Health Literacy – A Public Health Challenge



A partnership among Geisinger Commonwealth School of Medicine, Keystone College, King's College, Lackawanna College, Luzerne County Community College, Marywood University, Misericordia University, Penn State Scranton, Penn State Wilkes-Barre, The Wright Center, University of Scranton, and Wilkes University

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Executive Summary

The health care system is complex and often changing, with illnesses, medical conditions and their treatments quickly increasing its complexity. Health literacy is broadly understood to involve the knowledge required to seek medical care, take preventative measures, and locate and understand health information in the complex environments of health and health care. The absence of health literacy has been associated with a range of negative health-related outcomes.

Functional literacy and formal educational attainment have both been identified as strong predictors of health literacy. Additionally, differences in cultural and/or language can contribute to lower levels of health literacy. Literacy, and further, health literacy, is often linked to and included in discussions of social determinants of health.

Differences in levels of health literacy have been linked to disparities in preventative measures, such as mammography and vaccination, as well as in subjective and clinical health. Lower health literacy has also been associated with higher mortality, as well as with negative mental health outcomes. The path from health literacy to outcomes is complex. Some evidence suggests behavioral risks, while other evidence supports disease knowledge, and separately, participation and adherence to maintenance behaviors.

Health literacy may be of increased interest as it offers a leverage point for individual or clinical intervention within the network of social determinants. Several types of interventions have been shown to effectively improve health literacy. These include collaborative learning strategies, social support, and other counseling

strategies. Additionally, reorganizing paperwork and sources of information, improving referral channels and the process of getting an appointment, may positively affect health literacy.

In this report, survey data from a 2012
Community Health Needs Assessment in
Lackawanna and Luzerne counties is revisited,
with a focus on questions related to health
literacy. Some evidence is presented to support
a link between subjective health and formal
educational attainment, as well as desired types
of health education.

Health Literacy: Background

Health literacy is linked to individual and community context, and is often linked to if not included in the discussion of social determinants of health. Improving health literacy may be a crucial step in addressing disparities in health, as one, modifiable determinant. Health literacy is a propitious point in the network of social determinants as interventions can be deployed on individual or community levels.

Understandings of health literacy have been a subject of discussion over the past several decades. The major implications of this debate have been related to measurement. The two dimensions of health literacy include, perspectives of health literacy as a risk factor: a potential risk that needs to be managed, or as an asset: a means by which greater control can be exercised over a person's life. Additionally, there is debate about the degree to which health literacy is a dynamic system, interacting with setting, environment, and time.^{2,3}

Baker (2006) suggests the delineation between these two perspectives can be seen in

definitions of health literacy offered by the World Health Organization, and the (then) Institute of Medicine (now the National Academy of Medicine):

- (i) The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.⁴
- (ii) The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.⁵

The first displays an asset-based approach, while the second presents a risk factor perspective. This paper remains terminologically neutral, attempting to synthesize health management and health promotion perspectives, with dynamic elements where available.

Promoting health literacy, a key determinant of health



Source: Budhatholis, S. S., Polidrarel, P. K., Good, S., Limbu, S., Bhattachan, M., & Osborne, R. H. (2017). The potential of health literacy to address the health related UN sustainable development goal 3 (SDG3) in Nepal: a rapid review. BMC health services research, 17(1), 237.

Factors Associated with Health Literacy

Individual

Education

Functional literacy and numeracy, the ability to read and write and facility with numbers; and deploy these skills in everyday situations, is often understood to be a foundation for health literacy, from which a range of complementary capacities develop.6 Completion of formal education is often a strong predictor of general literacy as well as health literacy, that is, higher levels of education are associated with improved health literacy. One 2006 analysis of a national health literacy assessment found nearly 50 percent of adults who had not completed high school (and were not currently enrolled) to have "below basic" health literacy (the lowest rating, unable to read a short set of instructions and identify what is permissible to drink). This percent dropped to 15 percent for high school graduates, and three percent for bachelor's degree recipients. A study of Medicare recipients found increased odds of "inadequate or marginal" health literacy with lower levels of education. Those that completed grade school or less were at six times the risk of inadequate or marginal health literacy than were those who had completed something more than high school.8



A 2001 study suggested that factors related to lower educational levels account for nearly half of the deaths of US working-age adults. Specifically, they suggest that about 48 percent of male deaths and 38 percent of female deaths in 2001, could have been avoided if all rates (accounting for those within race and gender) were reduced to the level of those with the highest level of education (16 or more years).9 Additionally, lower levels of educational attainment have shown a strong association with risk of suicide. 10 Although the association between formal education and health outcomes is widely acknowledged 11,12 its causal mechanisms are less understood. 13,14,15 One interpretation, however, suggests that health literacy is included among a number of lifestyle choices and economic circumstances that emerge from educational attainment that affects health.

