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# UAMS Summer Health Literacy Study

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## Citation

**UAMS Summer Health Literacy Study**

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Abstract

**Background:** Health Literacy is a barrier to self-care; patients often lack the skills to understand complicated instructions that deal with medications, wound care, follow up schedules, and preventative care. Patients who undergo hip and knee replacements are often older adults, a population that normally struggles with various aspects of health literacy. Patient education materials are a common means of communicating with these individuals. However, if the patient does not understand the materials that they are given, they are more likely to experience negative side effects after their operation. **Purpose:** The purpose of this study is to compare the health literacy levels of patients to the readability of the materials in a preoperative "Joint Academy" education class for hip and knee replacement patients. An additional purpose is to see if there is a difference in health literacy levels between "health coaches" and the patients themselves.

**Methodology:** A convenience sample of 26 patients and health coaches enrolled at the UAMS Joint Academy classes were recruited and consented by a trained research assistant. Patients and coaches scheduled for either hip or knee replacements will be eligible for inclusion. Once consented, the individuals will be asked a series of demographic questions. The research assistant will then administer a health literacy aptitude test to the patient or coach. **Results:** 18 of the individuals tested had adequate health literacy scores to understand the materials presented in the Joint Academy classes. 8 individuals were deemed as having inadequate health literacy levels to understand the classes. Patients with low health literacy scores were more likely to choose a coach with adequate health literacy scores than patients with adequate health literacy scores.

**Discussion:** Patients with inadequate health literacy may choose coaches with adequate health literacy to compensate for skills that they lack. Further research needs to be conducted to

determine if this generalizes to other clinical settings. When patients with inadequate health literacy have coaches with higher skill levels, those coaches can help patients to better understand important health information that they may not comprehend on their own. When patients understand surgery information better, poor surgical outcomes related to patient understanding can be avoided.

Chapter 1: Introduction

Health Literacy refers to the ability of a patient to obtain, communicate, and process information related to health services. Most adult americans have a difficult time reading and understanding basic health information. This ultimately leads to billions of dollars in unnecessary health costs (Shealy and Threatt 2015). New ways of measuring health literacy levels are being used to combat this growing epidemic. Specifically, the Newest Vital Sign (NVS) is a useful tool used to assess the level of literacy of a patient. The NVS categorizes patients into 3 categories, which are: high likelihood of limited health literacy, possible limited health literacy, and adequate literacy. Tools like NVS will allow healthcare officials to get certain patients the help they need to succeed in post-operation settings (Shealy and Threatt 2015). Health Literacy is a barrier to self-care; patients often lack the skills to understand complicated instructions that deal with medications, wound care, follow up schedules, and preventative care. Patients who undergo hip and knee replacements are often older adults, a population that normally struggles with various aspects of health literacy. Patient education materials are a common means of communicating with these individuals. However, if the patient does not understand the materials that they are given, they are more likely to experience negative side effects after their operation. Elderly people are known for having some of the worst health

literacy levels, and normally need more help with basic post-operation needs than other populations.

Recently, patients have started involving other people in their surgical recovery, called "health coaches." This is a revolutionary way to help the lower literacy patients succeed post-operation. This pilot study aimed to determine the health literacy of both orthopedic surgery patients and their coaches. It was hypothesized that the reading level of patient materials is higher than health literacy recommendations for the health literacy level of the sample patient population. It is also thought that there will be a significant difference between patient expectations for patients with low health literacy compared to those with adequate health literacy as measured by the Newest Vital Sign (NVS). Third, it was believed that the health literacy screening question in Epic will be at least 80% effective at detecting low health literacy as measured in a direct, validated measure (NVS). Finally, it was hypothesized that patients with lower health literacy levels will have coaches with higher health literacy levels to compensate for skills that they may lack.

Chapter 2: Literature Review

This chapter describes literature relevant to the research purposes of this thesis. It is organized into four sections: (1) Health Literacy; (2) Health Literacy and Orthopedics; (3) Health Literacy of Caretakers; and (4) Systems of Measuring Health Literacy and the Newest Vital Sign. At the end of each section, the relevance of the literature to the research reported in this thesis is discussed.

