

INTEGRATING HEALTH LITERACY INTO OCCUPATIONAL THERAPY

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DEDICATION

This dissertation is dedicated to the memory of my parents Greta and N.G. They taught me to believe in the value of hard work, the inherent goodness of people, and the evidence of things not seen.

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ABSTRACT

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Health literacy impacts a person's ability to manage chronic disease, observe preventative healthcare practices, and navigate the healthcare system. Health literacy is affected by both individual and system factors. The purpose of this descriptive study was to implement a health literacy initiative that included: an assessment of health literacy; a readability analysis; focus group findings; and development of a patient education manual for occupational therapists.

This dissertation is comprised of three studies. Study I was a two part descriptive study that examined the relationship between patients' health literacy level and the analyzed readability of patient education forms. Fifty outpatient clients participated in the study and 16 educational forms were analyzed. In the first part of the study the participants were assessed with the Short Test of Functional Health Literacy in Adults (S-TOFHLA) and were asked to complete a demographic questionnaire. In the second part, education forms were analyzed using the Lexile Analyzer. The data were analyzed using descriptive and inferential statistics. Study II used a qualitative design based on a focus

group of eight occupational therapists. This study provided insights into the knowledge and experience of therapists about health literacy.

The aim of Study III was to develop a manual of health literacy education strategies for occupational therapists. The manual was designed to be used in varied practice settings with strategies to address communication barriers to health literacy.

The results of Study I indicated that 38% of the sample had less than adequate health literacy, reading below the tenth grade level. Educational handout analysis revealed 89% were written at a level above the eighth grade. In Study II, the focus group identified deficits in therapists' knowledge of health literacy and lack of strategies for treating patients identified as having low health literacy. Study III produced a manual entitled, "Health Literacy: Patient Education Strategies for the Occupational Therapist." The manual features general information about health literacy, techniques to modify therapy for patients with low health literacy and experiential exercises specific to areas of practice.

Future studies are needed to explore health literacy and occupational therapy interventions using written and verbal communication to educate patients managing chronic diseases and conditions. Further studies are also needed to explore environmental factors that affect the level of health literacy.

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CHAPTER I

INTRODUCTION

Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p.4). The success and effectiveness of occupational therapy (OT) is influenced by factors that include health literacy. Health literacy impacts numerous tasks in the healthcare environment such as compliance with home programs, chronic disease self-management, and preventative healthcare. (Weiss, 2007). Low health literacy has been associated with older adults, clients with English as a second language, poverty, and limited education (Kutner, Greenberg, Jin, & Paulsen, 2006). Low health literacy negatively affects the ability to maneuver the complexities of the healthcare system and perform necessary tasks and roles associated with access to care and treatment. To address limitations of low health literacy and barriers to participation in the healthcare environment, the clinician must consider the interaction between the clients health literacy skills and the demands of the environment.

Statement of the Problem

In the last decade, low health literacy has been recognized as a public health crisis. According to the 2003 National Assessment of Adult Literacy (NAAL), 14% of

Americans cannot read basic text. They cannot read or understand complicated and complex information including health and medical information (Kutner et al., 2006). Those most affected by low health literacy include the aging population, people living in poverty, and people with English as a second language (*National Action Plan*, 2010). A majority of the patients in public health care systems share these high-risk characteristics for low health literacy. To improve patient comprehension and healthcare outcomes, it is important that occupational therapists and health care workers be aware of low health literacy and how it affects patient outcomes.

Statement of the Purpose

The overall purpose of this study was to examine the impact of health literacy upon OT practice and offer strategies that may promote optimal health outcomes. In order to achieve this purpose, three studies were completed. The first study was a comparison of patients' health literacy level to the reading level of patient education and information material. The second study was a focus group of OT's to obtain their experience and perspective of health literacy and the third study was the development of an educational strategies manual for OT. Research questions were:

- 1) Are required hospital documents written at an appropriate reading level for patient comprehension?
- 2) What is the health literacy experience and knowledge of occupational therapists?
- 3) What content is needed for an education manual of treatment strategies and guidelines for occupational therapists treating patients with low health literacy?

Specific Aims

Study I

The first study evaluated the health literacy level of a convenience sample of patients and compared that to the reading level of written documents including introduction to occupational therapy, attendance requirements, and educational handouts currently available in a local outpatient rehabilitation clinic. The research question for this study was: Are required forms and patient educational handouts written at an appropriate reading level to ensure patient comprehension?

Study II

For the second study, a focus group was conducted that included eight occupational therapists from varied practice areas of a large urban hospital system. A semi-structured interview guide included questions about the concept of health literacy, the ways in which health literacy affects patients, and the approach of integration into practice. The research question was: What is the health literacy experience and knowledge of occupational therapists?

Study III

For the third study, a manual was created to provide health literacy education strategies for occupational therapists. The manual information, based on results from Study I and thematic data from the focus group in Study II, provides guidelines for treating patients with low health literacy. The research question was: What content is

needed for an educational manual of treatment strategies and guidelines for occupational therapists treating patients with low health literacy?

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Low health literacy makes it difficult for millions of Americans to effectively manage their healthcare. Written and verbal communication provided through established rehabilitation programs is often unclear and difficult to understand. Although healthcare professionals are reluctant to acknowledge it, instructions using typical medical terminology are at a level beyond the comprehension of most patients (Doak, Doak & Root, 1996). The efforts to integrate health literacy into the healthcare system must include all healthcare professionals including occupational therapists (Nielsen-Bohlman et al., 2004).

Therapists routinely issue written information to patients to support their home program verbal instructions. The patient's ability to benefit from this information depends on his ability to understand and apply the information. The degree of health literacy skills will affect the extent of his comprehension (Smith & Gutman, 2011).

National Response to Low Health Literacy

Literacy is defined by the National Assessment of Adult Literacy as:

Skill-based: The knowledge and skills an adult must possess in order to perform prose, document, and quantitative tasks using printed and written information and

Task-based: The ability to use printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential (National Center for Education Statistics, 2006).

Health literacy can be thought of as literacy in the framework of health and wellness. Conceptually, there is a link between low literacy skills and low health literacy skills.

Health literacy skills are needed for dialogue and discussion, reading health information, interpreting charts, making decisions about participating in research studies, using medical tools for personal or family health care—such as a peak flow meter or thermometer—calculating timing or dosage of medicine, or voting on health or environment issues (Nielsen-Bohlman, et al., 2004, p. 31).

The 2003 National Assessment of Adult Literacy (NAAL) illuminated the problem of low health literacy. The assessment, given to 19,000 adults (16 years and older) incorporated 28 health-related questions. Health literacy was reported in three types of literacy including prose, document, and quantitative. Each type of literacy was reported in four proficiency levels: *Below Basic*, *Basic*, *Intermediate*, and *Proficient*. In the *Below Basic* level, 14% indicated very simple or concrete health literacy. The individual may be able to find a date on a clinic appointment slip. At the *Basic* level, 22%, it has been suggested that the person could read a leaflet about a diagnosis and from that information understand the need for preventive medical exams. At the *Intermediate* level, 53% of participants could read and understand a medicine label, or use a table or graph to determine ideal weight. At the *Proficient* level, 12% would have the literacy and numeracy skills to analyze complex health information. A summation of the findings of the 2003 NAAL were as follows:

- Women had higher average health literacy than men

- White and Asian/Pacific Islander adults had higher average health literacy than Black, Hispanic, American Indian/Alaska Native, and Multiracial adults
- Hispanic adults had lower average health literacy than adults in any other racial/ethnic group
- Participants who spoke English as their first language had higher health literacy than those with English as a second language
- Adults over 65 years of age had lower health literacy
- Adults living below the poverty level had lower health literacy
- Adults with less education had lower health literacy

(Kutner et al., 2006).