Age

Many studies treat health literacy as a static trait; however, one area in which its dynamism may be located is its fluctuation over the lifetime. Health literacy may be likely to decline over time, with rates accelerated in the context of neurocognitive conditions such as dementia. 16 The study of Medicare beneficiaries referenced above found increased odds of marginal or inadequate health literacy with each increase in age. Those individuals 85 or older were at over eight and a half times the risk of displaying marginal or inadequate health literacy than lower age brackets. 17 Low rates of health literacy among the elderly presents additional problems when taking into consideration that they are also the population with the largest burden of chronic disease. 18 19 20

Culture and Language

Cultural and language differences can be barriers to effective communication, and can contribute to low health literacy or compound existing deficiencies in health literacy. Language differences, cultural differences, and low health literacy have been termed the "triple threat" to effective communication.²¹ Language differences alone can be substantive barriers to effective communication, furthermore, these barriers may not be immediately evident in a fast-paced healthcare setting. Differences in culture may alter the meaning of words or body language, exacerbating low health literacy.²² Although interpreters (in person or web-based) may be able to deal with barriers related to language, not all patients who speak the same language will be from the same culture. This may implicate differences in expected medical care and/or stigmas around treatment or conditions.

System

(Un)Insurance

Low health literacy can be compounded by other disadvantages. Any emphasis on informed choice in healthcare is often marginalized by patients who experience barriers to accessing care (such as lacking insurance), in times when care is needed. The need to access care may take priority over communication with providers and establishing a shared understanding. Patients with obstacles to access may have limited knowledge of what to expect from a provider, as well as their rights as patients.²³ Low health literacy can be difficult to detect in clinical settings. Further, the trust of the patient may be required for an assessment of health literacy as well as for healthcare professionals to serve as providers of information related to health and illness.



Building rapport with patients with such barriers to care can be challenging as well, as they often do not see the same provider each time.²⁴

Health literacy has also been identified as an emphasis in public insurance programs. Market and program complexity may account for some of those both uninsured and eligible for publicly available insurance. ^{25,26} This may be due to the complexity of enrollment documents or being unaware of qualification, and may be a profound phenomenon as low health literacy has been linked to uninsurance, when controlling for employment. ²⁷



Communication

Many researchers have found evidence demonstrating that patient education materials or other forms of explanations of health services or benefits, are not understandable for a large segment of the patient population. 28 Patients with limited health literacy are more likely to report that they do not understand a doctor's words or that the doctor did not provide enough information about their conditions. 29 Some of this confusion has been credited to the physician using "medical jargon," that a patient who is not a medical professional does not understand. Medicine and health fields often make reference to anatomy, biological systems, and groupings of

diseases and disorders. These terms are not employed in everyday language, nor in conventional education through high school, and consequently many patients are unfamiliar with them.³⁰

Range of Implications

Outcomes

Health literacy is linked to many outcomes of interest. These include financial implications. One estimate suggests that adults in the lowest fifth of functional literacy scores have per capita medical expenses that are just under twice that of the per capita cost of the entire population. A 2007 study gave estimates of national cost of inefficiency from low health literacy ranging from \$106 billion to \$238 billion (or seven to 17 percent of all healthcare expenditures in 2007). 31

Health literacy has been suggested to be a strong mediator of racial/ethnic and educational disparities across several preventative outcomes, including mammography, vaccination, dental services, colon screening, and pap tests. 32,33,34 Health literacy has also been identified as a strong predictor of both self-reported health and clinical assessment. That is, low health literacy is associated with worse outcomes in both selfreported health and clinical assessment. 35,36 Patients with low health literacy are at increased risk of hospital admissions and of experiencing worse disease outcomes relative to those with higher health literacy. 37,38,39 Lower health literacy scores have been associated with higher mortality rates in several populations including individuals on Medicare, seniors, and users of one multi-state health management organization. 40, 41, 42 Additionally, lower health literacy is associated with worse



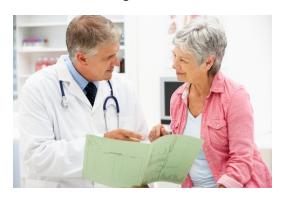
mental health outcomes, including increased likelihood of depression and psychological distress. ⁴³ Although research has yet to fully explore this link, some speculation has centered on lower utilization of care as a channel from health literacy to mental health, along with compounded shame and stigma. ⁴⁴

Process

Although lower levels of education have been linked to certain behavioral risks such as smoking, 45 more direct measures of health literacy are not strong predictors of risk behaviors such as smoking, alcohol consumption, or seat belt use, in the context of demographic and economic factors. 46 This brings focus to other possible channels from health literacy to the outcomes described above.

