An Exploration of Health Literacy Measurements and How They Can Protect the Rights of Patients

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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The Significance of Informed Consent

The first set of medical ethics was outlined by the Greek physician Hippocrates over two thousand years ago, and state that the oath taker must make the healing of the patient their top priority, and that the physician must do nothing to cause harm to the patient. The oath is no longer used specifically as there are elements that do not fit in a Western framework, but many medical schools base the oaths they have their students take on the oath (North, 2002), and medical ethics are still some of the most highly valued and strictly adhered to set of ethics in any field of study or practice. One of the pillars of modern medical ethics is the responsibility of a physician to uphold the patient's autonomy, which is their right to choose what to do in order to treat any disease or condition that afflicts them. As an extension and protection of this right to autonomy, the concept of informed consent has become crucial for doctors hoping to provide treatment.

Informed consent is essentially the requirement that the doctor tells the patient everything that is relevant about the patient's condition and what the doctor plans on doing in order to treat it. This includes everything from how long the treatment will take to work, how much it will cost and whether it is covered by the patient's insurance. In order to reach the "informed" threshold, there are five elements that need to communicated to and understood by patients: the nature of the procedure, the risks and benefits of the procedure, reasonable alternatives, risks and benefits of alternatives, and an assessment of the patient's understanding of these elements. This shows that the patient's understanding of risk is the key factor in their ability to be informed. There are three standards of communication for this information: what would the patient need to know to make an informed decision, what would an average patient need to know to be an informed participant in the decision, and what would a typical physician tell a patient about the procedure.

Most hospitals use the second standard because it is good enough for a typical patient (Shah et al., 2023). Informed consent also obligates the doctor to answer any questions the patient has honestly and in a way that the patient can understand. Without informed consent, a doctor is not allowed to do anything to the patient with regards to treatment or diagnostics beyond what a doctor can simply observe.

With obtaining informed consent from a patient being a prerequisite for treatment, it is important that a doctor is able to (ensure that the patient they are treating is capable of understanding the treatment that the doctor is prescribing. A key aspect of this understanding is a patient's health literacy. The World Health Organization defines health literacy as "the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health." The WHO goes on to state that there is broad agreement that health literacy constitutes more than the ability to follow instructions regarding treatment. A patient with a low level of health literacy might be entirely reliant on their doctor's judgement in their treatment, which would fundamentally remove their agency, and thus their ability to give informed consent. This means that the functionality of the various tests available to a care provider are extremely important. This brings up the questions of how the tests are structured, how these tests were validated, and how the results can be applied to a patient's ability to give consent.

A Background of Medical Ethics

Before any investigation into the question is done, it is important to first understand what some of the other binding ethical principles a doctor must observe are. This is because the first consideration a doctor will have to make when looking for informed consent from a patient will have to be what they can do without violating any ethical rules. These ethical rules are derived

from recognized human rights, and are designed to ensure that these rights are protected. The first ethical principle is beneficence, or that a doctor is obligated to act in the best interest of the patient. In terms of the original Hippocratic oath, physicians vowed to "help the sick" in a way that will improve their physical health. In addition to beneficence is the principle of nonmaleficence, that a doctor "shall do no harm". This principle is generally a little more flexible than beneficence or patient autonomy, as many treatments involve doing something that would normally qualify as harm in order to improve the patient's overall health. An example would be a surgery where a doctor has to cut a patient open. Normally cutting a patient would be off limits, but because the surgery will presumably make the patient better, it is ethically allowed. The next principle is the patient-provider fiduciary relationship. This means that the patient can trust that their doctor is acting with their best interest at heart. That last principle is justice, that all patients will be treated the same regardless of background (Olejarczyk & Young, 2022). It should be noted that while these are the core ethical principles of the medical field, they are not necessarily legally binding, although for the most part they have legal statutes backing them up. For the purposes of this paper, it should be noted that in America, a patient's right to autonomy is enshrined in law (Bazzano et al., 2021). Moreover, a doctor that violates one of these principles will definitely expose themselves to possible civil action.

