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HEALTHCARE PROVIDER BIAS IN ESTIMATING THE HEALTH LITERACY OF PARENTS IN A PEDIATRIC EMERGENCY DEPARTMENT

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ABSTRACT

Health literacy, defined as an individual's capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions, is a growing concern due to its significant effect on clinical communication and health outcomes. One aspect of this clinical communication is the ability of the provider to estimate the health literacy of the patient/caregiver. In this study, providers are asked to perceive descriptive factors and estimate the health literacy of parents/guardians in the Primary Children's Hospital Emergency Department. Then, the health literacy of the parent/guardian is tested using the Short Assessment of Health Literacy (SAHL), and cross tabulated with provider estimates. Additionally, qualitative information is collected from families about the specific miscommunications that they experience during their visit.

Preliminary results show that providers correctly estimate the health literacy of the parents/guardians 61.56% of the time, and misestimates are often underestimates (26.53%) rather than overestimates (11.9%). The results also suggest that the ability of a provider to estimate the health literacy of a parent in the Pediatric Emergency Department is influenced by their role/experience as a provider, racial biases, gender/parenting role biases, and biases related to the language spoken by the caregiver. Most notably, providers overestimate the health literacy of 24.07% of fathers and only 9.4% of mothers. They correctly estimate the health literacy of 64.34% of English-speaking participants compared to 27.27% of Spanish-speaking participants, and underestimated the health literacy of 54.55% of Spanish-speaking participants and only

24.26% of English-speaking participants. When providers perceive a participant to be a part of a racial or ethnic minority group, they only correctly estimate health literacy 35% of the time compared to 71.36% of majority (white) participants. They underestimate the health literacy of 52.5% of these minority (non-white) participants, while only underestimating the health literacy of 16.9% of majority (white) participants. These results suggest a need for further health literacy research and interventions in provider education and clinical practice.

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INTRODUCTION

As an Academic Associate in the Pediatric Clinical Research Program, I observed many moments of confusion and miscommunication in the Primary Children's Hospital Emergency Department between families and providers when words and phrases were used that the patient/caregiver did not understand. Some miscommunications that were observed include patients and families using the word "acute" to mean severe, interpreting "positive" vs. "negative" results as "good" vs. "bad," not understanding how to make a follow-up appointment with a primary care provider, confusion regarding prescription instructions, and others. These types of communication problems are often rectified if the provider or family indicates that there is confusion, but it is also easy to see how these problems can go undetected and have a range of consequences on patient care, including incomplete/improper evaluation and inadequate home care. Additionally, these situations can make patients and caregivers feel embarrassed or alienated by the healthcare system.

Do these miscommunications happen because providers do not have the language or time to communicate with patients/families? Or do they happen because providers do not even know that patients and families lack the specific ability to understand and utilize the information they are being given? With the support of Dr. Maija Holsti, Director of Pediatric Research Education, and Dr. Howard Kadish, Division Chief of the Primary Children's Hospital Emergency Department, I developed a clinical research study to answer this second question. The overall goal of the study is to determine how accurate provider estimates of a person's health literacy are and what factors influence those estimates. *Aim One* will quantify the ability of healthcare providers to estimate the health

literacy of the parent or guardian who is with a child in the Emergency Department and identify descriptive/demographic factors of both the family and the physician that might be related to overestimates or underestimates of health literacy. *Aim Two* will be a collection of qualitative information about specific language used by providers that families in the Emergency Department do not understand. This Honors Thesis will explore the context of this study and its preliminary results.

LITERATURE REVIEW

The field of health literacy emerged primarily in the 21st century, bringing together experts in both adult education and healthcare to address communication disparities in healthcare.[1] A seminal text in the field is the first study that defined and quantified functional health literacy, which was published by Dr. Mark Williams and his colleagues at Emory University and titled "Inadequate Functional Health Literacy Among Patients at Two Public Hospitals." The study identified three levels of health literacy proficiency (adequate, marginal, and inadequate) in the development of methods for determining the prevalence of limited functional health literacy using the Test of Functional Health Literacy in Adults (TOFHLA).[2] The study defined health literacy similarly to how it is defined now by the U.S. Health Resources and Services Administration as, "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions."[3] This initial study's purpose was to identify limited functional health literacy as a prevalent concern and make clinical recommendations. By doing so, the text became a foundation for extensive research to better understand health

literacy as a key determinant of health outcomes such as mortality, hospital readmission, and safety of care.[2] Health literacy was likely identified by many in the preceding years as a contributing factor to patient experience, but without scientifically significant quantification, the medical community had limited motivation and direction for change. The results of the study showed statistically significant decreases in functional health literacy between young and elderly patients, as well as English and Spanish speaking patients. The prevalence of inadequate or marginal functional health literacy ranged from 35% to 83% across these groups. The results were broken down into numeracy questions and reading comprehension passages. Some of the most significant findings were that 26% of patients were unable to understand information about when a next appointment was scheduled, 41.6% of patients were unable to comprehend directions for taking medications on an empty stomach, and 59.5% of patients could not understand a standard informed consent document.[2] To quantify a problem is to ask how extensive it is, who it affects, what impacts it has on any given group of people or system, and where the problem is worst. Further work to solve a problem is limited when these questions have yet to be answered, which is why this study that asked how much and where the problem existed, was foundational to the field of health literacy and continues to be relevant in health literacy research.

In a 2006 report from the National Center for Education Statistics, it was estimated that only 12% of adults are health literacy proficient, which was defined as being able to perform complex literacy activities including tasks needed to function in the health care system. The report utilized three different measurement categories: prose literacy, document literacy, and quantitative literacy.[4] On one hand the results are very

troubling, but in taking a closer look at the categorization of results and comparing them to other studies, the study is not exactly suggesting that 88% of people can't function in the health care system. Fourteen percent of people were labeled "below basic," 12% were labeled "basic," and 53% were labeled "intermediate," which suggests that those in the "intermediate" and even "basic" group had the ability to read and comprehend "a clearly written pamphlet."[4]

Currently, the three most commonly used tests of functional health literacy are the Test of Functional Health Literacy in Adults (TOFHLA), which uses a series of questions to test comprehension and numeracy, the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Short Assessment of Health Literacy (SAHL) (Appendix A and B), which both use a list of medically relevant words to identify language recognition skills, as well as comprehension in the case of SAHL.[5] While it might be noted that these tests do not have a way of assessing many aspects of "functionality" in the health care system, they are easy to administer and provide an excellent picture of at least how much of the language used in the medical setting is recognized and understood by the patient. In validation studies that compare SAHL to more complex assessment tools, it has been determined that a SAHL score below 14 out of 18 can be classified confidently as low health literacy. Based on this criterion, the SAHL validation study showed that 24% of English speakers and 27% of Spanish speakers had a low level of health literacy.[5] A literature review of studies that measured health literacy with these three tools concluded that the prevalence of low health literacy was 26%.[6] These studies provide evidence of the challenge of mapping assessment results onto labels of health literacy proficiency, pointing to a need for standardization and use of validated tools.

Expanding on the value of quantifying low health literacy, multiple studies have presented a correlation between various demographic characteristics and low health literacy. The same 2006 report from the National Center for Education Statistics that detailed the specific levels of literacy mentioned previously also addressed demographic characteristics. The results of the study suggest that men, people older than 65, people below the 2003 poverty threshold, and people with high school or less than high school education had lower average health literacy compared to women, people younger than 65, people above the poverty threshold, and people with college education.[4] The study also noted that people belonging to a racial or ethnic minority had lower average health literacy[4], which was also reflected in the SAHL validation study that resulted in a lower percentage of Spanish speaking participants testing above the threshold for low health literacy than English speaking participants.[5] Similarly, the previously noted literature review of studies that measured health literacy using primarily the TOFHLA and REALM tools noted that people of lower education level, older age, and non-white ethnicity had lower average health literacy. However, this literature review stated that low health literacy was not associated with gender.[6] These complex background characteristics that may be correlated with low health literacy are valuable to study as a way of determining which groups of people are at a high risk of experiencing the negative outcomes associated with having low health literacy.

Claiming direct effects of low health literacy on health outcomes may seem just as presumptuous as claiming direct effects of demographic characteristics on health literacy proficiency. However, the correlations between low health literacy and negative outcomes are an important motivator for improving health literacy and communication in

the health care system. According to the CDC, low health literacy is associated with higher mortality rates,[7] which was also the conclusion drawn by a British study of mortality rates in older adults.[8] Higher mortality rates that correlate with low health literacy have also been seen among disease-specific patient populations, such as those with heart failure.[9] Other outcome measures such as lower quality of life and limited physical function have been associated with low health literacy among patients with chronic illnesses such as asthma.[10] Another impact measured in relation to low health literacy is government health care spending, which is seen to be significantly higher for groups with low health literacy,[11] as well as overutilization of Emergency Departments.[10,12,13] A 2011 systematic review of low health literacy and health outcomes reflected similar findings: both poor health outcomes and poor use of health care services were shown to be correlated with low health literacy.[1] While it might be tempting to assume that low health literacy is associated with poor outcomes as a side effect of the demographic and socioeconomic factors that are associated with it, the American Medical Association Ad Hoc Committee on Health Literacy reported that low health literacy is a stronger indicator of health than race, education level, employment status, and income.[14] The conclusion that these many studies come to is that low health literacy poses one of the greatest risks for negative outcomes and less effective use of the healthcare system, and that providers are currently missing the opportunity to fill these knowledge gaps.