Health literacy has implications for processes of healthcare involvement and is a strong predictor of knowledge related to chronic disease including diabetes, HIV, cancer, and others. 47,48 Effects of lower disease knowledge may include lower participation in maintenance behaviors and believing that seeing physicians is only required for acute symptoms. Additionally, health literacy has implications for medication and lifestyle adherence, as patients with higher health literacy have higher rates of adherence.⁴⁹ This is of increased importance for patients with chronic illnesses; health literacy and communication have been linked to enhanced self-management of chronic conditions. 50 Patients with lower health literacy have also shown lower comprehension of materials such as nutrition labels and health plans. 51 Lacking the appropriate information, patients with low health literacy are often categorized as non-compliant, or as having lowadherence.52

The health literacy of family members can impact experiences with healthcare and medical conditions. A study of the health literacy of parents of children with asthma found that lower health literacy among parents was associated with poorer interactions with healthcare providers, lower quality of life, and a greater amount of worry related to the child. 53 Other studies of the topic have found lower health literacy associated with worse asthma care. 54 Some evidence exists suggesting parents with low health literacy have an increased likelihood of having an uninsured child. 55



Interventions

Interventions targeting health literacy have taken a range of forms, as well as in diverse settings. Health literacy interventions can take place in clinical, community, or home settings. Health literacy interventions can be deployed by medical professionals, trained peers, or other health educators.

A 2016 meta-analysis of health literacy interventions found over 90 percent of the studies found positive effects for patient health literacy. Additionally, pooled results suggested that a patient who participates in a health literacy intervention is 2.45 times as likely to have higher levels of health literacy. ⁵⁶ This suggests that these interventions are generally effective in improving health literacy. The intermediate outcomes which have been shown



to be responsive to intervention include increased disease knowledge, higher levels of self-efficacy, and improved behavior. Some more prevalent methods are mentioned in the following sections.

Extra-clinical

Collaborative learning (co-learning), where knowledge is gained within a community through sharing and interaction, has received attention as a propitious intervention strategy. One of the stronger forms of co-learning is support groups, a sharing experience regarding treatment of and coping with disease. Information related to communicating with professionals is also valuable in this setting. Other forms of co-learning, such as the incorporation of children in education and clinical settings, have resulted in older adults increased learning about their conditions, as well as decision making. Social support offers a second method by which to improve health literacy. Social support can come in diverse forms, such as emotional, instrumental, informational, and appraisal.⁵⁷ Social support and co-learning offer a diverse range of intervention points as they can involve family, community members, peers, and/or health care professionals. Separately, a two-week, one-onone intervention with asthma patients focused on discharge regimen and self-management techniques found that the low health literacy group improved to adequate health literacy levels (in retaining instructions). 58 These two methods may represent what one systematic review cited as the tailored counseling approach, an approach that has been demonstrated to be an effective strategy for addressing low health literacy. However, authors have cautioned about group learning, as those with low health literacy may be

ashamed to reveal traits of low literacy in groups. ⁵⁹

Various efforts have been made to re-organize the presentation of information in healthcare settings outside of the clinical interaction. This may include pamphlets, paperwork, or prescriptions to fit patient preference. 60,61,62 In healthcare settings, educational materials below elementary level have been effective in improving patient understanding of health information. 63, 64, 65 This often takes the form of privileging practical information. Although reducing complexity may conflict with changes to a patient's choices of provider or health plans, as reduction of complexity may include the reduction of options, 66,67 smoothing the path to care can obviate some of the difficulties encountered with low health literacy. Examples of reducing obstacles to care include electronic referrals to specialists or medical homes as "one-stop-shopping," as well as simplifying website navigation.⁶⁸

Other extra-clinical strategies for addressing health literacy that have received less attention include self-care algorithms, periodic reminders, and the reevaluation of payment structures. Some authors have suggested that restructuring payment schedules to incentivize improvement in quality indicators may stimulate improvements in health literacy. ⁶⁹ Others have suggested that engaging clients with reminders or specific algorithms (for dosing) may help reduce the effects of health illiteracy. ⁷⁰