This report of profound health literacy limitations has been the impetus of several national healthcare programs as well as numerous governmental reports. These reports have been published with specific goals and plans to address the implications of low health literacy in the United States. Several national healthcare initiatives have been launched in response to this mounting dilemma of health literacy. In 2000, Healthy People 2010, an initiative by the Centers for Disease Control (CDC), called for several objectives to foster a healthy America in the coming decade (U.S. Department of Health and Human Services, 2000). This included increased access to health services and improved health communication. Healthy People 2020 now continues the effort to address and promote health literacy into the next decade (U.S. Department of Health and Human Services, 2011).

In 2004, the Institute for Medicine (IOM) published a report calling for action to increase health literacy in our society. The report “A Prescription to End Confusion” was developed by a committee of healthcare and health literacy experts. Their report was a comprehensive evaluation of the limitations and barriers to health literacy in America. This included findings and recommendations for health professional training (Nielsen-Bohlman, et al., 2004).

In 2004, the Department of Health and Human Services Agency for Healthcare Research and Quality (AHRQ) completed a systematic review of research to examine the effect of health literacy. This report found low health literacy resulted in patients’ decreased participation in preventative health measures, greater chronic disease and more frequent hospitalization (AHRQ, 2004). Based on this review, the National Action Plan (NAP) was published in 2010. The NAP called for a national effort on the part of health care organizations and professionals to meet the needs of those most affected by low health literacy. These include the aging population, people living in poverty and people with English as a second language (*National Action Plan*, 2010).

In 2010, the Patient Protection and Affordable Care Act (ACA) became law. It also supports a national movement to promote access to healthcare and healthcare equity including information offered at a comprehensible level. The success of this healthcare reform legislation will depend on the increased efforts to improve health literacy (Somers & Mahadevan, 2010).

Low health literacy has been identified as a barrier to effective health care not only throughout our nation but throughout the world. The results of a recent European Health Survey of eight countries report 46.3% of participants have limited health literacy (HLS-EU, 2012). Limited health literacy has been acknowledged as a national and global problem that is limiting full access to healthy living for millions of people (WHO, 2012)

Occupational Therapy and Health Literacy

Occupational therapists are trained to consider factors and skills of the client and how they affect participation in daily activities or occupations. OTs strive to assist their clients in effective and productive participation in varied occupations and environments. Health literacy is one dominant client factor that prevails in the healthcare environment (AOTA, 2015).

OT literature acknowledges the importance of understanding the components of health literacy. Health literacy is considered an interaction between the client's skills and the demands of the healthcare system. Using clearly written information and plain language is recognized as a basic element for this interaction. Confirming comprehension through techniques such as a teach-back method and encouraging patient inquiry has been found to improve patient self-management (Costa, 2008; Levasseur & Carrier, 2010, 2012; Smith, Hedrick, Earhart, Galloway, & Arndt, 2010). Levasseur & Carrier (2012) identified six specific ways to integrate health literacy into OT practice. These included (1) increase awareness of health literacy (2) develop standards or position statements that speak to the

issue of OT and health literacy, (3) develop or modify material to meet the needs of literacy levels, (4) increase culturally sensitive interactions with patients, (5) provide intervention when needed for improved health literacy, and (6) collaborate with other community professionals to advocate for improved health literacy. As suggested by Levasseur and Carrier (2012), to create changes in healthcare that encompass health literacy one must initially raise awareness of the problem. This is considered significant for new therapists as well as those with experience in the field. This research endeavors to examine the effectiveness of OT communication techniques for low health literacy patients and to develop definitive methods for improving written and verbal exchange. Official occupational therapy documents have been published that define health literacy and how it relates to OT practice. The Occupational Therapy Practice Framework (AOTA, 2014) includes health promotion as an intervention. In order to promote health and well-being, therapists must be mindful of the client's health literacy.

The American Occupational Therapy Association has recognized the role of occupational therapists in an effort to address health literacy. A societal statement published in 2011 asserts:

Occupational therapy can promote health through the development and use of health education approaches and materials that are understandable, accessible, and usable by the full spectrum of consumers. Occupational therapy practitioners can assist in ensuring that all health-related information and education provided to recipients of occupational therapy or other health related services match that person's literacy abilities; cultural sensitivities; and verbal, cognitive, and social skills. In line with the

health communication objectives (U.S. Department of Health and Human Services, 2010), the American Occupational Therapy Association strives to ensure that occupational therapy practitioners possess appropriate communication and education skills that can help enable all people to gain access to, understand, and use occupational therapy and other health-related services, information, and education to promote self-management for optimum health and participation. (AOTA, 2011)

The Canadian Occupational Therapists Association has published similar guidelines: The Canadian Association of Occupational Therapists (CAOT) acknowledges that health literacy is a resource for daily living. Health literacy influences life's occupations as it enables optimal access to and utilization of relevant and meaningful health information and services, and allows informed health decision making and action. Occupational therapists are in a privileged position to enable clients' health literacy through their professional expertise and focus on supporting clients in occupations that are meaningful to them. CAOT recognizes the major impact of health literacy skills on health for individuals, families, groups, communities, organizations, and populations and supports increasing health literacy skills as a mean to achieve a just and inclusive society. (CAOT, 2013).

Awareness of health literacy and the importance of integrating it into OT education is reflected in the recent AOTA accreditation standards.

Standard number B5.18

Demonstrate an understanding of health literacy and the ability to educate and train

the client, caregiver, family and significant others, and communities to facilitate skills in areas of occupation as well as prevention, health maintenance, health promotion, and safety (ACOTE, 2012, p. 26)

Occupational therapy is positioned to play an important role in improving health literacy for our patients. Occupational therapists have the expertise to analyze individual skills needed to manage health care in consideration of the current demands of the healthcare system. Skills included in health literacy incorporate reading, verbal comprehension, numeracy, and organization. These skills are dynamic and change depending on the patient's age, health, education, previous experience and environment. With a distinct understanding of health literacy skills, the OT practitioner should be able to facilitate the client's health prevention and promotion through the challenging healthcare environment (Smith & Gutman, 2011).

Conceptual Model and Health Literacy

Traditional health education models consider the complexities of the health care system and the significance of patient's skills in understanding intricate diagnoses. The Person-Environment-Occupation-Performance (PEOP) model was designed to examine the specific tasks required for occupational performance and to analyze the type and level of skills needed to be successful in completing these tasks. Conceived by Christiansen and Baum (1997), and incorporating the unique viewpoint of OT, the PEOP model takes into consideration the interaction of intrinsic and extrinsic factors and their impact on the patient's well-being and quality of life. Intrinsic factors include physiological, psychological and cognitive factors. Extrinsic factors include aspects of the environment

such as the physical and natural environment, culture and social system. In their study, Smith and Hudson (2012), adapted the classic PEOP model by including health literacy as a factor in occupational performance and participation. The adapted model considers the specific skills and tasks needed to meet the demands of the health system (see Figure 1). Through a patient-centered evaluation, the therapist and patient determine limitations that serve as barriers in their attempt to manage the individual's health care needs. Interventions based on this model support the occupational therapist's efforts to address occupational performance issues that exist due to low health literacy.

This study referenced the adapted PEOP model proposed by Smith and Hudson to describe the therapeutic process for integrating health literacy into occupational therapy practice. Health literacy is a factor in the occupation of healthcare management. Successful performance combines reading comprehension, numeracy and listening skills together with the demands of the health care system. Based upon the study findings, the Smith and Hudson model was further adapted identifying a greater emphasis on the healthcare environment (see Figure 2, Chapter 6).

