Macro-Level Factors (Societal Level)**
 - The role of the media in shaping perceptions of low health literate patients
 - Health literacy as a national issue – Healthy People 2020, NIH funding, conferences, etc. – raising awareness of the problem



Next Steps

- Raise awareness about the stigma associated with health literacy as part of provider training
- Create shame-free healthcare environments
- Develop patients' health literacy

Conclusion

- Stigma associated with health literacy is a pressing issue for both research and practice
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