Provider-Patient Interaction

Aside from separate training and education strategies, interventions for health literacy can be built into healthcare processes. Interaction between providers and patients has been shown to be one area where these interventions are effective. The "teachback" method is one strategy that has shown to work well in such settings. 71 Teachback can be implemented as part of a patient-centered approach, and in some cases the learner is asked to demonstrate understanding to the satisfaction of the healthcare professionals. A 2006 commentary suggested that "confirming comprehension should be the standard in clinical care." 72 Simple implementation is made by asking a patient how they plan to take their medications. This method can be of increased utility when instruments (such as inhalers, glucose meters, etc.) are in play. 73

Providers have also been encouraged to utilize multimedia communication techniques. These include visual aids or automated instructions, which can be used at several points in or outside of the traditional healthcare setting (pre-visit, after-care, or outreach). ^{74,75} Organizations can re-allocate resources to give providers in regions at risk of higher rate of inadequate health-literacy more time with patients or clients as well as other resources. ⁷⁶



Community Health Needs Assessment

In the fall of 2012, The Institute conducted a Community Health Needs Assessment (CHNA) for Luzerne and Lackawanna counties. Part of this involved a survey distributed by mail to households in both counties, which received 1,457 responses. The instrument included questions on behavior, healthcare use, subjective health, and demographic information. The data presented in the table below uses CHNA responses to provide insight into local health literacy. Limitations are acknowledged related to the age of the survey. Additionally, few questions related to health literacy were included and educational attainment level is analyzed as a proxy for health literacy.

Table 1, below, shows the distribution of education level by the participant's subjective health rating.



Table 1

| | Less than | | High | | | |
|-----------|-----------|-----------|----------|-------------|----------|----------|
| | High | Some High | School | 1 - 3 years | College | Graduate |
| | School | School | Graduate | of College | Graduate | degree |
| Excellent | 0 | 1 | 33 | 37 | 46 | 43 |
| | 0% | 1% | 8% | 12% | 23% | 21% |
| Good | 8 | 20 | 185 | 148 | 112 | 107 |
| | 26% | 26% | 43% | 48% | 56% | 53% |
| Average | 8 | 19 | 119 | 69 | 32 | 36 |
| | 26% | 25% | 28% | 22% | 16% | 18% |
| Fair | 12 | 30 | 65 | 41 | 10 | 10 |
| | 39% | 39% | 15% | 13% | 5% | 5% |
| Poor | 3 | 6 | 25 | 14 | 1 | 5 |
| | 10% | 8% | 6% | 5% | 0% | 2% |
| Total | 31 | 76 | 427 | 309 | 201 | 201 |

However, a clearer picture may be seen when the education categories are collapsed to a dichotomy: those who graduated from college (or more education), those with less education. Table 2 displays the subjective health rating by the collapsed education categories.

Table 2

Collapsed Subjective Health and Education

| Conapsed Subjective Health and Education | | | |
|--|-----------|--------------|--|
| | Less than | College | |
| | College | Graduate and | |
| | Graduate | Higher | |
| Excellent | 71 | 89 | |
| _ | 8% | 22% | |
| Good | 361 | 219 | |
| _ | 43% | 54% | |
| Average | 215 | 68 | |
| _ | 26% | 17% | |
| Fair | 148 | 20 | |
| _ | 18% | 5% | |
| Poor | 48 | 6 | |
| | 6% | 1% | |
| Total | 843 | 402 | |

This table shows a difference in the groups (Mann-Whitney U, p < .001), as a higher concentration of respondents in the higher

education category are found in each of the top two subjective health rankings.

Table 3 shows those with lower levels of education at higher risk of having received care in an emergency room in the past 12 months (χ^2 after correction 14.9, p < .001).

Table 3

Care in ER by Education Level

| | Less than | | College | |
|-------|-----------|--------------|---------|---------|
| | College | Graduate and | | |
| | Graduate | Percent | Higher | Percent |
| Yes | 230 | 26% | 63 | 15% |
| No | 638 | 74% | 353 | 85% |
| Total | 868 | | 416 | |

CHNA participants were also asked to identify the types of health education they would like to see in their area. When separated by the county of the participant's zip code (sample size was then reduced to 1,269 as 188 participants did not provide ZIP codes), significant differences (using chi-square with Yate's correction, and a threshold of α = .05) were found in Alcohol and Drug Education, as well as in STD education. This provides evidence of a relationship between these areas of desired education and county. This is displayed in figure 1.