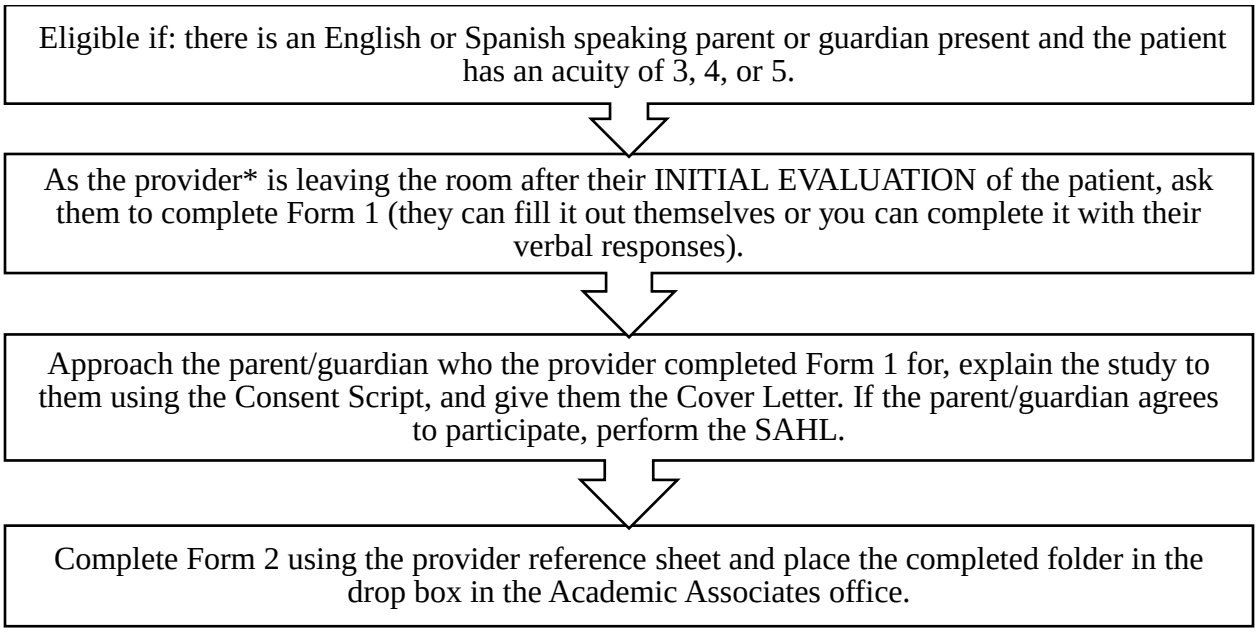
One aspect of filling these knowledge gaps relates to the ability of health care providers to communicate with patients and recognize who is at risk for the negative outcomes associated with low health literacy. A 2007 study showed that physicians overestimated the health literacy of 54% of African American, 11% of white non-

Hispanic, and 36% of other race/ethnicity patients.[15] However, there has been no study of the potential correlation between physician overestimates and descriptive factors of parents/guardians of children being brought to emergency departments, specifically including a significant sample of Spanish-speaking participants. Additionally, there has been no study of the potential correlation between the level of experience of the provider and their ability to estimate patient health literacy. These factors could be useful in identifying where to target efforts to improve communication between providers and families in the Emergency Department.

METHODS

Aim One

The procedure for conducting assessments of parents/guardians and obtaining estimates from providers is primarily conducted by Academic Associates in the Pediatric Clinical Research Program. The Academic Associates go through the process of obtaining access to the Primary Children's Hospital Emergency Department for research purposes by completing a background check, drug screen, immunizations, HIPPA certification, Conflict of Interest reporting, TB testing, and a quiz to test knowledge of the safety protocols at the hospital. Additionally, throughout the program, they are provided with a thorough education of research ethics, the IRB process, and Good Clinical Practice standards. Under the supervision of teaching assistants and study coordinators, the Academic Associates screen patients every day of the week from 6:00am to 12:00am for 8-10 different projects. *Aim One* proceeds with the following flow:



*The provider can be an attending, fellow, resident, or nurse practitioner. If more than one provider was present for the evaluation, have the person who is available at that time complete the survey.

First, the Academic Associates determine eligibility for the study by scanning the Emergency Department tracking board through the electronic medical record system, iCentra. If a patient is assigned an acuity level of 1 or 2, their parent or guardian is excluded from the study so as not to add undue responsibility or stress to a life-threatening situation. If a patient has a suspected COVID-19 infection, the family is excluded to protect the study team and limit potential disease spread. Additionally, if a family is not English or Spanish speaking, they are also excluded because we do not have a validated SAHL assessment tool that can be used for other languages. Spanish-speaking participants are not excluded from the study because they are a significant proportion of the Utah population[16] and the SAHL tool is validated in Spanish (Appendix B).[5] However, in order to avoid translating the consent document from English to Spanish twice (once before the English document was approved by the IRB and once after

revisions were made), the IRB approved the study to include Spanish speaking participants only after an amendment was made that included the Spanish consent document translated from the English document that they approved once revisions were made. When a Spanish participant is identified, the hospital interpreter or a research interpreter is contacted either on an iPad or in-person to verbally interpret the consent process and assessment. The participant is also given a consent document in Spanish.

When an eligible family has been identified, the provider is then approached as they are leaving the patient room after their initial evaluation of the patient. They are given the following survey questions and can respond by reading and noting their responses or by verbally dictating their responses to the Academic Associate or other study team member to record. The latter option is provided in order to reduce the burden of the survey on providers.

Form 1: Provider Perception Survey

1. Who did you primarily interact with?
    - □ Mother
    - □ Father
    - □ Other: _____

2. Estimate their health literacy:
    - □ High
    - □ Low

3. Do you think they are part of a racial or ethnic minority group?
    - □ No
    - □ Yes, check all that apply
        - □ Hispanic or Latino
        - □ Black or African American
        - □ American Indian or Alaska Native
        - □ Asian
        - □ Native Hawaiian or Other Pacific Islander
        - □ Other, specify_____

4. How old do you think they are?
    - □ Younger than 20
    - □ 21-40

- □ 41-60
- □ Older than 61

5. Do they have other children?
   - □ Yes
   - □ No
   - □ I don't know

These survey questions ask for information the provider has already obtained in their first interaction with the patient and their parent or guardian, and should take less than 2 minutes to complete. None of this information is pulled from the medical record, nor is it specific enough to identify a patient or their caregiver, so it does not require consent from the participant to obtain.

Next, the Academic Associate or study team member approaches the family, specifically asking to speak with the person who the provider indicated on Form 1 they had the most interaction with and therefore filled out the survey in regard to. The consent script (Appendix C) is used by the person obtaining consent to introduce the study and a Cover Letter is provided to the participant. The Cover Letter includes all eight elements of consent: a description of the research, risks, benefits, alternatives, confidentiality, compensation, contacts, and voluntary participation and withdrawal. Implied consent is used, which means that the participant gives their consent by verbally agreeing to participate in the assessment. This method of consent was approved by the IRB, as opposed to written consent, because there is no protected health information or identifying information (name, date of birth, address, diagnosis, etc) collected as part of the study, so there is no risk of loss of confidentiality. Obtaining written consent would put the participant at risk of loss of confidentiality because the information would then

become identifiable. Additionally, these study procedures do not include anything higher than minimal risk, so implied consent is appropriate.

If the parent or guardian agrees to participate, the Academic Associate or study team member reads the instructions for the SAHL (Appendix A and B) and performs the assessment, recording the results. This particular assessment tool was chosen because it is validated in Spanish and includes both word recognition and comprehension. The assessment takes 2-3 minutes to complete.

After the assessment is complete, the Academic Associate or study team member completes Form 2 using a reference list of all of the relevant information about each of the providers in the Emergency Department.

Form 2

1. How old is the patient?
2. What is the role of the provider?
    - □ Attending
        - □ Less than 5 years of practice
        - □ 5-10 years of practice
        - □ More than 10 years of practice
    - □ Fellow
        - □ 1st year
        - □ 2nd year
        - □ 3rd year
    - □ Resident
        - □ PGY1
        - □ PGY2
        - □ PGY3
    - □ Nurse Practitioner
        - □ Less than 5 years of practice
        - □ 5-10 years of practice
        - □ More than 10 years of practice

3. Status of this study entry:
    - □ Complete
    - □ Incomplete, please explain:

Once completed, all of the forms are kept at the Primary Children's Hospital Emergency Department until they are brought by a member of the study team to the Williams

Building, where they are entered into REDcap, the secure clinical research database used by the University of Utah.

Aim Two

As part of the Pediatric Clinical Research program, students also have the opportunity to spend a semester as a Physician Extender, where they learn from physicians by assisting with basic tasks and communication in the Primary Children's Hospital Emergency Department. The Physician Extenders have a unique opportunity because their role includes them in the health care team and also does not require the same amount of rigor and responsibilities as a staff member, so they get to spend time with families and ensure that there are no gaps in communication. This positions them perfectly to conduct *Aim Two* of the study, which is about understanding the specific gaps in communication that are happening in the Emergency Department by recording responses to the following statement/question. *"Healthcare providers often use words or phrases that are unclear or don't make sense to patients and their families. What words or phrases have been used during this visit that are unclear or don't make sense to you?"* The information collected using Form 3 (Appendix D) will be used to compile feedback that can be presented to the Emergency Department providers. Physician Extenders fill out a copy of Form 3 at least 5 times per 6-hour shift and they are present in the Emergency Department every day of the week from 10:00am to 4:00pm and 7:pm to 1:00am.