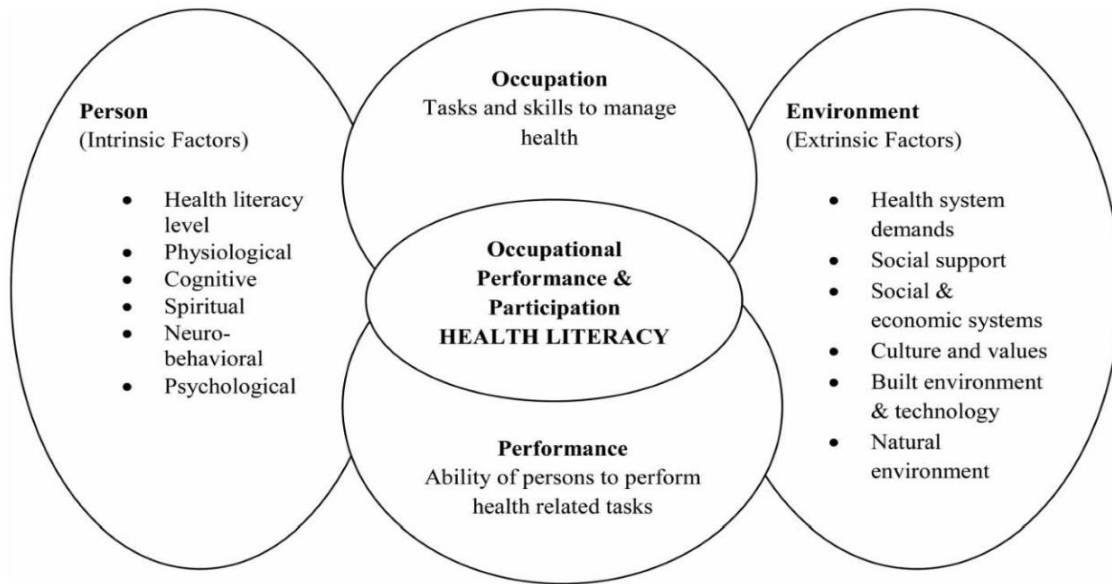


Figure 1: PEOP model adapted (Smith & Hudson, 2012)

Client-related Issues of Low Health Literacy

Low health literacy has been shown to be associated with poor health outcomes, frequent hospitalization, chronic disease, increased mortality, and increased healthcare costs. Clients with low health literacy have been found to ignore preventative healthcare often using the emergency room as their primary care clinic with ineffective results (Howard, Gazmararin, & Parker, 2005). Paasche-Orlow & Wolf (2007) refer to this connection of health literacy and poor health outcomes as a *causal pathway*, described as a combination of patients with low health literacy skills and complicated health systems. The lack of preventative healthcare and resultant poor health outcomes, especially in chronic disease patients, has been shown to increase healthcare costs by billions of dollars annually (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007).

Health Literacy and Chronic Disease

The prevalence of chronic disease is a major healthcare problem. It has been reported that each year, seven out of ten deaths are due to chronic disease such as stroke, diabetes, obesity and heart disease (“Chronic Disease Prevention”, 2015). A large number of patients today have more than one chronic disease that requires an even greater demand for self-management. Understanding pharmaceutical schedules and complex disease processes is challenging for those with low health literacy. Delivering health education for prevention and management geared toward specific diagnosis and treatment has been the focus of several recent studies. Kandula et al. (2009) studied multimedia programs for diabetes education. They found that a multimedia program combined with traditional written education increased understanding in patients with low health literacy skills. Gray, Turner, and Bentley (2010) also studied patients living with diabetes. This study reviewed the development and modification of educational material with an emphasis on low literacy and found it improved medication compliance. Eckman et al. (2012) studied patients with coronary artery disease and examined the use of video education plus written education versus written education alone. They reported a trend toward improved scores with the combined video/written format. Rudd, Rosenfeld, and Gall (2007) reviewed articles from rheumatology research and health literacy. Their findings revealed a majority of education materials were written above the sixth grade level and patients’ literacy skills did not allow them to effectively read and follow simple instructions including prescription labels. They suggest that to successfully manage rheumatoid arthritis the patient needs above basic literacy skills. Chronic disease

including multiple diagnoses is pronounced among patients with low health literacy. It was reported that these patients are often not able to thoroughly understand the complexities of their diagnoses. New instructional methods to assist in the education and self-management of chronic disease and recurring illness are necessary in the scheme to improve health literacy (Schillinger, Bindman, Wang, Stewart, & Piette, 2004).

Health Literacy and Age

Adults over 75 years of age have been found to have multiple chronic diseases and low health literacy with which to manage these disorders (CDC, 2009). Findings from the 2003 NAAL literacy survey reported adults 65 years and older tended to have lower health literacy skills and these skills decreased with age (Kutner et al., 2006). Studies of older adults have identified limited skills with tasks such as adherence to medication and recall of healthcare information (McCarthy et al., 2012). In a study by Chew, Bradley, Flum, Cornia, and Koepsell (2004) older adults were found to be less apt to adhere to preoperative medication directions due to lack of recall of medical instructions. Ruppar, Conn, and Russell (2008) also reported similar lack of medication adherence in patients 65 years and older. This study emphasized poor medication adherence and lack of self-management as factors leading to increased hospitalization and mortality. Another study also examined the relationship of the elderly and low health literacy. Gazmararian, Williams, Peel, and Baker (2003) studied 653 Medicare enrollees over 65 years of age with low health literacy. They found a majority of participants had significant knowledge deficits about their disease including treatment and medication protocol. Older patients often have greater challenges including low vision, hearing loss, and the inability to read

and write (Desai, Pratt, Lentzner, & Robinson, 2001). When preparing information for older patients, a combination of written instructions and verbal directions has been found to be more effective (Redman, 2004).

Health Literacy and Low Income

Patients with low income are also vulnerable to low health literacy (Kutner et al., 2006). Studies of patients with low income and low health literacy have a reported lack of preventative health measures including colorectal screenings and mammograms (Ojinnaka et al., 2015; Katz et al., 2012; O'Malley, Forrest, & Mandelblatt, 2002) and decreased adherence to diabetes medication and diet (Al Sayah, Majumdar, Egede, & Johnson, 2015). The low-income patient tended to use the emergency room to address resultant emergent and chronic health problems instead of establishing a primary care physician. Lack of preventative healthcare and habitual use of emergency services result in poor health outcomes and increased healthcare costs (Owens & Mutter, 2008).

Health Literacy and Culture

The Hmong language has no word for cancer, or even the concept of the disease. “We’re going to put a fire in you,” is how one inexperienced interpreter tried to explain radiation treatment to the patient, who, as a result, refused treatment (Morse, 2003, p.1).

The influence of culture in healthcare is described as the difference in a health outcome between patients of ethnicity, race, age, and various political and social beliefs (Muñoz, 2007). The U.S. is now more than ever a diverse “melting pot” with people from every part of the world. Each culture has its own beliefs and thoughts about health

and healthcare. The context of culture (Nelson, Smedley, & Stith, 2002) guides individual understanding of wellness and illness and how they are connected. Various cultural experience will affect how health information and education is received (Cooper et al., 2003).

Cultural differences among patients and healthcare providers can significantly affect health literacy. Culture is constantly changing and evolving. Immigrants bring their experience from their home countries and it is melded and shaped with their experience in the U.S. healthcare system. Differences in language, past cultural experience, and lack of understanding of current experience can be a barrier to adequate health literacy (Nelson, et al., 2002).

Methods of Education Delivery of Healthcare Information

A reoccurring issue in the review of health literacy literature concerns the delivery of health education through written and verbal communication with health care providers (Rudd, et al., 2007; Bryant, 2011; Davis, Wolf, Bass, and Thompson, et al., 2006; Donovan-Kicken et al., 2012). Vezeau (2016) explored several myths about literacy and dispelled them with examples from literature. These included assuming literacy correlates with years of education and that the clinician can determine if the patient can read by simply asking him. This article reiterated the need to adjust information to meet the needs of the patient with low literacy. The connection between health literacy and poor health outcomes was explored by Paasche-Orlow and Wolf (2007). They indicated that health literacy is influenced by the patient's literacy level in combination with the

degree of task complexity. Together these will determine the quality of healthcare outcomes.

Bryant (2011) reported results of a study using the Rapid Estimate of Adult Literacy in Medicine (REALM), a screening tool for adult literacy. The results of this study revealed 21 of 80 patients tested scored below the 9th grade reading level. Of these 21 patients, reading levels were found to be between the third grade and eighth grade level. Davis, Wolf, Bass, and Middlebrooks et al. (2006) reported reading and comprehension levels were consistently low when patients were asked to read prescription labels and explain the proper dosage information. This study evaluated 395 patients and reviewed a total of 1975 responses. Of the responses, 18.9% were incorrect and 46.3% misunderstood one or more of the instructions. Understanding disclosure documentation was the focus of the study by Donovan-Kicken et al. (2012). This study reported older adults and minorities demonstrated lower health literacy and had difficulty understanding documentation.