Health Literacy

Health Literacy refers to the ability of a patient to obtain, communicate, and process information related to health services. Almost one out of four Americans have a difficult time reading and understanding basic health information. This ultimately leads to billions of dollars in unnecessary health costs (Shealy and Threatt 2015). Evidence shows that race, ethnicity, educational level, gender, disability, and geographic location are all important factors that need to be taken into account when describing health literacy in the United States (Baker 2006). Accessibility to healthcare services, discrimination, and language and cultural barriers can also lead to health disparities within the US healthcare system (Office of Minority of Health 2009). Many other factors can also contribute to a person's health literacy. Depending on the healthcare provider, the type of information being shared, whether the news is positive or negative, and the health problem being experienced, a person's health literacy level can vary (Heinrich 2012).

Cultural barriers such as race, language, and socioeconomic status can further the gap between physician and patient understanding. Howard, Sentell, and Gazmarian (2006) found significant differences in the health literacy levels of patients with chronic illnesses when educational level and race was taken into account. In fact, it was shown that these differences in understanding lead to significantly worse outcomes for the minority groups. Research showed that if these two groups had similar levels of health literacy the minority group could increase their levels of successful health status by 25%. Likewise, Schillinger et al. (2002) found that diabetic patients with low health literacy levels were much more likely to have poor glycemic control than their counterparts with adequate levels of health literacy.

Of all the factors, however, it has been shown that patient-provider understanding is the most crucial. In order to properly explain the methods of treatment and the recovery plans, trust and understanding between the two parties is necessary (Heinrich 2012). One of the most difficult barriers to overcome with respect to this relationship is that healthcare providers often lack awareness that their patients don't fully understand the information that they have been given. Most patients forget approximately 80% of the information they were given at the doctor's office, and 50% of the information the patients retain is incorrect information (Clear Health Communication Initiative, 2007). This lack of awareness has been well documented with physicians, but a recent study shows that nurse's also have a problem with overestimating patient's health literacy levels. In this study, 63% of patients had a high likelihood of limited health literacy. However, the nurses only reported that 19% of their patients had a high likelihood of limited health literacy. Nurses also reported that 68% of the patients had adequate health literacy, overestimating the the actual number of patients with adequate health literacy by over 40% (22% adequate health literacy). This finding is important because nurses are responsible for the majority of patient communication (Cromwell et al. 2013). Without an accurate awareness of patient health literacy levels, there could be issues in the discussion of follow-up appointments, new medications, dietary restrictions, and activity levels after discharge. As a result of the overestimation of patient's health literacy levels, nurses may be communicating to the patient in a way that they are incapable of accurately understanding. This could attribute to poor levels of hospital readmission rates. (Cromwell et al. 2013).  Implications of this study would suggest that nurse training in health literacy is needed for inpatient nurses. Further research should be an important priority for healthcare officials because this would be an easy and efficient way to cut

down on the number of poor health outcomes and readmission rates seen within the United States Healthcare System (Cromwell et al. 2013).

Similarly, providers should anticipate that they will admit patients with low health literacy levels and should take the necessary precautions to ensure the accurate understanding of medical information. Alternative means of understanding such as using visual aids, avoiding the use of acronyms, and implementing programs like the "teach-back" methods could go a long way in the clarification of difficult information being shared with the patient (Heinrich 2012). Educational programs for patients have been developed and implemented in some hospital settings. These programs are designed to be informational for the patient, and easy to understand because of the use of basic language. This gives patients with low health literacy levels a realistic ability to understand the material that is presented to them. If more institutions begin to adopt these programs, the potential to lower health disparities across the country could rise (Heinrich 2012).