While IRB approval was necessary for *Aim One* because the results may be included in a formal paper to be submitted for publication, *Aim Two* is framed as a quality improvement project and would not need to be approved by the IRB if only

applied to the purposes of quality improvement. However, because *Aim Two* could result in the collection of information that might be publishable along with the results of *Aim One*, it was included in the IRB proposal. This project was approved by the Institutional Review Boards of both Primary Children's Hospital and The University of Utah on February 27, 2020 and April 6, 2020, respectively.

Statistical Analysis

The provider's perception was cross tabulated with the parent/guardian's actual health literacy. Chi-squared tests were used to look for differences in potential confounding variables such as race, age, and type of provider. To determine the sample size, we assumed providers accurately estimate a parent/guardian's health literacy 70% of the time and in the remaining instances providers are twice as likely to overestimate health literacy as opposed to underestimate it. With that assumption, we knew we would have 80.3% power if we collect scores from 250 provider-parent/guardian pairs with an alpha level of 0.05. The sample size at the time of preliminary statistical analysis is 294 provider-parent/guardian pairs. Chi-squared tests were performed only when $N > 5$ for at least 80% of the cross-tabulated frequencies.

RESULTS

The following results include data that was collected between September 11 and October 21, 2020, and does not include results for *Aim Two* of the study due to limited preliminary qualitative data collection. This preliminary dataset includes 294 provider-participant pairs for *Aim One* of the study. Of the 294 participants, 233 (79.5%) were identified by the provider as being the mother of the patient, 54 (18.4%) were identified

as fathers, and 6 (2.0%) other (grandmother and aunt). 186 (63.3%) participants were identified by the provider has having high health literacy and 108 (36.7%) were identified has having low health literacy (Figure 1). 80 (27.2%) were identified by the provider as being part of a racial or ethnic minority, 214 (72.8%) were not. Of those 80, 57 (71.3%) were identified as Hispanic or Latino, 7 (8.8%) Black or African American, 4 (5.0%) American Indian or Alaska Native, 5 (6.3%) Asian, and 6 (7.5%) Native Hawaiian or Other Pacific Islander. Providers estimated that 207 (70.4%) participants were ages 21-40, 83 (28.2%) were ages 41-60, 1 (0.3%) was younger than 20 years old, and 3 (1.0%) were older than 61 years old. Providers responded that 156 (53.1%) participants had other children, 18 (6.1%) did not, and they were unable to answer this question for 120 (40.8%) participants. The patients with whom the participants presented to the Emergency Department were differentiated by age. 41 (13.9%) were 0 to 23 months of age, 75 (25.5%) were 2 to 5 years old, 102 (34.7%) were 6 to 12 years old, and 76 (25.9%) were 13 years old and older. Of the 294 enrollments, 119 (40.5%) involved an attending physician, 31 (10.5%) involved a fellow, 103 (35.0%) involved a resident, and 41 (13.9%) involved a nurse practitioner. No preliminary analysis was completed for the breakdown of years of experience within each provider group because the sample size was too small for chi squared analysis ($N < 5$ for greater than 20% of the frequencies for each group). 272 (92.52%) enrollments were completed in the English language and 22 (7.48%) were completed in the Spanish language with a hospital interpreter, the SAHL-S, and a Spanish cover letter. Enrollment will continue until the percentage of Spanish-speaking participants is at least 10%, which will more closely represent the Spanish-speaking population of Utah based on recent census date.[16] Lastly, 230 (78.2%) scored 14

or higher on the SAHL and were thus identified as having high health literacy, while 64 (21.8%) scored below 14 and were identified as having low health literacy (Figure 1).

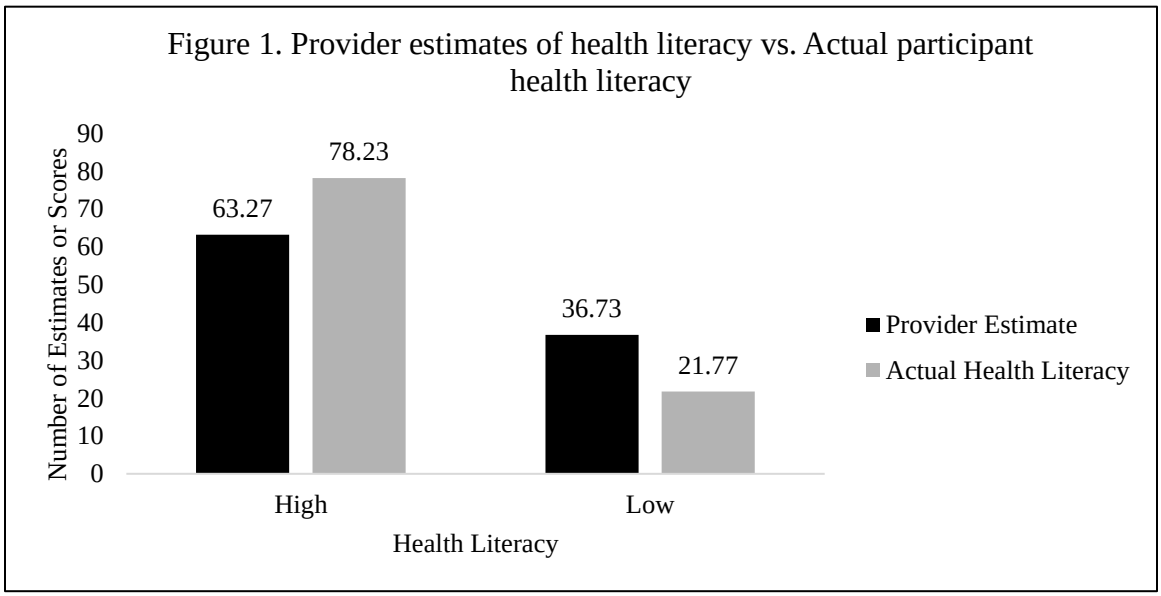


Figure 1. Provider Estimates Of Health Literacy Vs. Actual Participant Health Literacy, as recorded on Form 1 and as measured by SAHL-E and SAHL-S. **X^2 (1, N = 294) = 15.91, p < .001.**

In this preliminary analysis of 294 provider-participant pairs, providers correctly estimated the health literacy of 181 (61.56%) participants, overestimated the health literacy of 78 (26.53%) participants, and underestimated the health literacy of 35 (11.9%) participants (Figure 2). Statistically significant correlations between provider estimates/misestimates of health literacy and provider-identified characteristics of participants were found for race/ethnicity, language spoken, and participant relationship to the patient (Figure 4-6). However, no statistically significant correlations were seen for the age of the patient, the provider-perceived age of the participant, or whether the participant had other children (Figures 8-10). Additionally, the role of the provider (attending physician, fellow, resident, or nurse practitioner) correlated with their ability to estimate health literacy (Figure 3), but breakdowns of experience in years were not

analyzed for statistical significance (N < 5 for greater than 20% of the frequencies for each group) (Appendix E).

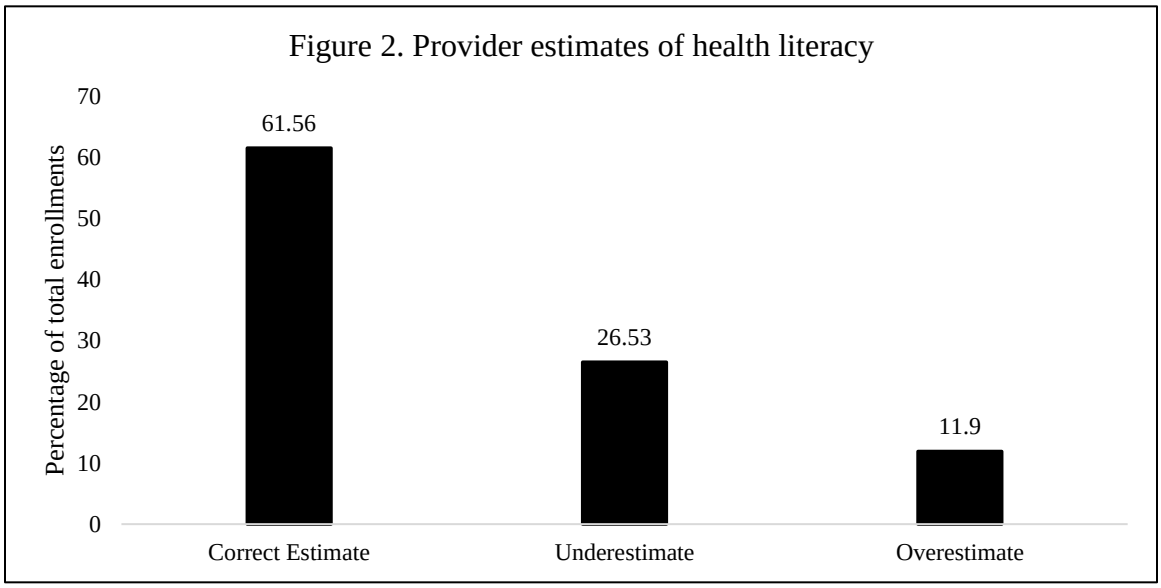


Figure 2. Provider Estimates of Health Literacy. Correct estimates include provider estimates of high health literacy when participants scored 14 or above on the SAHL and estimates of low health literacy when participants scored below 14 on the SAHL. Underestimates include provider estimates of low health literacy when participants scored 14 of above on the SAHL. Overestimates include provider estimates of high health literacy when participants scored below 14 on the SAHL.