Literature Review Regarding Health Literacy

The metrics by which health literacy is measured are not standard, but usually includes regular written literacy, understanding of statistics and risk, and pre-existing knowledge of medical terminology. It is important to reiterate, however, that the exact definition of health literacy is not agreed upon, and indeed has changed quite a few times in the past decades (Berkman et al., 2010). This may have compounding effects on how tests for health literacy were

developed depending on what definition the creators focused on while creating the test. The first task of this paper will be to identify the metrics that are commonly used, and then determine any strategies that a doctor can use to circumvent the problems caused by a patient falling short in one or more of those metrics. Before doing that, it is important to understand that a patient's health literacy has implications for their health that extend beyond their ability to give meaningful informed consent. Patients with low health literacy have worse overall health care outcomes, with correlations existing from not following treatment regiments to not scheduling follow-up visits (R. Parker, 2000).

Methods

To collect data relating to my research question, I first did a more thorough literature review of research papers about health literacy to establish common elements and metrics. It was important that I avoided following reference chains from the papers I found on the subject in order keep from getting too much overlap in the metrics. I had aimed to identify 3 different health literacy tests that are structured differently from each other. I then explored the rationale provided in the literature as to why the creators decided to structure the tests the way they did. I also examined how well each test could be used to determine how well a patient could understand informed consent.

Results

There are several ways of defining health literacy, with many of the definitions focusing on being able to comprehend written information in a medical context to meet their individual health needs. To this end, many of the tests that have been conceived of to measure health literacy rely on word identification medical terms and correctly interpreting the information

given to a patient for something like taking medication or preparing for a procedure. There are a variety of published tests that health care professionals and researchers can use to measure the reading and comprehension skills of a patient, but I will be focusing on three that I found interesting in their methodology for determining literacy.

The Test of Functional Health Literacy in Adults (TOFHLA) was developed to evaluate reading comprehension and numeracy, the ability of a person to understand numerical information, not necessarily the ability to do mathematics. The test establishes reading comprehension by having a passage with a word missing every five to seven words. The patients than must select the appropriate word from four multiple choice options. The multiple-choice answers that are incorrect are intentionally meant to be similar to the correct answer, either grammatically or a word that is similar in spelling. The literacy section was developed from reading material found in a hospital, including an instruction pamphlet on preparing for gastrointestinal procedure and an informed consent form. The numeracy section uses actual forms from hospitals involving following direction with numbers, such as monitoring blood glucose or filling out financial aid forms (R. M. Parker et al., 1995). The construct validity, its measure of the extent the test accurately measures what it is testing for, of the TOFHLA was demonstrated by showing statistically similar results to the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Wide Range Achievement Test (WRAT).

The Health Literacy Questionnaire (HLQ) was developed to measure health literacy across nine different facets of health literacy, including a patient feeling understood by their health care provider, having sufficient information to manage their health, and having social support for their health. The test asks a series of questions related to the fields and patients respond either on a agree/disagree scale or rank the difficulty they have with a particular task

(Osborne et al., 2013). The HLQ was developed using the conceptions of patients as a basis for the 9 facets. Patients were posed the question “Thinking broadly about your experiences in trying to look after your health, what abilities does a person need to have in order to get, understand, and use health information to make informed decisions about their health?” Participants would then sort possible answers for this question together, and a computer program grouped frequent responses together to get 11 domains. Individual questions related to these domains were then iterated through both health care professionals and groups of patients to test for how appropriate the question would be to include in a test. Initial diagnostic tests were administered by professionals who would monitor the test taker, and would ask the test taker how they felt about questions that they took a long time or visibly hesitated to answer. These questions were constructed with feedback from patients sourced from several hospitals.

The REALM was designed to be an extremely fast diagnostic tool for health literacy. The full version features sixty-six words that the patient has to try and pronounce. The test taker has five seconds to make their attempt or else the word is marked as missed. The pronunciations are scored against a provided dictionary pronunciation guide. This method of testing was chosen because the Slosson Oral Reading Test-Revised (SORT-R) has been used to predict literacy levels in non-medical circumstances, and is structured in the same way. The words are arranged in order from easiest to hardest difficulty. The test is designed to serve as an alternative to the (SORT-R) and WRAT (Murphy et al., 1993). The REALM was validated by comparing results of the REALM to those of the SORT-R and WRAT, with the results being statistically similar to both tests.

Discussion

Before interrogating the merits and short comings of each test, it is important to understand the setting that these tests will be used in and how this influences their design. These tests will mainly be administered by hospital staff, not necessarily the patient's actual doctor. The tests ideally need to be quick to administer so that staff is not occupied with administering the tests all day. They also need to be easy to understand so that the test taker can engage with the tests properly. Additionally, because the requirements for being "informed" are based on an understanding and comparison of risk for possible courses of action, the tests' ability to measure this is the lens for this discussion.