Jolles, Clark, and Braam (2012) and Arnold, Coran, and Hagen (2012) described the need for greater personalized contact with patients when considering their ability to understand and analyze the information and instructions being introduced; the need for patient and physician education in communication skills was emphasized. McCarthy et al. (2012) and Schillinger et al. (2003) published articles almost a decade apart; however, both articles determined that patients do not recall or even understand half of what they are told during a clinical visit. They suggest that physicians become more aware of the gap in comprehension and find a more efficient approach to verify understanding of health

information. In summary, research suggests that healthcare providers should recognize the gap in comprehension and find a more efficient approach to confront low health literacy.

Assessment of Low Health Literacy

The literature describes various health literacy assessments and screening tools for clinical and research application. Assessments of health literacy vary from lengthy assessments and brief screening tools to analyzing reading levels of various documents given patients during hospital visits. It has been reported that a majority of written material provided, including prescription labels, are not understood by persons with low health literacy (Davis, Wolf, Bass, and Middlebrooks et al., 2006).

Health literacy assessments were first published two decades ago. One of the earliest tools developed was a word recognition test. The Rapid Estimate of Adult Literacy in Medicine (REALM) was developed by Davis and colleagues in 1993. It was developed to assess the reading level of patients from a public health clinic. The original test consisting of 125 words was shortened to 66 words in the 1993 edition. It was found to have high content and criterion validity as well as face validity. Test results are assigned corresponding to grade level (Davis et al., 1993). The Rapid Estimate of Adult Literacy in Medicine—Short Form (REALM-SF) is a shorter form of the REALM, a 7-item word recognition test that provides a quick screening of patient's health literacy. The REALM-SF has been found to have high agreement with the REALM (Arozullah et al. 2007). These tests are available in English and Spanish.

The Test of Functional Health Literacy in Adults (TOFHLA) was created by Ruth Parker and colleagues at Emory University (Parker, Baker, Williams & Nurss, 1995). The TOFHLA includes a 50 item reading test and a 17-item numeracy test. The text uses a modified *cloze* procedure with information from actual hospital instructions. Assessment results are reported by categories including Adequate, Inadequate, and Marginal. The TOFHLA correlates with the REALM at 0.84. The TOFHLA reported excellent measures of internal consistency and test-retest reliability. There is also a short form, the S-TOFHLA, that contains fewer reading questions and no numeracy questions (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Both forms are available in English and Spanish.

The Newest Vital Sign (NVS) (Weiss et al., 2005), asks the patient to answer some questions about an ice-cream nutrition label. This test considers reading and numeracy skills. Developed by Pfizer, this test has been validated in English and Spanish at the University of Arizona and University of North Carolina.

The Health Literacy Management Scale (HeLMS) (Jordan et al., 2013) tests eight different domains or components of health literacy. The statements are scored on a 5-point Likert scale with lower scores indicating lower health literacy. This is a recently developed test that measures factors determined to be important in self-management, but also factors that could possibly be modified. The factors include knowing when and where to access health information.

The Short Assessment of Health Literacy-Spanish and English (SAHL-S&E) was published in 2010. It includes 18 test items that test the client's comprehension and

pronunciation of medically related words. Low health literacy is a score 0-14. This instrument has good reliability and validity of 0.80 and 0.89. This assessment is quick and could be useful as a screening tool (Lee, Stucky, Lee, Rozier & Bender, 2010). (see Table 1).

Table 1

Assessments and Screening Tools

Instrument	Description	Validation	Administration time
Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al. 1993)	Word recognition, 66 words, short version	English/Spanish	5 minutes, Short form, 2-3 minutes
Test of Functional Health Literacy (TOFHLA) (Parker et al., 1995)	Prose passages, numerical questions, short version	English/Spanish	22 minutes, Short form, 7 minutes
Newest Vital Sign (NVS) (Weiss et al., 2005)	Question from nutrition label, screening	English/Spanish	3 minutes
Self-Report Question (Chew, Bradley, & Boyko, 2004)	1-3 questions, screening	English/ Spanish	<3 minutes
Short Assessment of Health Literacy (SAHL) (Lee et al., 2010)	Word recognition, 18 words, recognize word with related meaning	English/Spanish	2-3 minutes

Even with the assessments available today, health literacy experts have suggested that clinicians should follow universal precautions guidelines and treat every patient as if they had low health literacy. The Universal Precautions Toolkit was designed to offer guidance to the clinician addressing low health literacy. The Toolkit, now in its second edition, offers 21 tools to assist the clinician using written or spoken communication and

self-management skills for improved patient outcomes. (Brega et al., 2015). Also, Ask Me 3® sponsored by the National Patient Safety Foundation, is a formal program that was designed to help patients better understand their health conditions. Patients are given handouts and posters are displayed with the message ASK ME 3. The three questions are as follows: What is my main problem? What do I need to do? Why is it important for me to do this? It is believed that these three questions will give the patient greater insight into their condition (Ask Me 3, n.d.).

The literature reviewed for this study examined many areas of health care that are negatively affected by low health literacy. The connection of poor health literacy to poor health outcomes has been established and the negative implications are profound. The literature reviewed for this study supports the importance of developing and modifying educational materials and communication with healthcare providers. This study sought not only to increase the occupational therapist's knowledge of health literacy, but also to develop a client education manual to offer strategies to improve written and verbal communication for low health literacy.

CHAPTER III

AN ASSESSMENT OF HEALTH LITERACY LEVELS IN RELATIONSHIP TO
PATIENT EDUCATION IN AN URBAN COUNTY HOSPITAL

Study I

Statement of the Problem

In the last three decades, it has been demonstrated through health literacy research that a great deal of patient education handouts and patient information was written at a reading level too advanced for the patient to comprehend. The National Assessment of Adult Literacy (NAAL) survey in 2003 and the recent Program for the International Assessment of Adult Competencies (PIAAC) (Goodman, Finnegan, Mohadjer, Krenzke, & Hogan, 2013) examined the degree of limitation of adult literacy in America. The NAAL findings reported 14% of participants, representing 30 million people demonstrated health literacy at a below basic level (Kutner et al., 2006). This low level of literacy becomes a barrier to self-management and navigation of the healthcare system.

Statement of the Purpose

The first study evaluated the health literacy level of a convenience sample of patients and compared that to the reading level of written documents including introduction to occupational therapy, attendance requirements and educational handouts currently being used in a local outpatient rehabilitation clinic. The research question for this study was: Are required forms and patient educational handouts written at an appropriate reading level to ensure patient comprehension?

Background and Significance

National Literacy Assessments

An early examination at how adults relate to the written word was documented in 1985 through the National Center for Education Statistics. The Young Adult Literacy Assessment (YALA) included 3600 participants between the ages of 21 and 25 years of age. It is notable that this was the first assessment that reported literacy in the categories of prose, document and quantitative literacy (Venesky, 1987). Prose literacy includes materials written in continuous text. This would include newspapers, magazines, pamphlets, and books. Document literacy is material written in non-continuous text. An example of document literature would be forms, schedules, and graphs. Quantitative literacy requires the participant to complete numeric tasks (Nielsen-Bohlman et al., 2004).

Taking into consideration the three types of literacy, Kirsch and Jungeblut (1986) reported literacy skills were lower in participants with less education, minorities and the unemployed. It was found that higher scores coincided with higher parental education. In consideration of these findings, Kirsch and Jungeblut (1986) recommended investing in intervention and prevention strategies to increase the literacy skills of young adults to better prepare them for the technological challenges of the 21st century.