Among providers, the groups that most often correctly estimated health literacy were attending physicians and fellows (68.91% and 70.97% rate of correct estimates, respectively), while residents and nurse practitioners were more likely to misestimate health literacy (57.28% and 43.9% rate of correct estimates, respectively) (Figure 3). Of the misestimates, residents and nurse practitioners underestimated health literacy for 33.01% and 34.14% of participants, respectively, compared to 21.85% and 12.9% for attendings and fellows, respectively. Overestimates were most often made by nurse practitioners, then fellows, then residents, then attending physicians (21.95%, 16.13%, 9.71%, and 9.24%, respectively) (Figure 3). Breakdown of these results by the number of years of experience within each provider group might further suggest relationships

between experience and ability to estimate health literacy, but sample sizes were too small to conduct preliminary statistical analysis (Appendix E).

Figure 3. Role of the provider vs. estimates of health literacy

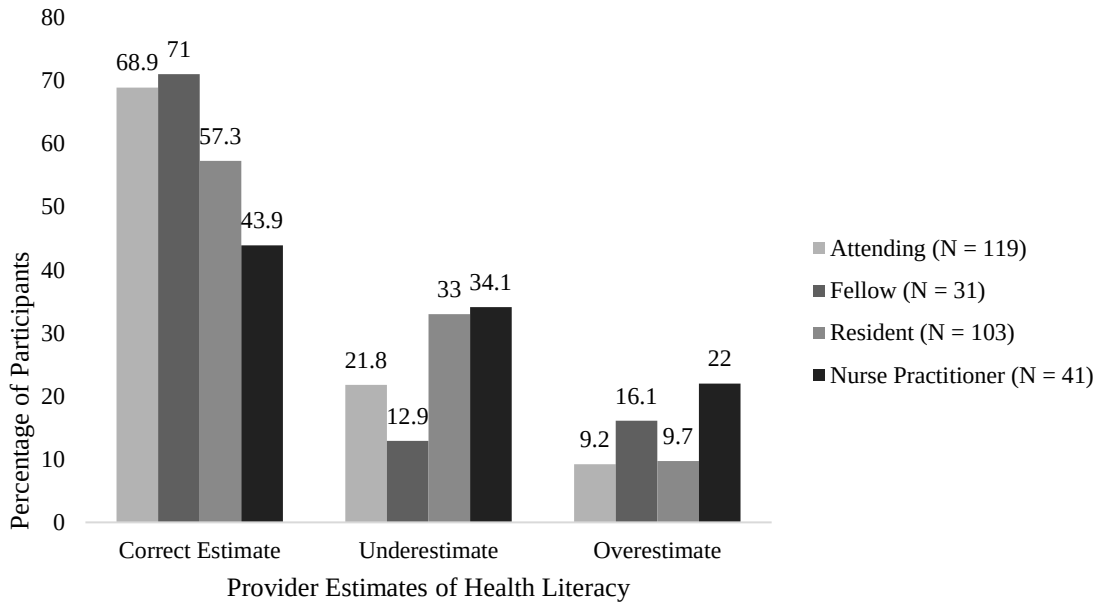


Figure 3. Role of the provider vs. estimates health literacy, as recorded on Form 1 and Form 2. **X^2 (6, N = 294) = 14.62, p = .023.**

Providers were more likely to correctly estimate or underestimate the health literacy of mothers (64.1% and 26.5%, respectively) compared to fathers (53.7% and 22.22%, respectively) (Figure 4). Providers overestimated the health literacy of 24.07% of fathers and only 9.4% of mothers (Figure 4). Providers correctly estimated the health literacy of 64.34% of English-speaking participants compared to 27.27% of Spanish-speaking participants (Figure 5). Further, providers underestimated the health literacy of 54.55% of Spanish-speaking participants and only 24.26% of English-speaking participants, while similarly overestimating health literacy for both English and Spanish-speaking participants (11.4% and 18.18%, respectively) (Figure 5). When asked if they thought the participant was part of a racial or ethnic minority, providers correctly estimated health

literacy 71.36% of the time when their response was “no” and only 35% of the time when their response was “yes” (Figure 6). When providers perceived a participant to be a part of a racial or ethnic minority group, they underestimated their health literacy 52.5% of the time, while only underestimating the health literacy of 16.9% of majority (white) participants. There was no significant difference in overestimates. While the breakdown of these results by racial or ethnic group is not statistically significant due to a small sample size, these preliminary results suggest that there are differences between the groups, such as providers being potentially more likely to overestimate health literacy when they perceive a participant to be Asian compared to all other racial or ethnic groups (Figure 7).

Figure 4. Percentage of correct and incorrect physician estimates of health literacy for different participant relationships to the patient

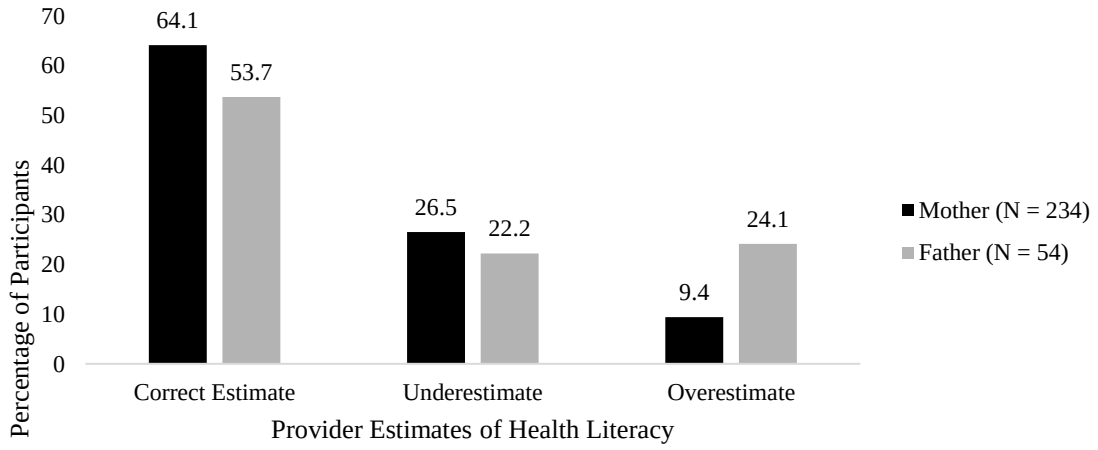


Figure 4. Provider estimates of health literacy for different participant relationships to the patient (mother vs. father), as recorded on Form 1 and as measured by SAHL-E and SAHL-S. **X^2 (2, N = 287) = 8.85, p = .012.**

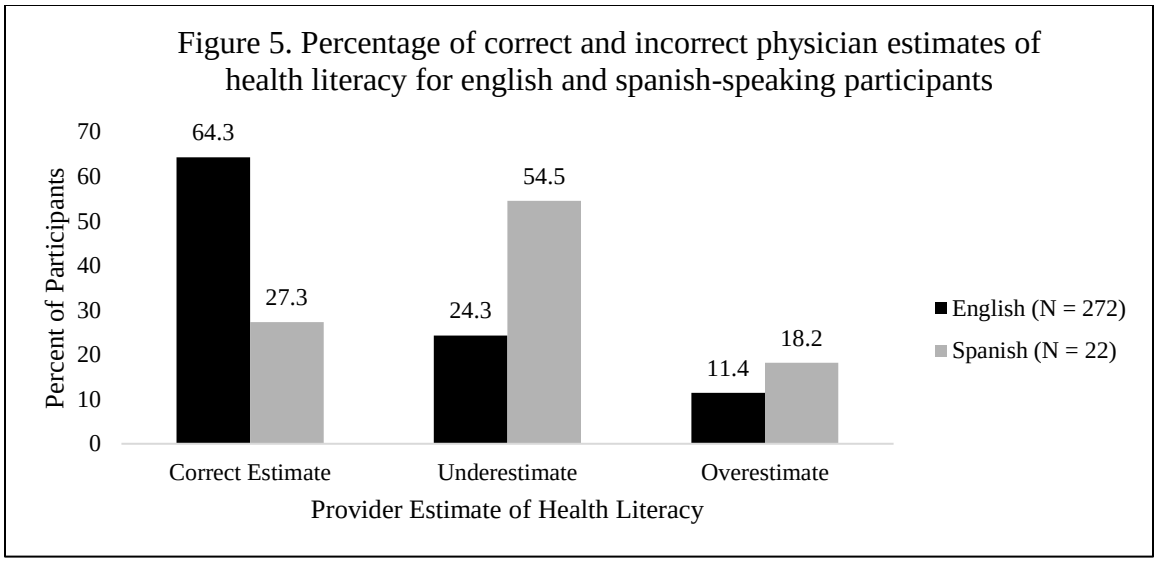


Figure 5. Percentage of correct and incorrect provider estimates of health literacy for English vs. Spanish speaking participants, as recorded on Form 1 and as measured by SAHL-E and SAHL-S. **X^2 (2, N = 294) = 12.36, p = .0021.**