Another way of addressing poor health literacy levels could be to focus on the anxiety or alienation that patients with low understanding feel when their health literacy levels are assessed. Patients could be labeled as having low literacy levels and treated differently from the patients that are deemed as having adequate levels of health literacy (Heinrich 2012). Patients with low health literacy often do not understand the materials given to them. As a result, they often feel a severe lack of information, which can lead to nervousness and anxiety when having health-related conversations. Research shows that a patient-centered approach is associated with better patient understanding. Of all the factors involved in patient-centered communication, empathy is known as the most influential factor. Using empathy as an effective communication tool can lead

to multiple benefits in the patient-provider relationship, such as, encouraging patients to better describe their symptoms and concerns, enhancing the efficiency of collecting and understanding new information (leading to better diagnosis rates), increasing patient participation in their treatment and recovery, and helping to relieve patient stress in a manner beneficial to all parties (Chu and Tseng 2013). A recent study showed patients that perceived their doctor to have a high level of empathy towards them had strong positive correlations of health literacy. More empathy from doctors may help patients understand information better regardless of a patient's low level of health literacy. Likewise, the study showed that low levels of perceived doctor empathy may negatively affect a patient's ability to understand new information. Evidence also suggests that when opportunities for empathy are continually missed or ignored, visits tend to be more time consuming and frustrating for both physicians and patients (Chu and Tseng 2013).  Low health literacy levels can take considerable amounts of time to improve, so it is important to utilize means of increasing patient understanding. If healthcare providers can focus on using empathetic ways of communication, their relationship with their patients has the potential to improve. As a result of this, many medical schools have developed certain curriculums that focus on physician-patient relationships with an emphasis on empathy (Chu and Tseng 2013).

Once the factors pertaining to adverse health literacy have been addressed, health providers ultimately want to improve the informed consent process. This is how the patients make informed, autonomous choices regarding their healthcare (Abrams et al. 2011). It is critical to present this information in a way that the patient can make educated decisions about their medial procedures. Implementing a more transparent informed consent process can create many challenges for healthcare systems as they try to balance liability concerns for themselves and

providing the patient the information necessary to formulate their own decisions. Consent forms

are often very vague and designed solely to get a signature from the patient (Abrams et al. 2011).

If healthcare providers focus more on the patients during this process, it will become less

frustrating for all parties involved. If the patient is confident that they are making the right

decisions with regards to their health, they will be more involved in the treatment. This could

ultimately lead to higher patient satisfaction rates and lower the prevalence of unwanted health

outcomes.

<div align="center">Health Literacy and Orthopedics</div>

Low health literacy is a growing problem in orthopedics because of the aging population

the specialty deals with. Although nearly half of all Americans have inadequate general health

literacy, studies show that limited musculoskeletal health literacy may be even more prevalent.

This makes it even more difficult for orthopedic surgeons and their staff to accurately explain

information to their patients (Mulligan et al. 2015). Surgery for meniscal repairs is the most

commonly performed orthopedic operation in the United States. A recent study showed that

patients seeking orthopedic care for a meniscal operation could only answer 50% of questions

about meniscus structure, function, symptoms, and treatment (Brophy et al. 2015). In fact, 62%

of patients in the survey rated their knowledge about the meniscus as "little to no knowledge,"

and only 48% of patients knew that weakness was the main symptom of a meniscal injury

(Brophy et al. 2015). Regarding treatment, the most common procedure for a meniscal repair is

partial or complete removal of the meniscus. However, 68% of patients surveyed thought that

repair was the most common treatment. Only 29% of respondents knew that removal was the

most common option. This is important because the meniscus can only be repaired in

approximately 15% of tears (Brophy et al. 2015). This information illustrates the gap in what patients perceive can be done for a meniscal injury and what is actually done. The same patients were asked what their major concern was with regards to their surgery, and the most common responses were needing additional surgery after their operation and the future development of osteoarthritis. There is a much higher risk of needing other surgeries after a meniscal repair than a meniscectomy. However, most patients initially believe they want their meniscus to be repaired, because there is a misconception that the full removal of the meniscus can cause osteoarthritis down the line. Recent studies show that there is no evidence that a meniscal repair will protect patients from the development of osteoarthritis. The results from this study suggest a need for clear communication by the surgeon regarding the short-term and long-term consequences of meniscal surgery. It is important for surgeons to understand the issues that are most important to the general public. If physicians begin to target the factors that are most important to the patients, their overall attentiveness and comprehension may improve (Brophy et al. 2015).