In 1992, the YALA was followed by the National Adult Literacy Survey (NALS). This survey included 13,600 adults (persons aged 16 years and older) selected from random households. Inmates from 87 federal and state prisons (1,150) and an additional 1000 participants from each of 12 states in the State Adult Literacy Survey were

included. The definition of literacy used for this survey had been proposed earlier by a national panel of experts for the YALA survey:

“Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (Kirsch, Jungeblut, Jenkins, & Kolstad 1993, p.2)

In their report, Kirsch et al. (1993) described the survey results as being reported in scores from 0-500. The scores were divided into five levels: from Level 1 (0-225) to Level 5 (376 – 500). A total of 20% of the participants were in the lowest Level 1 in prose literacy. Of that 20%, 25% were born outside the United States (U.S.) Sixty-two percent of the participants had not completed high school, and 33% were over 65 years old. Level 1 represented about 40 million people. Level 2 included about 24% of participants. Thirty percent fell into Level 3 and Levels 4 and 5 included about 39%. A majority of participants scored in the middle and upper levels, with approximately 40% in the lowest levels of literacy. Comparing the results of the YALA to the NALS, White participants again scored higher than Blacks or Hispanics. As in the 1982 survey, participants with higher education scored higher.

Repeating the survey in 2003, the National Assessment of Adult Literacy (NAAL) surveyed 19,000 adults (16 years old and older), plus 1200 inmates. Similar to the 1992 NALS, three types of literature were measured; prose, document and quantitative. The 2003 NAAL added 28 questions pertaining to health literacy allowing for variables to be related to health literacy. These questions inserted into the three types of literature, were designed to address health management, prevention and navigation of the healthcare

system. Scoring divided the answers into 4 levels. In Prose, *Below Basic* scored between 0-209. *Basic* scored 210-264, *Intermediate* scored 265-339 and *Proficient* scored between 340 and 500. Similar scores were determined for document and quantitative literacy. Comparing the 1992 NALS to the 2003 NAALS, there were fewer adults in the *Below Basic* level (documentation and quantitative) in 2003 than 1992. There were fewer adults in the *Proficient* level (prose and documentation) in 2003 than 1992. In the adults with *Below Basic* Prose literacy in 2003, 55% had not completed high school compared to 62% at level 1 in 1992. Forty-four percent of adults at *Below Basic* Prose literacy in 2003 did not speak English as their first language, compared to 25% in 1992. In 2003, 26% of *Below Basic* Prose literacy were over 65 years old compared to 33% at Level 1 in 1992. In 2003, the percentage of adults in the analysis of health literacy were as follows: 14% *Below Basic*, 22% *Basic*, 53% *Intermediate*, and 12% *Proficient*. Similar results in 2003 reported adults over age 65 years old had lower health literacy scores as well as those participants who had not completed high school. The percentage of people with English as a second language increased by 20% (Kutner et al., 2006).

The findings of these national studies were the incentive for health literacy research in the U.S. The literacy skills of millions of Americans were much lower than previously thought and the social factors were evident. Individuals with low health literacy were found to be less educated, poor, a member of a minority group, or over the age of 65 . The apparent indications for health relationships and possible consequences for health outcomes have become the focus of health literacy studies.

International Literacy Assessment

Outside the U.S., European surveys found similar results. The European Health Literacy Project completed from 2009 to 2012, studied eight European countries, including Germany, Bulgaria, Austria, Spain, Netherlands, Ireland, Greece. and Poland. A random sample of 1000 people from each country was included. The results found limited health literacy among the very old, those with low socioeconomic status, those with low levels of education, and those with multiple chronic illnesses. An overall limited health literacy of 47% was reported (Sørensen et al., 2015)

In 2011-2012, the Program for the International Assessment of Adult Competencies (PIAAC) an international literacy study that included 5000 adults was completed in the U.S. The U.S., along with 22 other countries surveyed participants to assess the basic skills and competencies for work, social participation and learning. The survey measured numeracy, reading, literacy, and problem-solving abilities. In the PIACC literacy scale, average scores were from 250 in Italy to 296 in Japan. The U.S. scored 270. Twelve countries scored higher, and five countries were lower than the US score. On the numeracy scale, average scores were from 246 Spain to 288 Japan. The U.S. scored 253. Eighteen countries were higher than the U.S. (Goodman et al., 2013). These studies indicate a considerable number of adults in a majority of industrialized countries have difficulty accurately and reliably using the printed word. This has a profound implication for civic, economic and health activities.

Impact of Low Health Literacy

These national and international surveys are strong indicators that a large percentage

of adults have limited literacy and limited health literacy. In addition, multiple research studies have been published that have confirmed low health literacy across a wide spectrum of diagnoses. In a systematic review of health literacy research (AHRQ, 2004), it was found that the consequences of low health literacy included decreased participation in preventative healthcare, increased chronic disease, and more frequent hospitalizations. In the past two decades, the effect of low health literacy on the relationship between disease self-management and patient education has been the focus of health literacy research (Rudd, 2013).

Diabetes and other chronic diseases have been examined to determine the impact of health literacy. In a study by Williams, Baker, Parker, and Nurss (1998), patients with high blood pressure and/or diabetes were studied at two different county hospital sites, Atlanta and Los Angeles. The TOFHLA was used to assess health literacy level. The patients were given a questionnaire to test their knowledge of their disease prevention and treatment from written information. This study found that patients with inadequate health literacy lacked knowledge of their disease and treatment outcomes. In another study, Rudd, Rosenfeld, and Gall (2007) reviewed articles from rheumatology research and health literacy. Their findings revealed a majority of education materials were written above the sixth grade level and patients' literacy skills did not allow them to effectively read and follow simple instructions including prescription labels.

Similar results were reported by Schillinger et al., (2002). This research found a positive association between low health literacy and poor clinical outcomes with patients diagnosed with Type 2 diabetes. Conducted at a public hospital in San Francisco, 408

English and Spanish speaking adults were recruited. The researchers used the S-TOFHLA to assess health literacy. This study reported that inadequate health literacy was associated with limited understanding of diagnosis resulting in decreased glycemic control and greater diabetes complications including retinopathy.

Health literacy research with patients experiencing chronic kidney disease suggest transplant patients with low or marginal health literacy would not be able to fully participate in the intricacy of immunosuppressant therapy. Transplant patients were required to continue prolonged maintenance especially in medication routine requiring critical numeracy skills (Chisholm, Fair, & Spivey, 2007).

The impact of low health literacy has also been studied in patients with coronary heart disease. Gossey et al. (2011), evaluated an educational effort to increase the use of statins in patients with low health literacy. It was found that an audio booklet accompanied by printed material resulted in increased knowledge and knowledge retention compared to usual written materials. Knowledge retention has also been studied with stroke patients (Sanders et al., 2014) investigating the differences in patients with inadequate health literacy compared to adequate health literacy. This study reported that patients with marginal or adequate health literacy scored higher on educational post-tests and had better knowledge retention than patients with inadequate health literacy.

Readability Formulas

Health education information has been found to be written at a reading level too high for most patients to understand (Costa, 2008; Smith et al., 2010). Various readability assessments are available to determine the ease or difficulty of readability of written

information. The Lexile Analyzer is a readability tool developed by the MetaMetrics company in 1988 to measure the difficulty of text (Metametrics, 2016)

Readability formulas were first developed in the 1920s. Originally, Thorndike's *The Teacher Word Book* (Thorndike, 1921), introduced a way to assess how difficult words were. Thorndike's book was followed by the Bertha, Lively, and Pressey readability formula. In 1923, "*A Method for Measuring the 'Vocabulary Burden' of Textbooks*" (Lively & Pressey, 1923) reported a way to determine difficulty of text through a word counting approach. The first to study sentence structure and text characteristics, Vogel and Washbourne (1928) produced a readability formula using a regression equation. Later in 1938, Washbourne and Morphett developed a formula with grade placement scores. Rudolph Flesch published the Flesch Reading Ease Readability, in the article *A New Readability Yardstick* (Flesch, 1948). Along with the Dale and Chall (1948) method, these two formulas were used widely in education. In a key development, in 1963, Daniel and Byron developed a formula generated by a computer. Also in 1963, Fry developed a formula that used a readability graph. Another significant contribution to readability formula, the SMOG formula was created by Harry McLaughlin in 1969. The SMOG formula determines a score by counting words with polysyllables within a text (McLaughlin, 1969). The development of readability formulas have provided a system whereby the ease of readability of health pamphlets and information can be defined.