The various tests for health literacy were not at all structured the way I was expecting them to be, and the overall usefulness of what each test tells about the test taker seems to vary wildly. The REALM test only measures the subject's ability to pronounce the words given to them, and does not test if the subject knows what the words mean, or even if they have heard the words before. People read words that they have never seen and have to pronounce them as a regular part of everyday life. Additionally, it is entirely possible that the patient has heard the word before and has not seen it written down. The most glaring flaw with the setup of the REALM is that since the patients do not have to define what the words mean; the test is not really a measure of the patient's knowledge of medical terminology. In an alternate version of the test where a patient has to define the words in addition to giving a pronunciation, this could help establish a baseline of the patient's knowledge of medical terminology, which could be useful for a doctor when describing any conditions the patient might have. The score is also correlated to a grade reading level, from below 3rd grade to high school, but the score is based on the number of correct responses. The intended difficulty of the word to pronounce is not accounted for. Furthermore, it is my opinion that a lot of the words can be sounded out fairly

accurately. A sample test has been included in the Appendix (Appendix A), and from that list, the only words I would say are particularly tricky to pronounce would be “impetigo”, “osteoporosis”, “hemorrhoids”, and “anemia”. The tests used to validate the REALM are similar word recognition tests used to determine regular literacy. This approach makes sense if the test is for a patient’s ability to read and understand instructions for continuing treatment, such as taking a regiment of pills. The fact that the test will only take a few minutes makes it appealing for use in a clinical setting. As far as using the test to establish a patient’s ability to give informed consent, the test can help establish the extent of the patient’s vocabulary, and can inform the health care providers if the medical consent forms need to be reworded for the patient, or if someone needs to be present to walk them through what each part means. This would not necessarily ensure that the patient understands the risks of the treatment, but it could increase how attentive the doctors are to the patient’s discomforts. The results would also inform the doctors how carefully they need to explain the risks to the patient, as that is a key part of obtaining informed consent.

The HLQ is more comprehensive than the REALM in the number of aspects that it covers with its questions. The test covers aspects of a patient’s medical health, such as their ability to navigate paying for their health care and how well patients are able to understand and interact with their doctors. The main problem with the test is that all of the measurements are self-reported, so there is not an objective way of measuring how well the patients are able to do the tasks that the questionnaire asks. This leaves the potential for a patient to over report their abilities, and then not be able to engage with a doctor on a level that the doctor is expecting them too. This can lead to the doctor having to spend time going back over the information again with the patient, while simultaneously trying to determine at what level the patient can actually

engage with the information. The patient also might not behave in a way that is consistent with their response to the test. One of the questions is “I have at least one person who can come to appointments with me”, and while someone may answer honestly that they do, they may be reluctant to use them as a resource, which could have negative effects on their health outcomes. In extreme cases, the patient may not tell the doctor that they do not understand what they were told out of either pride or shame (Arozullah et al., 2007). The HLQ has a similar problem to the REALM in terms of using as a test to establish someone’s ability to give informed consent in that it does not provide an objective measurement of a patient’s understanding of the risks they are taking. The self-reporting aspect of the test actually makes it a little worse in this context because there is no way for the administrator to confirm the answers given, and if the test taker over reported their abilities, they may be too embarrassed to tell the doctor that this is the case. The HLQ does have the benefit of giving more information than the REALM on aspects such as the patient’s ability to make and keep a follow-up appointment, being able to fill out insurance information, and having a support network for their health at home. All of these are important for improving health outcomes.

The TOFHLA has the benefits of using answers with objective answers as measurements for both literacy and numeracy. It also has the benefits of taking a shorter time to administer than the HQL and being more comprehensive than the REALM. The main shortcoming of the test is that the reading comprehension section does not include a practical application portion. Including a portion where a patient demonstrates that they can follow the instructions given to them and not just recall what the instructions were would help ensure that doctors are equipping the patient with everything they need to administer their own care. The TOFHLA using the REALM as the standard to validate itself against shows that the creators of the test had the

intention of measuring the same kind of ability as those that made the REALM, namely their ability to understand and follow instructions. This gives the test the same problems when it comes to establishing an ability to give informed consent.