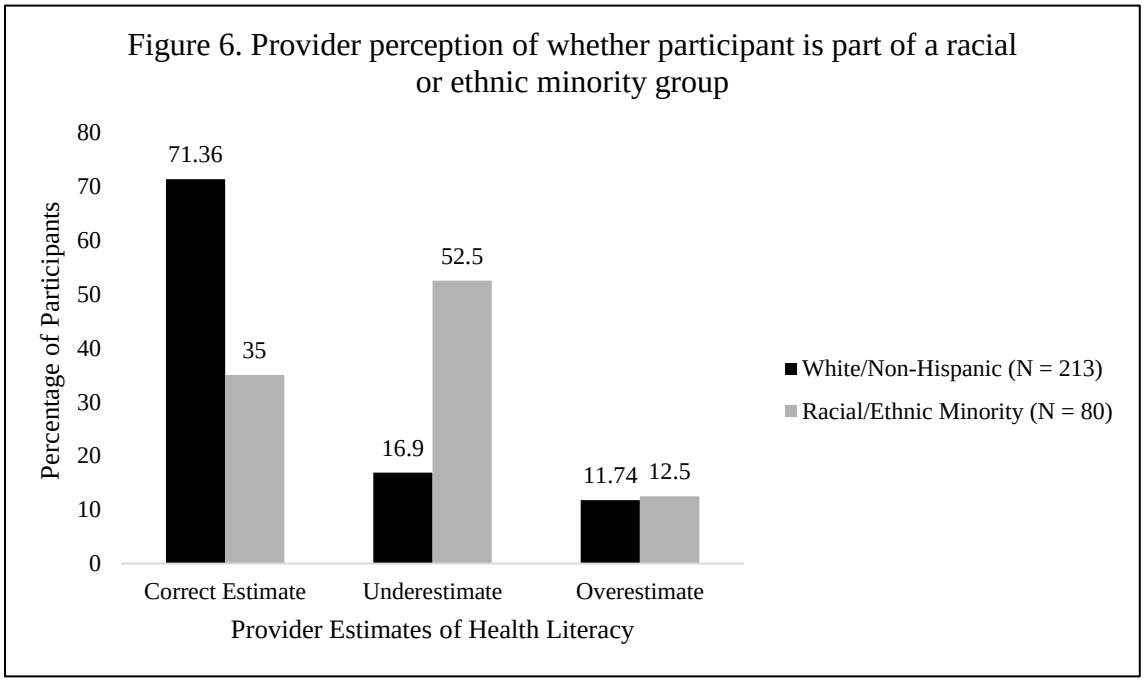


Figure 6. Provider estimates of health literacy vs. provider perceptions of whether a participant is part of a racial or ethnic minority, as recorded on Form 1. **X^2 (2, N = 294) = 40.23, p < 0.001.**

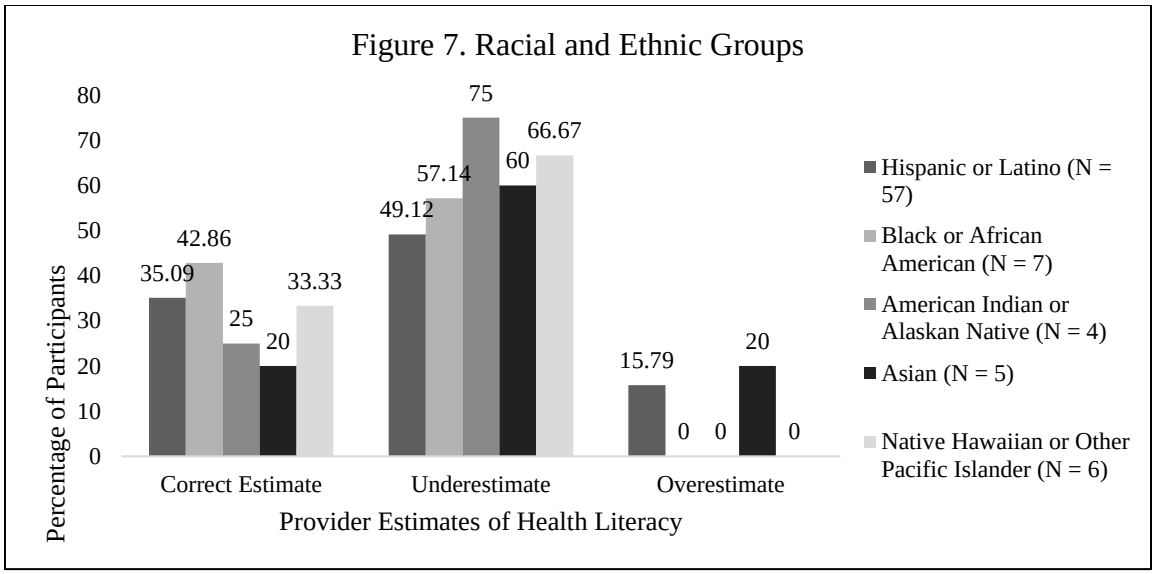


Figure 7. Breakdown of racial and ethnic minority groups, as perceived by providers and recorded on Form 1. No chi-squared analysis because sample size is too small (N < 5 for greater than 20% of frequencies).

Provider estimates of participant age did not have a statistically significant impact on estimates of health literacy (Figure 8), nor did the age of the patient (Figure 9). Providers were somewhat more likely to correctly estimate health literacy when they noted that the participant did not have other children (72.22%) than when they noted that the participant did have other children (56.41%) (Figure 10). However, these results are not statistically significant when including the participants whom the providers did not ask about other children, nor without this group due to small sample size.

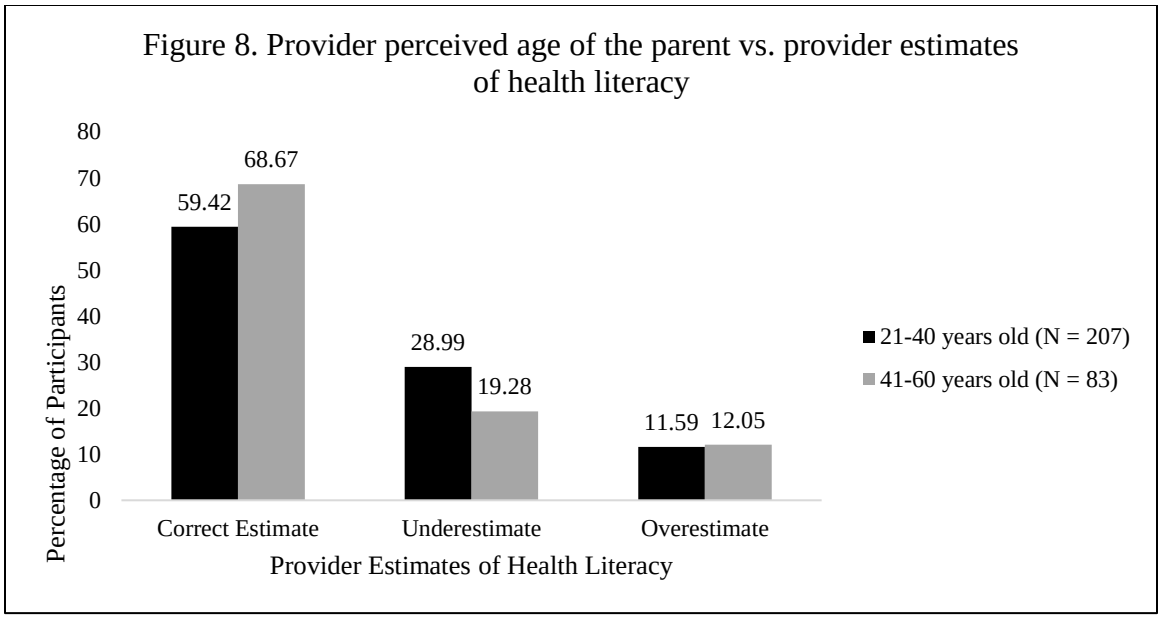


Figure 8. Provider estimates of health literacy, as recorded on Form 1 and tested with the SAHL, vs. the age of the participant, as perceived by the provider**. X^2 (2, N = 294) = 2.96, p = .23.**

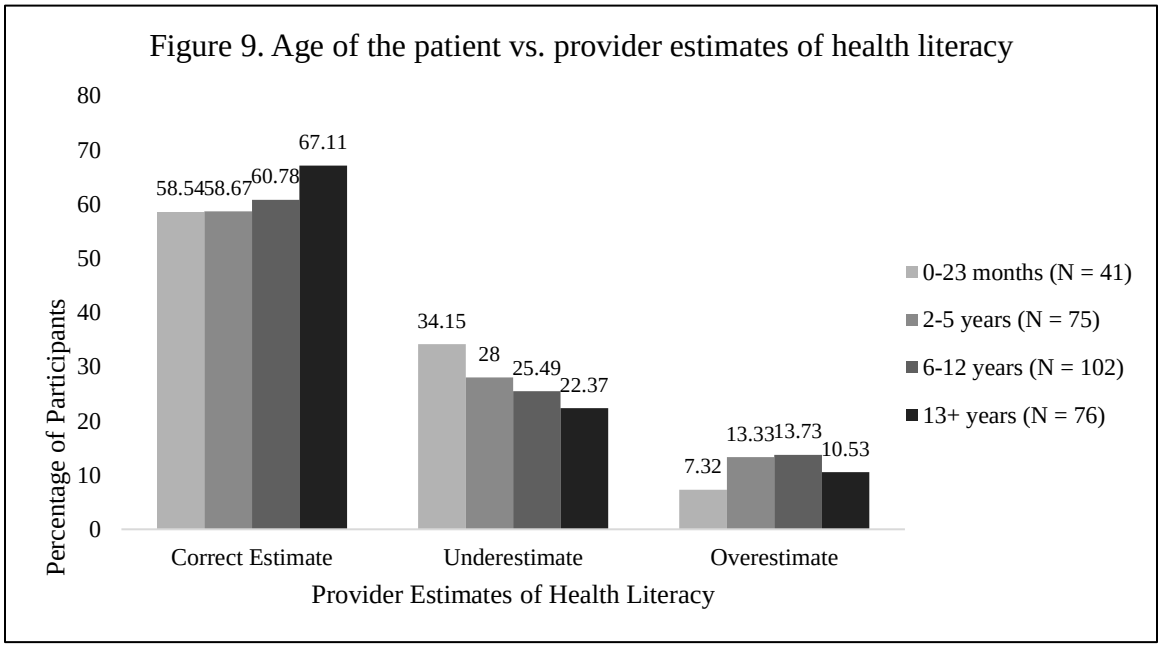


Figure 9. Provider estimates of health literacy, as recorded on Form 1 and tested with the SAHL, vs. the age of the patient, as noted in the medical record. **X^2 (6, N = 294) = 6.44, p = .38.**