These health literacy disparities span throughout all orthopedic subspecialties. Hand surgery office visits for patients with limited health literacy are 20% shorter than patients with adequate health literacy (Menendez et al. 2016). This could be because patients with limited health literacy choose to ask fewer questions, and are uncomfortable addressing their concerns with their doctor. This could particularly be the case if the at-risk patient is suffering from cultural or language barriers. A study of audiotaped physician visits showed that providers were more verbally dominant, less empathetic, and less patient-centered in their approach with non-white patients with low levels of health literacy (Menendez et al. 2016). In a highly specialized

field like hand surgery, basic understanding of human anatomy by patients is needed for active participation and understanding of treatment. If anything, patients with lower levels of health literacy should be visiting with the doctor for longer not shorter. Hand surgeons need to make a conscious effort to engage with their lower literacy patients, and make sure that they are accurately understanding the information which they are being presented (Chen et al. 2016). The use of alternative means of explanation like visual aids and analogies could go a long way in helping patients understand difficult information. It is well documented that a patient-centered approach leads to higher patient satisfaction rates in hand surgery patients. Patient-perceived surgeon empathy is the most important factor in regards to patient satisfaction (Chen et al. 2016).

Health Literacy of Caretakers

Knowing the health literacy levels of a patient and their caretaker is critical because the caretaker is the one who is responsible for assisting the patient with medication, managing daily health care tasks, and helping the patient to make decisions that are best for their health. If a care giver does not adequately understand information pertaining to the patient, poor health-related outcomes can become more frequent (Espinoza et al. 2013). Little is known about caregiver's health literacy and its association with the patient's health literacy. It is important to study these relationships, because they could be vital in improving readmission rates and poor health outcomes in the low health literacy community. A recent study examined the association of health literacy levels between elderly hispanic patients and their caregivers across 174 patient-caregiver dyads (Espinoza et al. 2013). As people grow older, age related cognitive impairment can present serious problems for patient communication. This is no surprise because elderly people are well documented for having some of the worst levels of health literacy. Many people

assume that caregivers always have adequate levels of health literacy, but that is not always the case. In this study, 64.9% of the elderly patients within the sample showed inadequate levels of health literacy. Although, caretakers were more likely to have an adequate level of health literacy than the patients, 31% of the caretakers surveyed had inadequate health literacy scores. This is a very concerning result because a caregiver's low health literacy level may negatively affect the health outcome of their patients, regardless if the patient has an adequate level of health literacy (Espinoza et al. 2013). A caregiver with low health literacy could unknowingly make mistakes that lead to poor outcomes for the patient. Healthcare providers should me mindful of this, and attempt to tailor instructions for caregivers with low health literacy. Physicians often assume that the caregivers will have adequate levels of health literacy, which sometimes leads to insufficient health outcomes and hospital readmission (Espinoza et al. 2013).

<p style="text-align:center">Systems of Measuring Health Literacy and the Newest Vital Sign</p>

Health literacy levels can be measured by a variety of reliable systems. The Rapid Estimate of Adult Literacy in Medicine (REALM) is a test that consists of 125 medical terms and is used to estimate a patient's health literacy level. It does not grade the patient's ability to understand the words, just whether or not they are able to read them. The REALM test is only available in English at this time (Caskey et al. 2011). The Test of Functional Health Literacy in Adults (TOFHLA) is a Spanish test that looks at a person's ability to read and comprehend a medically relevant passage that does not contain numbers. This test measures an individuals reading level and takes about twenty-two minutes to administer (Caskey et al. 2011). Health literacy levels can also be determined by the Medical Term Recognition Test (METER). This tool

takes two minutes to complete and asks patients to respond if they recognize certain medical

terms (Caskey et al. 2011).