Given that none of the tests can directly measure a patient's ability to give informed consent, I would argue that it is not so much that a patient with low health literacy would withhold consent, but that a doctor should be very careful with the informed consent that is given. An analysis of research papers focusing on health literacy found that one fourth of the subjects across all the papers qualified as having low health literacy, with another one fifth qualifying as having marginal health literacy (Paasche-Orlow et al., 2005). Obviously, if low health literacy was functioning as a barrier to patients providing informed consent, there would be an epidemic of people not getting the treatments that their doctors recommend. This indicates that patients with low health literacy tend either to trust the fiduciary relationship they have with their doctor or that they do not feel like they can safely express concerns they have. Doctors in this situation need to take great care to not abuse this trust or try to identify and assuage these fears, respectively. Abuse of this kind of unequal power balance is what leads to long term and systemic mistrust of doctors (Jaiswal & Halkitis, 2019). A test that would be able to assess a patient's understanding of the risks each course of action presents would be ideal for establishing understanding, but the main problem would be that each test would have to be tailored to each patient because treatment options would vary widely. The test would have to be structured in a way that demonstrates the patient understands possible side effects. For example, if one of the side effects of a treatment was nausea, the question would ask the test taker to identify how that would affect them, such as feeling the need to vomit, being unable to stand without feeling sick, stomach pains, and any other effects on their day-to-day life.

It is important to note that there are some potential situations were the tests might not reveal a patient's low health literacy. One of these situations would be when a patient's deeply held beliefs cause them to believe something that is not scientifically accurate. An example of this is Jehovah's Witnesses and their refusal to accept blood transfusions because of their belief that blood that has been outside the body is unclean (Thompson, 1989). Jehovah's Witnesses also believe that receiving a transfusion of the patient's own blood also qualifies as a sin (Bock, 2012). This leads to a Jehovah's Witness actively withholding consent instead of their consent being of questionable validity. This kind of health illiteracy would be much harder to screen for and work around compared to traditional low health literacy. In traditional cases, the doctor could continue to simplify an explanation until the patient understands; however, in a case such as a Jehovah's Witness, the problem lies solely with the patient in a way that the doctor is going to find difficult to overcome because the patient's understanding of the truth is irreconcilable with the medical truth.

Conclusion

The tests that were reviewed for this paper are good tests for establishing a patient's ability to understand the instructions given to them as part of their treatment that they need to complete on their own outside of a hospital, which is an important part of treatment. Most of the tests were focused on measuring the ability of the patient to administer their own care, rather than assessing the patient's ability to do any of the other tasks that cover health literacy, such as doing research about their treatment. The tests do not do an adequate job of demonstrating that they patient understands the risks involved in all of their treatment options, but the results could be used as a guide for how the doctors should explain the risks of any given treatment so that a patient's understanding is maximized. It is crucial that doctors are able be confident that patients

understand their treatment options thoroughly so that a patient's rights or a doctor's ethics are violated.

Appendix

Table 1
Rapid Estimate of Adult Literacy in Medicine (REALM)©

Patient name/subject # _____ Date of birth _____ Reading level _____
Date _____ Clinic _____ Examiner _____ Grade completed _____

List 1		List 2		List 3	
fat	_____	fatigue	_____	allergic	_____
flu	_____	pelvic	_____	menstrual	_____
pill	_____	jaundice	_____	testicle	_____
dose	_____	infection	_____	colitis	_____
eye	_____	exercise	_____	emergency	_____
stress	_____	behavior	_____	medication	_____
smear	_____	prescription	_____	occupation	_____
nerves	_____	notify	_____	sexually	_____
germs	_____	gallbladder	_____	alcoholism	_____
meals	_____	calories	_____	irritation	_____
disease	_____	depression	_____	constipation	_____
cancer	_____	miscarriage	_____	gonorrhea	_____
caffeine	_____	pregnancy	_____	inflammatory	_____
attack	_____	arthritis	_____	diabetes	_____
kidney	_____	nutrition	_____	hepatitis	_____
hormones	_____	menopause	_____	antibiotics	_____
herpes	_____	appendix	_____	diagnosis	_____
seizure	_____	abnormal	_____	potassium	_____
bowel	_____	syphilis	_____	anemia	_____
asthma	_____	hemorrhoids	_____	obesity	_____
rectal	_____	nausea	_____	osteoporosis	_____
incest	_____	directed	_____	impetigo	_____

Score	
List 1	_____
List 2	_____
List 3	_____
Raw score	_____

Figure 1. The list of words used in the REALM as administered in (Murphy et al., 1993)

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