The Lexile Analyzer reading framework has been used to determine readability of patient education using both written and verbal communication. By analyzing a video script (McCarthy et al., 2012), researchers provided information at a lower grade level for

better comprehension when read. Numerous studies have used the Lexile Analyzer to evaluate written patient education with both Spanish and English speaking patients (Green et al., 2011; Hansen, Wallace, & Devoe, 2011; Wexler & Miser, 2013; Davis, Wolf, Bass, Middlebrooks et al., 2006).

There are an estimated 200 readability formulas being used today. In education and research, readability formulas can assist the researcher or developer in arriving at a text readability below the sixth grade level. Creating or modifying educational handouts and information to a lower reading level has been reported as a vital intervention technique to promote self-management skills in patients with low literacy (Rudd et al., 2007; Schillinger et al., 2004).

This review of literature has described consistent impact of low health literacy on patients from varied backgrounds with varied diagnoses. Using assessments, and readability formulas, clinicians have been able to identify shortcomings of current written education material being used for low health literate patients. Health literacy and levels of health literacy are significant in self-management and navigation of health care systems. Studies of health literacy assessment and correlation to OT written communication are lacking. This research endeavored to evaluate specific OT health education and information and compare the reading levels to patients' S-TOFHLA health literacy comprehension levels.

Methodology

Research Design

Study I used a descriptive design and included 16 occupational therapy forms and home programs and an evaluation of their reading levels compared to the functional health literacy levels of a sample of 50 outpatients. The intent of the study was to identify communication needs of patients including their ability to read and understand written forms and health information. Results of the study provided a source of data that would later help to formulate guidelines for written and verbal communication when treating patients identified as having low health literacy.

Participants

Participants for Study I were recruited from patients registered at a publicly funded healthcare system outpatient clinic. The participants were recruited using a recruitment script. Consent forms were handed to interested outpatients. The patients were given the opportunity to ask questions about the study and discuss any concerns with the PI. Included were outpatients between 18 and 85 years old, English and Spanish speaking. The participants who were not able to read, or whose vision could not be corrected with glasses, were excluded. All participants who qualified and agreed to participate signed the consent form approved by the institutional review boards of Harris Health System and Texas Woman's University. A convenience sample of 50 outpatients both English and Spanish speaking were recruited. The study site was an urban hospital and the participants consisted of diverse ethnic background, gender, and age groups with various diagnoses. The study included 22 males and 28 females. Of these participants, 40 were

from 18 to 54 years old, 10 were older than 55 years old, and 2 participants were older than 65 years old. Ethnic categories included 18 African American, 26 Hispanics, and 3 Whites. One participant identified as American Indian and one participant identified as Asian. Of the 50 participants, 20 reported below high school education and 16 had some college experience. Twenty-six participants earned less than \$20,000 and 10 reported earnings of greater than \$20,000. Fourteen choose not to say. The participants were single visit outpatients as well as returning patients (see Table 2).

Data Collection Tools

The instruments used for study one included the Lexile Analyzer, the Spanish Lexile Analyzer (Lennon & Burdick, 2004), and the Test of Functional Health Literacy Short Form (S-TOFHLA) (Baker et al., 1999) (see Appendix A). A demographic questionnaire was also administered (see Appendix B).

Lexile analyzer. The Lexile Analyzer is a readability assessment software program. The program examines the syntactic (length of sentence) and semantic (frequency of words) features of text. A converted text file is uploaded to be analyzed. The result of the text analysis is a Lexile measure. The range of Lexile scores are from 0L to 2000L. Reading difficulty increases as the score increases. The Lexile Analyzer has been shown to have high construct validity with other standard tests, Stanford Achievement Test (9th ed.), (0.92), Stanford Diagnostic Reading Test (Version 4), (0.91), and the Metropolitan Achievement Test (8th edition), (0.93). (Stenner, Burdick, Sanford & Burdick, 2006).

El sistema lexile® para leer. The Spanish Lexile Analyzer examines the syntactic and semantic features of Spanish language text. Like the English language Analyzer, a

converted plain text file is uploaded using Unicode UTF-8 encoding, allowing for substitution of characters. The range of Spanish Lexile scores are from 0L to 2000L. Reading difficulty increases as the score increases (Lennon & Burdick, 2004).

The test of functional health literacy. Health literacy was assessed using the Test of Functional Health Literacy in Adults Short Form (S-TOFHLA). The Test of Functional Health Literacy in Adults (TOFHLA) was developed to test reading and numeracy skills. The test was designed with authentic text used in a hospital setting. The TOFHLA uses a modified cloze procedure. Using the cloze procedure, every fifth to seventh word is left out of the sentence and the participant is asked to choose from four word choices that might complete the sentence. The TOFHLA includes 50 reading items and 17 numeracy items that simulates reading a prescription label, glucose levels and an appointment slip (Baker et al., 1999).

Analyzed by SPSS, the test of internal consistency and test-retest reliability is good, Spearman-Brown (0.92), and Cronbach's Alpha (0.98). Correlation coefficients with the Rapid Estimate of Adult Literacy in Medicine (REALM) (0.84) and the WRAT-R (0.74) demonstrated good construct validity. The full version of the TOFHLA takes 22 minutes to complete.

A Spanish version of the TOFHLA was developed with Spanish literacy experts. The test was piloted in 1993 at Grady Memorial Hospital, Atlanta, Georgia and Harbor-UCLA Medical Center in Los Angeles, California. These are county hospitals with diverse populations (Parker et al., 1995).

The S-TOFHLA is an abbreviated form of the TOFHLA. This short form can be incorporated into a clinical setting. In the first section the information is taken from patient instructions for an upper gastroenterology exam. The later questions are taken from a Medicaid rights and responsibility pamphlet. Readability levels are at Gunning FOG fourth grade and tenth grade. Like the TOFHLA, the short form is timed. The S-TOFHLA is to be completed in 7 minutes. The test is easily scored and allows the clinician to arrive at a health literacy level quickly. The S-TOFHLA correlated with the REALM (0.81) and similar to the TOFHLA, the S-TOFHLA has a strong reliability coefficient of Cronbach's alpha (0.97). The S-TOFHLA is scored by counting the correct word choices. The score results are expressed as Inadequate (0-16), Marginal (17-22) and Adequate (23-36) (Baker et al., 1999).

General demographic questionnaire. General demographic data were collected that included age, gender, ethnicity, education and income.

Data Collection Procedures

Data collection was completed over a three-month period. Each participant completed the S-TOFHLA and the general demographic questionnaire. The English or Spanish version was used, depending on the patient's language preference. Per assessment instructions, S-TOFHLA directions were read verbatim to the patient to explain the process for completing the assessment. A Spanish interpreter was used to read the Spanish instructions. Once the patient began, a timer was set for 7 minutes. The patient was asked to end the assessment once the timer went off. The patient was then given the

demographic questionnaire to complete. This was also administered in English or Spanish. There was no time limit on completion of the demographic questionnaire.

Instructional and educational materials issued to the patient were evaluated using the Lexile Analyzer and the Spanish Lexile Analyzer. (see Appendix C).

Data Analysis

Using the scoring guidelines provided in the TOFHLA manual, the assessments were scored and categorized. Each test was scored and identified in the range of Adequate, Marginal or Inadequate health literacy. Analysis of the descriptive data was completed using SPSS cross-tabulation of the variables.

The handouts were analyzed using the Lexile Analyzer. The steps for evaluating text includes removing any non-prose content such as headings, sub-headings, bullet list of incomplete sentences, and possible URL addresses. The text can be typed or scanned and copied as a Word document. This document is then saved as a plain text converted using other encoding and US-ASCII format allowing character substitution. Once saved as a plain text, the document is submitted for a Lexile measure. Conversion of Spanish text uses a similar procedure with conversion using Unicode UTF-8 encoding with allowance for character substitution.