Figure 10. Provider perception of parental experience vs. provider estimates of health literacy

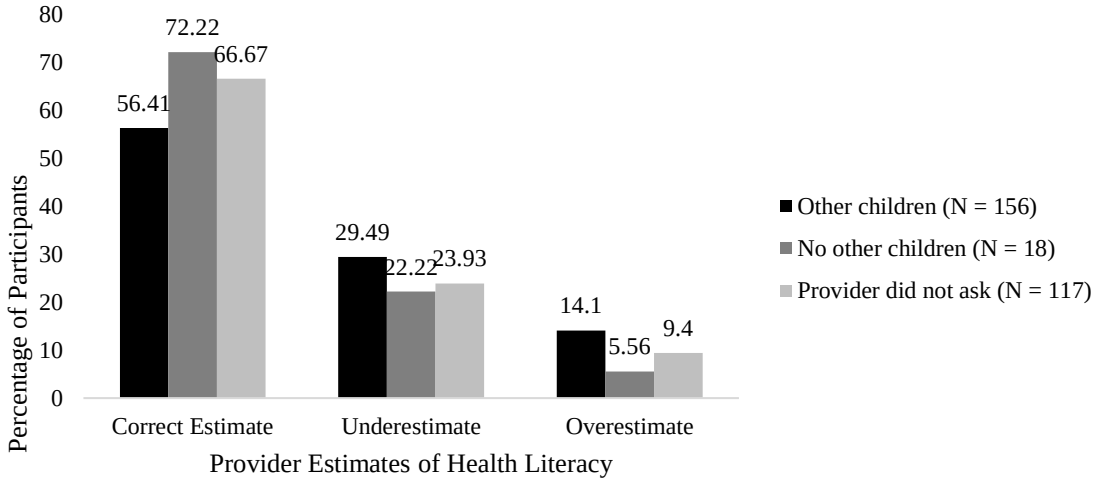


Figure 10. Provider estimates of health literacy, as recorded on Form 1 and tested with the SAHL, vs. the provider perception of the parenting experience of the participant, as noted by their response to the question "Do they have other children?" on Form 1**. X^2 (4, N = 294) = 4.3, p = .37.**

DISCUSSION

The primary goal of *Aim One* of this study was to quantify misestimation of health literacy by providers, as well as identify specific biases that might be present and how the experience of the provider might contribute to those misestimations or biases. These preliminary results show that providers only correctly estimate the health literacy of parents in the Pediatric Emergency Department 61.56% of the time, and misestimates are often underestimates (26.53%) rather than overestimates (11.9%) (Figure 2). This rate of correct vs. incorrect estimates of health literacy is consistent with a past research study, but these results suggest a larger problem with underestimates of health literacy than was previously identified.[15] This discrepancy suggests that providers in this study

may be more cognizant of health literacy as a potential barrier than was anticipated or suggested by past research. These results might also be a reflection of the novel population sample that was obtained for this study; caretakers of pediatric patients. It might therefore be the case that the sample is generally younger and healthier than patient populations that were previously studied with this assessment tool. Further, these factors might partially explain the higher health literacy of our participants compared to what was often estimated by providers. Regardless, this rate of provider misestimates of health literacy must be explored further to understand the impact and potential causes of miscommunication stemming from misjudgments of a person's health literacy level.

The potential negative outcomes of providers overestimating health literacy are more obvious than those of providers underestimating health literacy. When a provider overestimates health literacy, they might assume that the patient/caregiver understands the language they use or instructions they give. Further, this misjudgment can inflict material harm by resulting in inadequate home care, improper medication dosing, or other negative outcomes that directly affect patient health. However, indirect outcomes are similarly concerning, such as patient distrust in providers and the healthcare system. It has been suggested that this indirect impact of mistrust plays a significant role in the poor health outcomes of people with low health literacy.[14]

The other type of misestimates of health literacy that providers make, underestimates, might appear to be less concerning than overestimates because there is an assumption that providers only need to work on *reducing* the technicality of their language in order to remove communication barriers related to health literacy. However, a nuanced approach to patient communication also acknowledges the patient/caregiver's

perception of the way that the provider is communicating. A potential concern about providers underestimating health literacy is that it might affect the relationship between the patient/caregiver and the provider, similarly to how provider overestimates of health literacy might limit these relationships. While there may be fewer specific communication issues because the caregiver can understand the health information presented by the provider, they might interpret the providers attempts to explain something with less technical language as condescension. For example, if a parent in the Pediatric Emergency Department feels that the provider is speaking to them in a way that is condescending because the provider assumes their health literacy is lower than it actually is, that parent might feel belittled or not trust the provider, potentially leading to further barriers to good communication. By using both technical, medical language and common words/phrases to discuss health information, providers might be better able to communicate with families.

Aim Two of this study attempts to identify and understand the specific miscommunications that take place in the Primary Children's Hospital Emergency Department by asking families to report words or phrases that they did not understand. This aim was primarily developed to collect qualitative information about provider-patient/guardian interactions that likely involve an *overestimate* of health literacy in which a provider does not communicate well because they believe a parent can understand health information that might actually be above their health literacy level. However, it should be noted that some responses from parents included comments such as, "[the provider] dumbed it down too much, so it was confusing," in addition to reports of providers using medical jargon that was not understood by parents. While these results

have not been processed or analyzed in any way, it should be noted that they will contribute more information to the final observations made in this study when it is completed. The methods used to collect this qualitative data might also be applicable in considering solutions to the problem of miscommunication due to provider misestimates of health literacy. For example, the students in the Pediatric Clinical Research Program might be able to continue asking caregivers about the words or phrases that where not understood *and* whether they felt that the provider communicated at an appropriate level of technicality for their understanding of health information. This method serves not only the purposes of academic research but could also be applied in a direct quality improvement project in any given healthcare setting by allowing for patient responses to be circulated back to providers.

Importantly, the preliminary results of *Aim One* also suggest that the ability of a provider to estimate the health literacy of a parent in the Pediatric Emergency Department is influenced not only by their role/experience as a provider, but also by racial biases, gender/parenting role biases, and biases related to the language spoken by the caregiver (Figures 3-6). These results do not suggest statistically significant bias related to age or the amount of parenting experience of the participant (Figures 8-10).

The influence of the role/level of the provider is difficult to explain with these preliminary results. While there is a clear difference in health literacy estimation ability between the provider groups, the influence does not appear as a straightforward trend from least experienced (presumably residents) to most experienced (presumably attendings and nurse practitioners). Instead, these results suggest that certain groups may be more aware of health literacy as a concern for their clinical interactions, such as

attendings and fellows, who had the highest rates of correct estimates of health literacy (Figure 3). On the other hand, residents had the highest rate of underestimates of health literacy and a low rate of overestimates, which suggests that they are more likely to assume someone has low health literacy when they in fact have high health literacy. This result may be explained by changes in the way that the social determinants of health have been taught to medical students over recent years, especially considering that the field of health literacy research is relatively young. Another potential difference between these groups is their amount of experience with patient interactions, although the low rate of correct estimates by nurse practitioners with, on average, more experience than fellows, challenges this idea. Further analysis to determine potentially differing levels of bias among these groups may also provide insight into the differences between them.

Potentially the most important outcome of this preliminary analysis is the result that providers are much more likely to misestimate the health literacy of participants who they perceive to be part of a racial or ethnic minority (people of color) and Spanish-speaking participants compared to majority (white) and English-speaking participants. These results also suggest that providers are much more likely to underestimate the health literacy of people of color and Spanish-speaking participants than overestimate their health literacy. This result raises a different concern about racial bias in provider estimation of health literacy than has been observed in past research. It suggests that the concern of patients/guardians feeling “talked down to” by providers may be significantly more relevant among people of color. This adds to a growing body of evidence related to racial bias in healthcare. Racial bias is known to impact health outcomes and contribute to disproportionately negative relationships between white providers and patients of

color.[17] Specifically, people of color are more likely to report that they do not trust white healthcare providers due to perceive discrimination.[18,19] This heightened distrust among people of color has been shown to impact communication with providers.[17] For example, black women are more likely than white women to report that they do not trust their primary care providers, and they are less likely to communicate with their provider about health matters such as HIV.[20] The preliminary results of this study suggest that racial bias among providers is a relevant aspect of health literacy estimation and therefore clinical communication, and should be further studied and addressed in the interventions that result from this research.