Figure 1

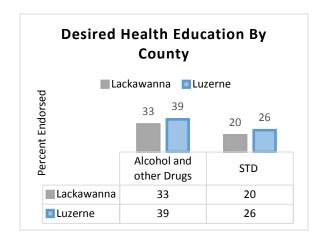


Table 4, below, shows the frequency and percent endorsement of desired education resources, for both counties and across education levels. It shows cancer was the most frequently endorsed, followed by diet and exercise, and Alzheimer's.

Table 4

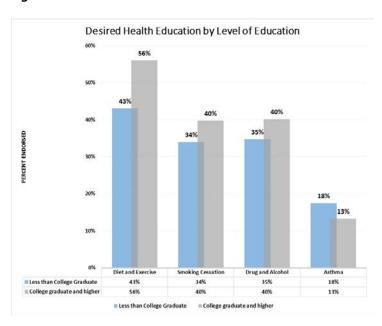
Types of health education participants would like to see in their area

| Transport Demont | | | | |
|-------------------------|-----------|---------|--|--|
| | Frequency | Percent | | |
| Cancer | 653 | 45% | | |
| Diet Exercise | 604 | 41% | | |
| Alzheimers | 587 | 40% | | |
| Stress Management | 542 | 37% | | |
| Child Abuse | 531 | 36% | | |
| Teen Sex | 503 | 35% | | |
| Heart Disease | 469 | 32% | | |
| Alcohol and Other Drugs | 466 | 32% | | |
| Smoking Cessation | 459 | 32% | | |
| Diabetes | 408 | 28% | | |
| Mental Health | 390 | 27% | | |
| STD | 296 | 20% | | |
| HIV/AIDS | 218 | 15% | | |
| Asthma | 204 | 14% | | |

When separated by level of education in figure 2, differences were found in diet and exercise education, smoking cessation education, alcohol and other drugs education, and asthma education. Of those with significant differences, the higher education category had higher rates of endorsement in each desired education category except asthma.



Figure 2



Recommendations

Assess the region's health literacy. As it stands, there is no publicly available data which can be used to obtain a deep understanding of health literacy at the county, community, or neighborhood level in this region.

Consequently, there are currently no estimates related to the specific health literacy of Lackawanna and Luzerne counties. Primary data collection on the two-county region's health literacy would permit more efficient allocation of resources when addressing health literacy.

Employing literacy assessment in health care settings with organizational support. If not currently in the practice of providers, assessment of health literacy in health care settings can be done using the "teachback" method described above. This provides a brief and informal assessment of the patient's health literacy and also increases the patient's knowledge about the condition and improves self-management skills. Many of the methods of evaluating or addressing health literacy in

clinical settings will require organizational support. Increasing resources for providers - such as time with clients or the availability of images, videos, and other methods of communication - cannot be done without organizational buy-in. For example, The Wright Center has a touch screen system in its exam rooms, incorporating a multi-media approach to educate patients on a wide variety of health conditions.

Collaborate for improved health

communication. In addition to the specific health communication strategies that have been described previously, a broad recommendation for collaboration in health communication is necessary to facilitate a supportive environment as well as reach a diverse audience. Communities, places of worship, public agencies, and social service and healthcare organizations, may have a meaningful impact on patient engagement. Collaboration regarding how to effectively communicate healthcare information also has implications for the efficiency of healthcare and the inclusion of diverse perspectives.



Eliminate cultural and language barriers whenever possible. The use of interpreters when patients and providers differ in native language may ease communication. Providers can also seek to avoid medical jargon or

specialized language in settings with patients. Videos and web-based resources can provide other opportunities to communicate in ways specific to a patient's native language.

Improve existing resources and procedures.

Efforts to simplify paperwork, appointments, websites, or insurance navigation can be made to facilitate increased health literacy by lowering the threshold for services.

Leverage existing social hubs for health literacy interventions. Examples of existing meetings hubs include schools and the network of senior centers. These hubs may provide favorable locations for educational interventions aimed at improving health literacy. Collaborative learning is possible in these areas as they normally have existing cohorts. Involving family, where possible, may strengthen these interventions. Additionally, content can be tailored, for relevance, to the audience of the intervention and the age group. Age appropriate programs for children can be delivered in health classes and/or after school programs.

Improve social support systems. Social support and social isolation have been linked to health literacy; engaging the aging with social and emotional support has the capacity to empower aging populations.

Promote or expand adult education. Education has been shown to be a strong predictor of health literacy as well as health. Promotion of education for the region's adults, at any level (viz. GED or higher education) may have implications for health through a number of mechanisms.

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