Health Literacy and Stigma: A Research Agenda to Improve Practice and Outcomes

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Purpose: Stigma associated with low health literacy – which practitioners may know of anecdotally but has received virtually no scholarly attention – could further exacerbate challenges and poorer health outcomes experienced by low health literate patients. The purpose of this presentation is to share an agenda for advancing research about the stigma associated with low health literacy, report the results of a first pilot investigating this issue, and discuss future directions for improving research and practice in this area.

Background and Rationale: Health literacy is the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions.¹ Patients who struggle with low health literacy – an estimated one third of U.S. adults – experience poorer health outcomes and contribute to unnecessary costs for the healthcare system.²,³ Increased recognition of the link between health literacy and poorer health outcomes has led to the development of manuals and training programs to help healthcare providers of all kinds more successfully interact with and care for lower health literate patients.⁴,⁵

One aspect of such training is becoming aware of how low health literate patients may try to disguise their challenges, such as claiming to have forgotten their glasses at home or needing to show paperwork to someone who is not present at the visit.³ This suggests lower health literate patients may experience stigma – defined as an attribute of a person that is deeply discrediting⁶ – related to their struggles with health information. Stigma can be enacted when “normal” individuals discriminate against those with a stigmatized attribute, or it can be felt when one perceives they are experiencing discrimination based on a stigmatized attribute. While there is limited research on stigma associated with low health literacy, research has found patients hide
their challenges from practitioners due to perceived stigma and that some members of the public seem to regard low health literacy as a blemish of individual character. Research on other stigmatized conditions such as mental illness and HIV status find that those who conceal a stigmatized attribute experience stressors related to disclosure, feelings of isolation, and a sense of detachment from their true identity. Thus, both stigma and low health literacy can exacerbate negative health outcomes associated with illness.

**Methods:** A nationally representative sample was recruited via an opt-in online research panel. The final sample ($N=265$) had an average age of 54.9 years (SD=13.9) and was predominantly White (75%), followed by Asian (4%), Hispanic (3%) African American (3%), and “other” (2%). A sizable minority of participants (11.7%) self-identified as working in healthcare. The majority of participants reported attaining a 2-year college degree or higher (64.1%), and the median annual household income was between $60,000-$69,999.

Survey items related to stigma were adapted from established research related to mental health and stigma. Participants were asked about their own health literacy, level-of-contact with others who struggle to understand health information, and stigmatized perceptions of those with low health literacy. To examine stigmatizing perceptions, participants were randomly assigned to read one of three vignettes about a man who struggles with health literacy. Contextual factors such as the man’s age and negative health outcomes were varied to explore how different factors – a lower health literate individual’s age and whether they or someone else was impacted – might affect stigmatized perceptions. Following the vignette, stigma-related constructs of pity, anger, and perceived responsibility were.

**Results:** When asked about their confidence filling out medical forms, only eight participants reported having “A little bit” of confidence or being “Not at all” confident in filling out medical forms, the two responses below the midpoint of the 5-item scale.

Participants were asked about their level of contact (LOC) with individuals who have low health literacy, which resulted in a score between 1-12 with higher scores indicating greater contact. Given the increased likelihood of working with patients of various health literacy levels, a t-test was utilized to examine the difference in LOC between healthcare workers and non-healthcare workers, which indicated healthcare workers had significantly higher LOC ($M=7.70$, $SD=2.42$) than non-healthcare workers ($M=6.36$, $SD=4.27$; $t[281]=2.589$, $p<.05$).

To assess how participants felt about a person who struggles with low health literacy, ANOVA was used to examine differences between the vignette conditions on pity, anger, and personal responsibility (see Table 1 for F-tests and estimated marginal means). Significant differences were detected for pity and anger, but not personal responsibility. Participants who read vignette one (“V1” – father/daughter) had significantly less pity than those who read vignette three (“V3” – older man); however, there were no significant differences between vignette two (“V2” – younger man) and either V1 or V3. Participants who read V1 had significantly more anger than those who read V3 and no differences were present between V2 and either V1 or V3.

In sum, participants report substantially more anger, which can be seen as a negative response, when a dependent suffered as a result of a parent’s low health literacy. There were no differences between healthcare workers and non-healthcare workers in their response to these vignettes.
Conclusion: Study results suggest that even in the context of an anonymous Internet survey, participants are reluctant to admit struggling with health information – a potential sign there is some perceived stigma around low health literacy. Contextual factors, in this case whether the person negatively impacted by low health literacy was an adult or a child, changed how people reacted to the situation presented in the vignette. Crucially, healthcare workers did not differ from non-healthcare workers in their response to the vignettes. The stigma associated with low health literacy has received almost no attention in the medical or health communication literature, and the results of this study indicate greater attention is needed both to better understand the issue and improve how healthcare is delivered to lower health literate patients.

Disclosure: The empirical data included in this abstract has been accepted for presentation at the International Communication Association annual conference in May 2015. It is also currently under review at the Journal of the American Medical Association.

References


Table 1. Means, standard errors, and F-tests for vignette scales

Vignette 1
Mr. S. is a 33-year old father of one. 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 (and 3)
Mr. S. is a 33-year (72-year) old man with high blood pressure and high cholesterol. He is on several medications to manage these conditions, but he does not always take his medicine correctly. Sometimes he takes too many pills in a day, sometimes he forgets to take them at all. He always feels fine, though, so he does not think there is any kind of problem. At his annual check-up, Mr. S.’s doctor explains that his high blood pressure and high cholesterol are getting worse - putting him at risk for a heart attack, a stroke, or even death. They discuss how Mr. S. is taking his medicine, and when asked Mr. S. assures the doctor he knows how he is supposed to take his medicine. Mr. S. feels like taking his medication should be simple, and he shouldn’t have any questions.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Vignette 1 M (SE)</th>
<th>Vignette 2 M (SE)</th>
<th>Vignette 3 M (SE)</th>
<th>F-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pity</td>
<td>5.78 (1.81)</td>
<td>6.10 (1.71)</td>
<td>6.62 (1.40)</td>
<td>$F (263) = 6.057^{**}$</td>
</tr>
<tr>
<td>Anger</td>
<td>5.04 (2.02)</td>
<td>4.65 (1.84)</td>
<td>4.09 (1.80)</td>
<td>$F (263) = 5.809^{**}$</td>
</tr>
<tr>
<td>Personal Responsibility</td>
<td>3.98 (2.66)</td>
<td>3.44 (1.99)</td>
<td>3.31 (1.90)</td>
<td>$F (263) = 2.299$</td>
</tr>
</tbody>
</table>

** indicates row means are significantly different at p<.01