Another interesting finding in these preliminary results is that providers were somewhat more likely to correctly estimate or underestimate the health literacy of mothers compared to fathers, and much more likely to overestimate the health literacy of fathers compared to mothers (Figure 4). This result might reflect the persistent gender bias that is seen in society wherein women are incorrectly assumed to be, on average, less intelligent than men.[21] The negative outcomes of this phenomena might include mothers being less likely to trust providers due to perception of bias or condescension from providers. Conversely, fathers might experience higher rates of poor communication in which they do not understand words or phrases used by providers because their health literacy is lower than the provider estimated.

Future directions for this area of research ought to include an investigation of the specific miscommunications that are prevalent among groups that are disproportionately affected by provider misestimation of health literacy. For example, the survey methods used in *Aim One* could be combined with an expanded version of the *Aim Two* methods

to provide qualitative information about what specific communications occur most commonly for white vs. non-white patients, mother vs. fathers, or different patient age groups. Other methods of studying the impact of low vs. high health literacy on clinical communication and health outcomes might include prospective studies of provider-patient/caregiver relationships.

Additionally, there are other factors that may influence provider estimates of health literacy that could be studied with the results of this study as an indicator that there are provider biases that may be important in understanding provider perceptions and communication choices. One specific factor that could be compared is the reason for patient visits to the Emergency Department, which might indicate that providers estimate health literacy based on whether they think the patient/caregiver chose the right healthcare service to address their concern. Other demographic factors that would be interesting to examine are the gender and race of the provider, as well as perceived socioeconomic status or general education level of the patient/caregiver.

Another future direction of this research is to develop a more comprehensive method of measuring health literacy than the SAHL. The SAHL is used in this study because it is a validated tool that can determine health literacy in a short amount of time in both English and Spanish-speaking populations. However, its limitations include a lack of discrimination between the highest levels of health literacy, intermediate levels, and low levels. Additionally, the ability of a patient/caregiver to function in the healthcare system may be better tested with additional survey questions regarding how to schedule a follow-up appointment, where to seek care for different health concerns, or how to interpret different instructions such as medication dosage or wound care.

The results of this study suggest not only areas for future research, but also a need for active responses by medical educators and clinical leaders to ensure that providers are aware of their potential biases and work to limit their impact on clinical communication and health outcomes. These educational interventions might involve curriculum for medical students and midlevel providers, as well as continuing education for providers to learn about health literacy, the importance of correctly estimating health literacy, and the potential biases that may affect those estimates. Additionally, using tools such as the Implicit Associations Test from Harvard University can aid providers in understanding their own biases as an early step in improving communication and relationships with patient/caregivers.[22]

The preliminary results of this study suggest a need for further investigation of clinical communication issues related to health literacy, particularly as these issues affect people of racial/ethnic minority, Spanish-speaking patients, and other marginalized groups that are not addressed by this study. Further, this study identifies provider biases that must be addressed through future research and interventions in provider education and clinical practice. Broadly, this research is contributing to a growing body of information about where, how, and why health literacy is such an important factor in health outcomes, and what solutions might look like in the context of the better understood problem.

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APPENDIX

Appendix A. English Short Assessment of Health Literacy (SAHL-E)

Instruction for Administering *SAHL-E*

SHORT ASSESSMENT OF HEALTH LITERACY-ENGLISH (SAHL-E)

Interviewer's Instruction

The *Short Assessment of Health Literacy-English*, or *SAHL-E*, contains 18 test items designed to assess an English-speaking adult's ability to read and understand common medical terms. The test could help health professionals estimate the adult's health literacy level. Administration of the test could facilitated by using laminated 4"×5" flash cards, with each card containing a medical term printed in boldface on the top and the two association words—i.e., the key and the distracter—at the bottom.

Directions to the Interviewer:

1 Before the test, the interviewer should say to the examinee:
"I'm going to show you cards with 3 words on them. First, I'd like you to read the top word out loud. Next, I'll read the two words underneath and I'd like you to tell me which of the two words is more similar to or has a closer association with the top word. If you don't know, please say 'I don't know'. Don't guess."

2. Show the examinee the first card.

3. The interviewer should say to the examinee:
"Now, please, read the top word out loud."

4. The interviewer should have a clipboard with a score sheet to record the examinee's answers. The clipboard should be held such that the examinee cannot see or be distracted by the scoring procedure.

5. The interviewer will then read the key and distracter (the two words at the bottom of the card) and then say:
"Which of the two words is most similar to the top word? If you don't know the answer, please say 'I don't know'."

6. The interviewer may repeat the instructions so that the examinee feels comfortable with the procedure.

7. Continue the test with the rest of the cards.

8. A correct answer for each test item is determined by both correct pronunciation and accurate association. Each correct answer gets one point. Once the test is completed, the interviewer should tally the total points to generate the *SAHL-E* score.

9. A score between 0 and 14 suggests the examinee has low health literacy.

The 18 items of *SAHL-E*, ordered according to item difficulty (keys and distracters are listed in the same random order as in the field interview)

Stem	Key or Distracter		
1. kidney	__urine	__fever	__don't know
2. occupation	__work	__education	__don't know
3. medication	__instrument	__treatment	__don't know
4. nutrition	__healthy	__soda	__don't know
5. miscarriage	__loss	__marriage	__don't know
6. infection	__plant	__virus	__don't know
7. alcoholism	__addiction	__recreation	__don't know
8. pregnancy	__birth	__childhood	__don't know
9. seizure	__dizzy	__calm	__don't know
10. dose	__sleep	__amount	__don't know
11. hormones	__growth	__harmony	__don't know
12. abnormal	__different	__similar	__don't know
13. directed	__instruction	__decision	__don't know
14. nerves	__bored	__anxiety	__don't know
15. constipation	__blocked	__loose	__don't know
16. diagnosis	__evaluation	__recovery	__don't know
17. hemorrhoids	__veins	__heart	__don't know
18. syphilis	__contraception	__condom	__don't know

Appendix B. Spanish Short Assessment of Health Literacy (SAHL-S)

SHORT ASSESSMENT OF HEALTH LITERACY-SPANISH (SAHL-S)

Interviewer's Instruction

The *Short Assessment of Health Literacy-Spanish*, or *SAHL-S*, contains 18 test items designed to assess a Spanish-speaking adult's ability to read and understand common medical terms. The test could help health professionals estimate the adult's health literacy level. Administration of the test could facilitated by using laminated 4"×5" flash cards, with each card containing a medical term printed in boldface on the top and the two association words—i.e., the key and the distracter—at the bottom.

Directions to the Interviewer:

1. Before the test, the interviewer should say to the examinee:
   "***Le voy a mostrar tarjetas con 3 palabras en ellas. Primero, me gustaría que usted lea la palabra arriba en voz alta. Entonces, yo leeré las dos palabras debajo a usted y me gustaría que usted me dijera cuál de las dos palabras es más similar a la palabra arriba. Si usted no sabe la respuesta, por favor diga, 'no se'. No adivine.***"

2. Show the examinee the first card.

3. The interviewer should say to the examinee:
   "***Ahora, por favor, lea la palabra arriba en voz alta."***

4. The interviewer should have a clipboard with a score sheet to record the examinee's answers. The clipboard should be held such that the examinee cannot see or be distracted by the scoring procedure.

5. The interviewer will then read the key and distracter (the two words at the bottom of the card) and then say:
   "Cuál de las dos palabras es más similar a la palabra arriba? Si usted no sabe la respuesta, por favor diga, 'no se'.

6. The interviewer may repeat the instructions so that the examinee feels comfortable with the procedure.

7. Continue the test with the rest of the cards.

8. A correct answer for each test item is determined by both correct pronunciation and accurate association. Each correct answer gets one point. Once the test is completed, the interviewer should tally the total points to generate the *SAHL-S* score.

9. A score between 0 and 14 suggests the examinee has inadequate health literacy.

The 18 items of *SAHL-S*, ordered according to item difficulty (keys and distracters are listed in the same random order as in the field interview)

Stem	**Key or Distracter**		
1. empleo	__trabajo	__educación	__no se
2. convulsiones	__mareado	__tranquilo	__no se
3. infección	__mata	__virus	__no se
4. medicamento	__instrumento	__tratamiento	__no se
5. alcoholismo	__adicción	__recreo	__no se
6. riñón	__orina	__fiebre	__no se
7. dosis	__dormir	__cantidad	__no se
8. aborto espontáneo	__pérdida	__matrimonio	__no se
9. estreñimiento	__bloqueado	__suelto	__no se
10. embarazo	__parto	__niñez	__no se
11. nervios	__aburrido	__ansiedad	__no se
12. nutrición	__saludable	__gaseosa	__no se
13. indicado	__instrucción	__decisión	__no se
14. hormonas	__crecimiento	__harmonía	__no se
15. abnormal	__diferente	__similar	__no se
16. diagnóstico	__evaluación	__recuperación	__no se
17. hemorroides	__venas	__corazón	__no se
18. sífilis	__anticonceptivo	__condón	__no se

Appendix C. Consent Script

[Dr. Maija Holsti] Page 1 of 1
[Provider Estimates of Health Literacy]

Consent Script

"My name is _____and I'm an Academic Associate with Primary Children's Hospital. We know that health care providers sometimes don't do a good job of explaining things to patients and families and sometimes use words that are not commonly understood by others, so we are trying to gather more information about this issue to improve communication in the Emergency Department. Would you be interested in learning more about the study we are working on to address this issue?"