The measurement used for this study is the Newest Vital Sign (NVS). It is available in

both Spanish and English and is a very common outpatient health literacy assessment tool. The

NVS uses an ice cream label and asks patients to answer six questions about it. It estimates a

person's health literacy level by looking at their ability to understand written and verbal forms of

communication, as well as their numerical skills (Caskey et al. 2011). During the examination,

patients are given questions to answer and their responses are recorded as either correct or

incorrect. Scores can range from 0-6. Scores from 0-1 almost always indicate a limited level of

health literacy, scores from 2-3 indicate the possibility of limited health literacy, and scores from

4-6 almost always indicate adequate health literacy. This process takes approximately three

minutes to complete and can be a very useful tool in identifying low literacy patients (Caskey et

al. 2011). In a recent study, it was concluded that it took less than thirty seconds to hand out the

NVS and explain the instructions of the test to new patients during their intake. Patients were

required to fill out the NVS while they filled out their routine paperwork in the waiting room.

Once the patient finished the test, they brought it to the front desk to be inputted into their

electronic medical record (EMR). Physicians then took two to five minutes to explain their

scores to the patient and tailored communication to the patient's specific health literacy level

(Caskey et al. 2011). At the conclusion of the study, Physicians were interviewed about their

utilization of the NVS in a clinical setting. It was found that the physicians and the hospital staff

believed that the use of the NVS increased their awareness of the importance of health literacy

tailored communication during patient visits. The majority of providers also admitted an inability

to correctly estimate a patient's level of health literacy without the use of the NVS as a screening

tool. Sixty-seven percent of the employees interviewed felt that using the NVS to identify

patients with limited health literacy improved the quality of care they were able to administer. As

a result, the staff was able to customize treatment communication to ensure better understanding

of information from at-risk patients (Caskey et al. 2011).

<div align="center">Chapter 3: Methodology</div>

This study was approved by the UAMS Institutional Review Board. Research assistants

were required to complete a CITI certification test before they could be involved in patient

contact. Participants were recruited from the UAMS Hip/Knee Academy surgery patient

education class in the summer of 2016. At the beginning of the class, a research assistant would

explain the purpose of the Newest Vital Sign (NVS) assessment and ask patients if they would

volunteer for the survey. Inclusion criteria is the ability to see, hear, speak and understand

English in spoken and written form. Exclusion criteria is any patient or coach who is not at least

18 years of age, or unable to meet the standards set in the inclusion criteria. Consented patients

and coaches were asked to complete a series of demographic questions in a secure online survey

(LimeSurvey) on an iPad that includes questions on the following: gender, race, age, level of

education, and patient/coach status.  Each patient and "coach" was recruited by a trained research

assistant and completed the NVS, demographic questions, and three additional questions

regarding their expectations for surgery. After the patient or "coach" was consented by a research

assistant, they were asked a series of six questions regarding an ice cream label, and their

responses were recorded as either correct or incorrect. All data was recorded on an iPad and was

stored for analysis at the conclusion of the study. The patient's medical record number was

recorded on the survey so that the data could be matched with the health literacy screening

obtained from NVS. For coaches, the corresponding patient's medical record number followed

by a "C" will be recorded on the survey in order to identify all coaches and link them to their

correct patients.

Descriptive statistics were used to describe the health literacy levels of the sample.

Statistical analyses was conducted using SAS 9.4 with a level of significance $p<.05$ in which the

dependent variable was patient expectation and the independent variable was health literacy

scores on the NVS. Demographics were confounders/control variables for the analysis. Patient

NVS scores were extracted from the Epic data warehouse and matched with the correct medical

record number for proper storage and analysis.

## Chapter 4: Specific Aim of Research

The goal of this project was to compare the levels of health literacy of patients and health

coaches at the UAMS orthopedic clinic. As seen in previous research, orthopedics is a specialty

that has elevated levels of poor health literacy. If a connection can be made between the health

literacy levels of the patient and health coach, further advances can be made in regard to

combating low health literacy in Arkansas.