Results

The following are results from the first part of the study including demographic information (see Table 2), and responses from the S-TOFHLA (see Figures 2, 3 and 4).

Table 2

S-TOFHLA Demographic Characteristics

Patient Characteristics	Adequate n=31	Marginal n=10	Inadequate n=9
Gender (n,%)	14 (63.6%)	5 (22.7%)	3 (13.6%)
Male	17 (60.7%)	5 (17.9%)	6 (21.4%)
Female			
Age (n,%)			
18-34	11(73.3%)	1 (6.7%)	3 (20.0%)
35-44	5 (50.0%)	3 (30.0%)	2 (20.0%)
45-54	9 (60.0%)	4 (26.7%)	2 (13.3%)
55+	6 (60.0%)	2 (20.0%)	2 (20.0%)
Education , (n,%)			
Less than High School	11 (55.0%)	4 (20.0%)	5 (25.0%)
High School	7 (58.3%)	4 (33.3%)	1 (8.3%)
College	13 (81.3%)	2 (12.5%)	1 (6.3%)
Ethnicity (n,%)			
Black	12 (66.7%)	4 (22.2%)	2 (11.1%)
Hispanic	14 (53.8%)	5 (19.2%)	7 (26.9%)
White/other	5 (83.3%)	1 (16.7%)	0 (0%)
Income (n,%)			
0-19,9999	15 (57.7%)	5 (19.2%)	6 (23.1%)
20,000 +	8 (80.0%)	2 (20.0%)	0 (0%)
Rather not say	8 (57.1%)	3 (21.4%)	3 (21.4%)
Employment (n,%)			
Employed	13 (61.9%)	5 (23.8%)	3 (14.3%)
Unemployed	18 (66.7%)	4 (14.8%)	5 (18.5%)

The S-TOFHLA revealed 62% of participants scored at the adequate level, 20% of participants scored at the marginal level (at or below tenth grade reading level and 18% fell into the inadequate level (at or below a fourth grade reading level).

Scoring revealed five out of six White/Other participants demonstrated Adequate literacy. In the total percent of participants, White/Other were 16% of the Adequate literacy and 10% of the Marginal literacy. The Hispanic participants were 45.2% of those with Adequate literacy, 50% of the Marginal Literacy, and 77.8% of the Inadequate literacy. The 18 Black participants were 38.7% of Adequate literacy, 40% of Marginal literacy, and 22% of Inadequate literacy (see Figure 2).

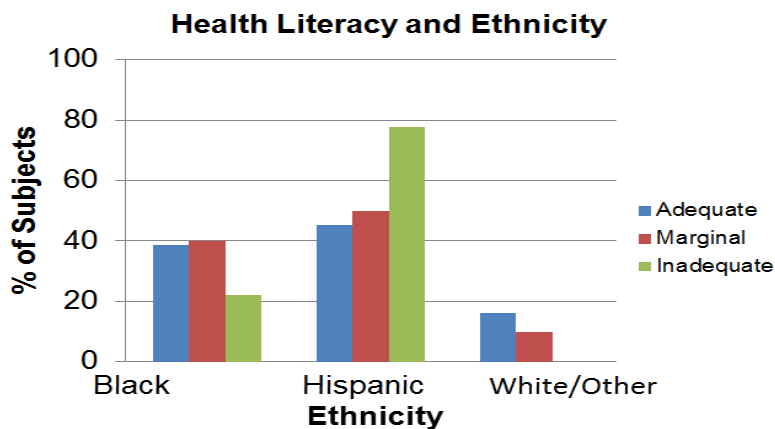


Figure 2 : Graph of health literacy and ethnicity

Analysis of the education characteristic indicated 40% of the participants reported less than high school education. Of these 20 participants, ten scored in the Adequate range and four in the Marginal range and six in the Inadequate range. Of the nine patients who reported they graduated high school, five (55%) scored Adequate literacy, three (33%) scored Marginal literacy, and one (11%) scored in the Inadequate range. Participants with some college education included 84.2% of those in the Adequate literacy range, 10.52% of the total Marginal literacy, and 5.26% of those with Inadequate literacy. Two participants who scored Inadequate literacy reported they would rather not say what their education level was (see Figure 3).

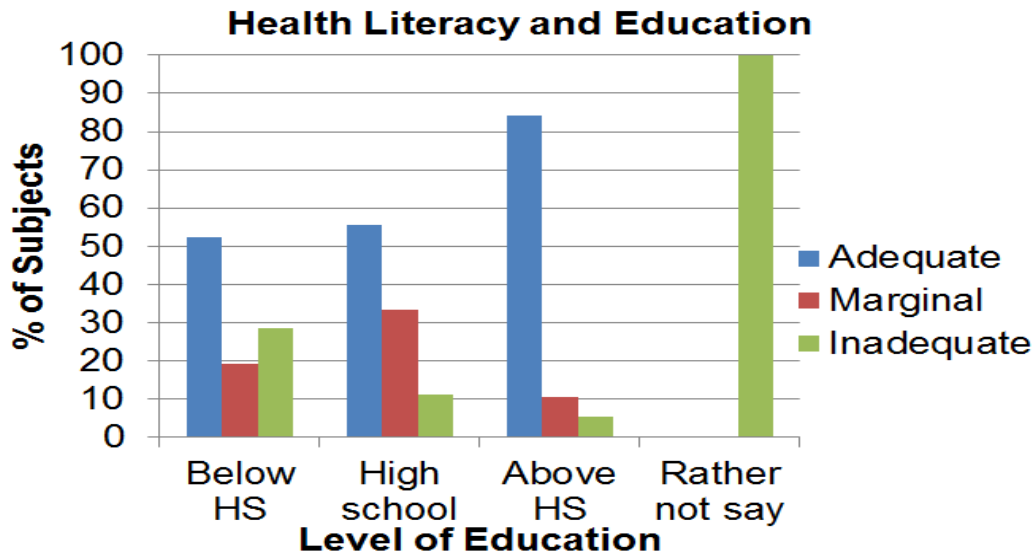


Figure 3: Graph of health literacy and education

The age demographics indicated that 11 of 15 participants 18-34 years of age scored in Adequate literacy, one (6.7%) scored in the Marginal literacy range, and three (20%) in the Inadequate literacy range. The 36-64 year old group included the largest number of participants, 20 had Adequate literacy, 8 (23.52%) Marginal literacy, and 6 (17.65%) scored in the Inadequate literacy range. The two participants 65 years or older scored in the Adequate literacy range (see Figure 4).

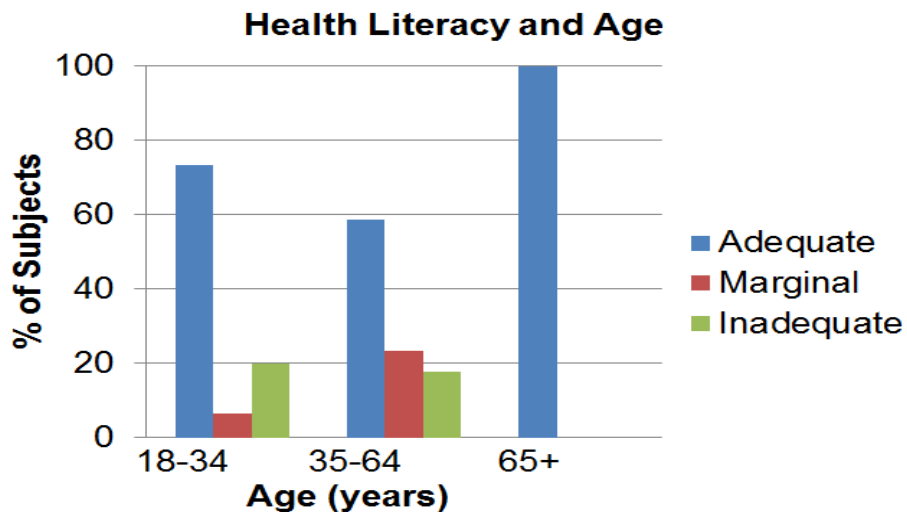


Figure 4: Graph of health literacy and age

Based on SPSS statistical analysis, crosstabs using chi-square and an ordinal regression were conducted to determine if there were any significant relationships between literacy and the demographic variables. No statistical differences were found between the demographic variables and literacy.