If no, thank the family and skip to the last question of Form 3.
If yes, continue.

"Participation in this study is completely voluntary, and your child's care will not be affected in any way by your participation in this study. If you choose to participate, you will be asked to read words from a set of flash cards and identify a key term associated with each word. Participation takes 2-3 minutes and you can withdraw at any time. There no risk of loss of confidentiality because we will not be collecting any identifying information. There is no direct benefit to you or your child from participating in this study and no compensation for participation, but we hope to use this study to improve communication and care for children at Primary Children's Hospital in the future. Would you like to participate?"

Appendix D. Form 3

Form 3

"Healthcare providers often use words or phrases that are unclear or don't make sense to patients and their families. What words or phrases have been used during this visit that are unclear or don't make sense to you?"

Record response:

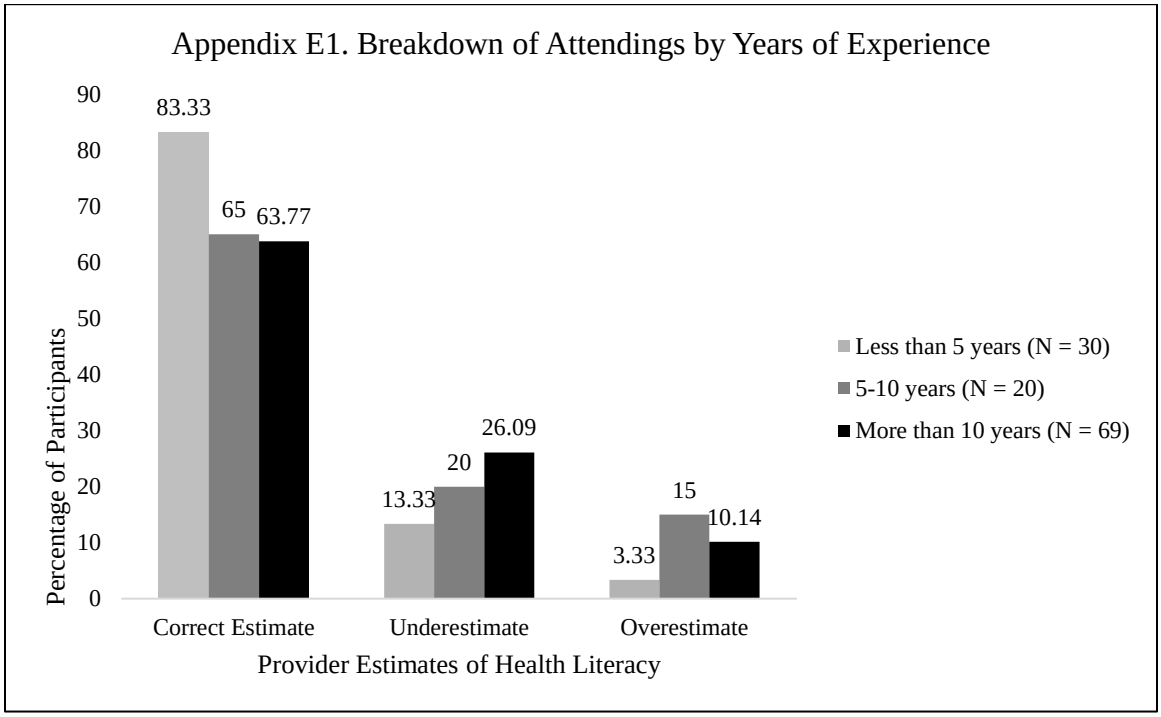
_____
_____
_____
_____

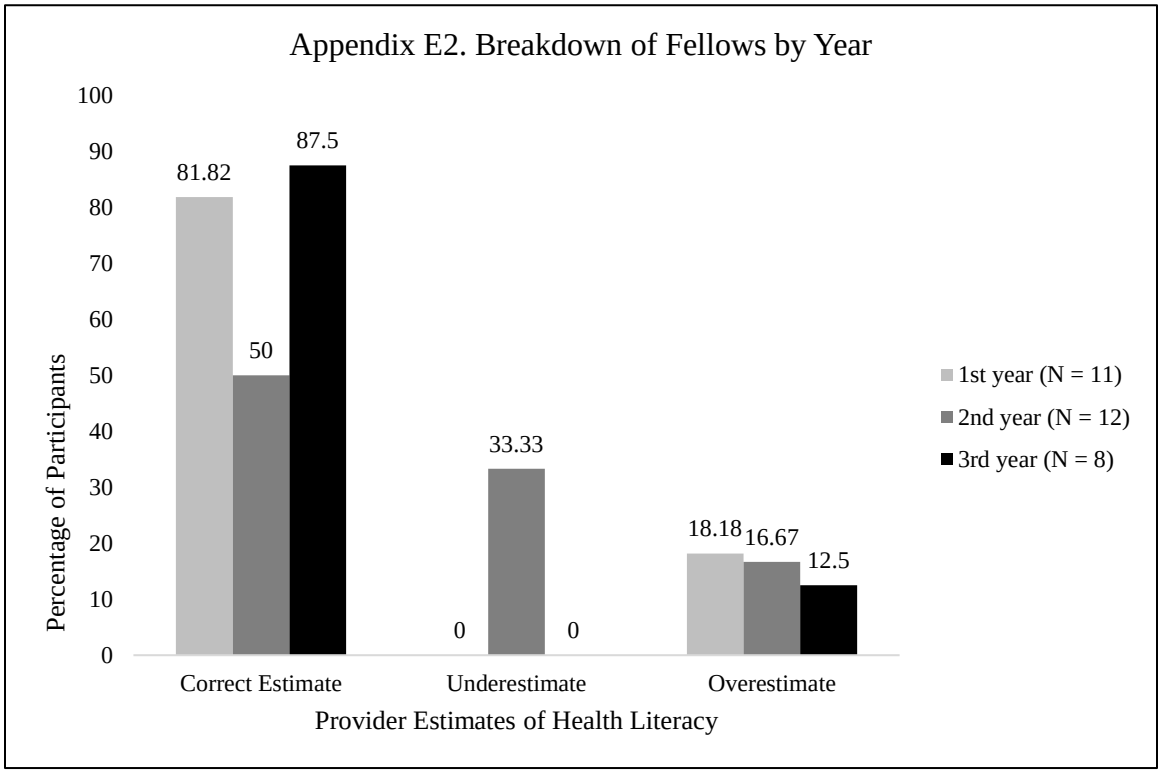
After which step in the care process did you ask this question?

- ❑ Initial evaluation
- ❑ Update
- ❑ Discharge teaching

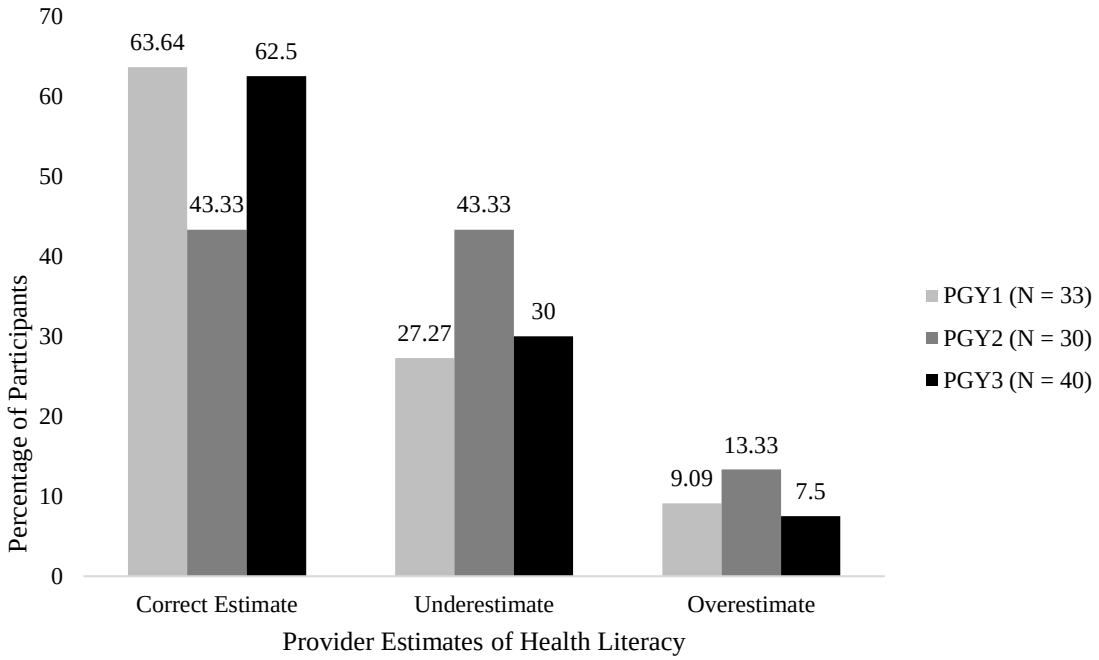
Other: _____

Appendix E. Breakdown of provider groups by years of experience in that role. No statistical analysis due to small sample sizes.





Appendix E3. Breakdown of Residents by Year



Appendix E4. Breakdown of Nurse Practitioners by Experience