## Chapter 5: Results

A total of 101 patients and coaches (age 18-84) were surveyed throughout this study. The

final patient/coach data included a convenience sample of 26 health coaches and patients. This is

because only pairs of coaches and patients were used in data analysis. Participant characteristic

data is included in Table 1.

Table 1. Demographics for patients and coaches

| Demographic (N = 54) | Category | Patient n (%) | Coach n (%) | Total n (%) |
|---|---|---|---|---|
| Gender | Male | 12 (22.2%) | 12 (22.2%) | 24 (44.4%) |
| | Female | 15 (27.8%) | 15 (27.8%) | 30 (55.6%) |
| | *Total* | *27 (50%)* | *27 (50%)* | *54 (100%)* |
| | | | | |
| Age | 18-20 | 0 (0%) | 1 (1.8%) | 1 (1.8%) |
| | 21-29 | 0 (0%) | 2 (3.7%) | 2 (3.7%) |
| | 40-49 | 3 (5.6%) | 1 (1.8%) | 4 (7.4%) |
| | 50-59 | 5 (9.3%) | 5 (9.3%) | 10 (18.6%) |
| | 60-69 | 11 (20.3%) | 9 (16.7%) | 20(37.0%) |
| | 70+ | 8 (14.8%) | 9 (16.7%) | 17 (31.5%) |
| | *Total* | *27 (50%)* | *27 (50%)* | *54 (100%)* |
| | | | | |
| Race | White | 23 (42.6%) | 24 (44.4%) | 47 (87.0%) |
| | Black or African-American | 3 (5.6%) | 2 (3.7%) | 5 (9.3%) |
| | Hispanic | 1 (1.9%) | 0 (0.0%) | 1 (1.9%) |
| | American Indian/Alaskan Native | 0 (0.0%) | 1 (1.9%) | 1 (1.9%) |
| | *Total* | *27 (50%)* | *27 (50%)* | *54 (100%)* |
| | | | | |
| Education | Less than high school | 1 (1.8%) | 2 (3.7%) | 3 (5.6%) |
| | High school graduate | 5 (9.3%) | 4 (7.4%) | 9 (16.7%) |
| | Some college | 5 (9.3%) | 8 (14.8%) | 13 (24.1%) |
| | College graduate | 8 (14.8%) | 6 (11.1%) | 14 (25.9%) |
| | Professional or graduate degree | 8 (14.8%) | 7 (13.0%) | 15 (27.8%) |

| | | 27 (50%) | 27 (50%) | 54 (100%) |
|---|---|---|---|---|
| *Total* | | *27 (50%)* | *27 (50%)* | *54 (100%)* |
| Adequate/Inadequate HL on NVS | Adequate | 18 (33.3%) | 15 (27.8%) | 33 (61.1%) |
| | Inadequate | 9 (16.7%) | 12 (22.2%) | 21 (38.9%) |
| | *Total* | *27 (50%)* | *27 (50%)* | *54 (100%)* |

About 67% of patients and 56% of coaches had adequate health literacy; 33% of patients and 44% of coaches had inadequate health literacy.

In this study, there was no difference in health literacy between patients and coaches if the patients had adequate health literacy, but if the patient had inadequate health literacy, their coach's health literacy was higher. In other words, it was found that patients with inadequate health literacy levels were more likely to have a coach with adequate health literacy. Patients with adequate health literacy were equally as likely to have a coach with adequate as inadequate health literacy. This relationship can be seen in table 1.

Table 1: Patient and coach adequate v. inadequate health literacy results

| Patient/Coach Adequate/Inadequate | Coach Adequate | Coach Inadequate |
|---|---|---|
| Patient Adequate | 9 (50%) | 9 (50%) |
| Patient Inadequate | 7 (75%) | 2 (25%) |

Figure 1: Patient and coach adequate v. inadequate health literacy results
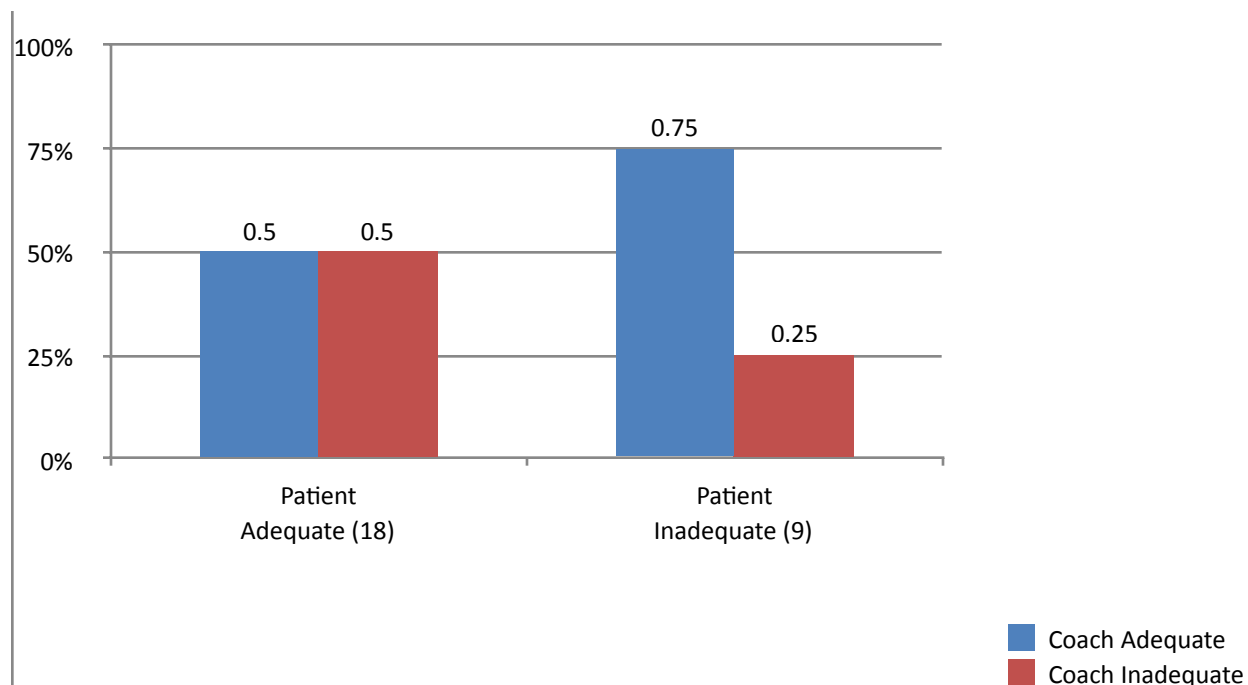
Chapter 6: Discussion

The purpose of this study was to compare the health literacy levels of patients to the readability of the materials in a preoperative "Joint Academy" education class for hip and knee replacement patients. An additional purpose was to see if there was a difference in health literacy levels between "health coaches" and the patients themselves. This study's sample showed that patients with inadequate health literacy levels were more likely to have a coach with adequate health literacy, and that patients with adequate health literacy were equally as likely to have a coach with adequate as inadequate health literacy. This was a pilot study and this was a very small sample, so further research needs to be conducted to determine if patients with low health literacy are more likely to select coaches with higher health literacy in other settings. If this is true, it is important because it suggests that patients with low health literacy may compensate for their lack of skills by selecting coaches with higher level skills. This could potentially result in better understanding for patients with low health literacy. If health services can properly

implement the idea of health coaches, it could help to close the gap between health literacy and post-operation success.

      Patients with inadequate health literacy may choose coaches with adequate health literacy to compensate for skills that they lack. This is extremely important, because the coaches are the people in whom the patient is placing their faith. If a care giver cannot adequately understand the health information presented, the patient will suffer. This could also mean that the patient relies too much on their coach, and could possibly become disengaged in their treatment. In order to successfully implement the use of caregivers, the patient, coach, and provider need to work together. It is important to study these relationships, because they could be vital in improving readmission rates and poor health outcomes in the low health literacy community.

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