In the second part of Study I, according to the Lexile Analyzer and Spanish Lexile Analyzer results, 13 (48%) of the patient handouts analyzed were found to be at the eighth grade (5), ninth grade (5), or tenth grade (3) level. Eleven (41%) of the patient handouts were written at an Eleventh grade level and above. Only three handouts (11%) were written at the fifth and seventh grade level. (see Appendix C). Compared to their scores, 38% of the participants would not be able to comprehend nearly half of the patient handouts evaluated (see Figure 5).

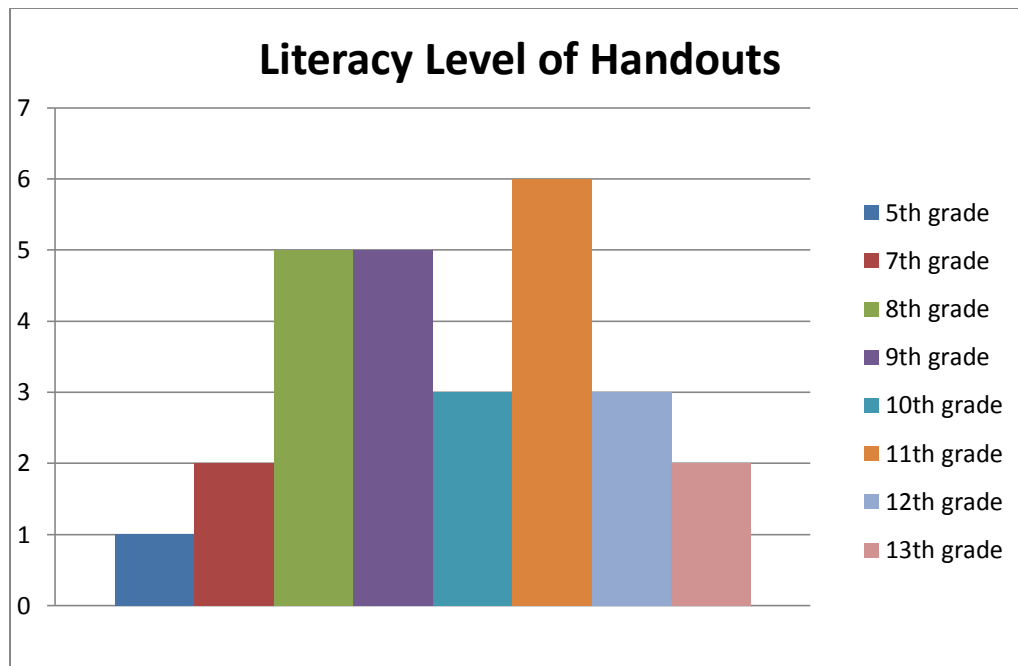


Figure 5: Graph of literacy level of handouts

Table 3

Handouts with Lexile Grade Assignment

Title of Handout	Lexile score	Grade level	Title of Handout in Spanish	Lexile score	Grade level
Outpatient Therapy Attendance Policy (2013) (Harrishealthsystem.Org)	980L	8.0	Normas de Asistencia a Terapia Ambulatoria (2013)(Harrishealthsystem.Org)	1010L	8.0
Diabetes (Patient Education Department 7/98, Rev 4/07)	1050L	10.0	La Diabetes (Patient Education Department 7/98, Rev 4/07)	1000L	8.0
Carpal Tunnel Syndrome Krames Communication, (1987)	1120L	10.0	Sindrome del Tunel Carpiano, Krames Communications, (1994)	960L	7.0
Stroke (Patient Education)	980L	8.0	El Accidente Cerebrovascular (ACV)	790L	5.0

Department 2/01, Rev 6/07) Harrishealthsystem. Org			(Patient Education Department 2/01, Rev 6/07) Harrishealthsystem.Org		
Advance Directive (Form no. 283322) (2011) Harrishealthsystem. Org	1180L	11.0	Instrucciones Anticipadas (Form no. 283324) (2013) Harrishealthsystem.Org	1110L	11.0
What to Expect at your Therapy Session (2013) Harrishealthsystem. Org	1090L	9.0	Que debe usted Esperar en sus sesiones de terapia (2013) Harrishealthsystem.Org	900L	8.0
Schizophrenia: What you Need to Know (Mental Health America, 2015)	1240L	12.0	Esquizofrenia: Lo que usted necesita saber. (Mental Health America, 2015)	1510L	13.0
AOTA online patient education					
Establishing Bedtime Routines for Children (2012)	1120L	11.0	Establecimiento de Rutinas para Ninos a la hora de Dormir, Borrero, (2011)	1110L	11.0
Remaining in your Home as you Age (2011)	1180L	11.0	Permaneciendo en su Hogar Mientras Envejece, Borrero, (2011)	1210L	11.0
Living with Arthritis (2012)	1190L	11..0	X	X	X
Managing Chronic Pain (2002)	1320L	12.0	X	X	X
Daily Activities After Hip Replacement (2000)	1550L	13.0	X	X	X
Understanding Mood Disorders (2002)	1290L	12.0	X	X	X
Adults with Traumatic Brain Injury, Neville & Golisz, (2014)	980L	8.0	Adultos con Lesiones Cerebrales Traumaticas,Contreras (2014)	920L	8.0

Living with Alzheimer's Disease	1230L	11.0	Viviendo con la Enfermedad de Alzheimer (2011)	1120L	11.0
Living with Spinal Cord Injury(2002)	1280L	11.0	X	X	X

Discussion

The following discussion section answers the study question: Are required forms and patient educational handouts written at an appropriate reading level to ensure patient comprehension? It includes discoveries, clinical implications, and future directions.

The analysis of the assessment results indicated an expected discordance between the reading level of the OT education handouts and the patients' health literacy. The majority of written material were found to be written at a readability level between eighth and tenth grade, with only one handout written at a below sixth grade level. It is noted that the majority of handouts analyzed from the hospital forms were found to be written at a lower reading level. Those patient education handouts offered on the official AOTA website were generally written at a higher level and were less appropriate for this population. As therapists, serving patients with low health literacy, it is important to look at the source for credible information, but to also consider the level of writing and how the information is presented. According to the literature, handouts and health information should be written at a below sixth grade level for most patients to read and comprehend (Rudd et al., 2005).

Scores from the health literacy assessment reported higher number of Adequate literacy than expected. Chi-square test and a regression model were run; however there were no significant results between the responses. At 62%, the majority of participants

scored at the Adequate level. The classification of ethnic groups was aligned with research findings. The majority of White/Other ethnicity scored in the Adequate literacy range, while a larger percentage of Black and Hispanic participants scored in the Marginal and Inadequate levels. Education and ethnicity would account for these differences. According to the demographic information, the education level of White/Other participants was reportedly higher than Black or Hispanics. Research finds patients with lower education levels and minorities have lower health literacy levels (Schillinger, Grumbach, Piette, & Wang et al., 2002; Schillinger, Piette, Grumbach, & Wang et al., 2003)

In the analysis of the age demographic, the youngest age group, 18-34 years old, was noted to be the largest percentage per group in the Adequate literacy range. This is in agreement with previous studies. In the 2003 NAL survey, younger age participants were reported to have higher health literacy scores (Kirsch et al., 1993). However, this survey also found health literacy declined after the age 65. This finding was not supported in our study. This study included only two participants over 65 years of age, one of whom was a college graduate, and the second reporting having some education past high school. Both of these participants scored in the Adequate literacy range. Their higher education could have been a factor in this outcome.

Health literacy is based on reading, writing, listening, and speaking skills and is situation dependent. Explaining diagnosis and treatment options to patients has usually been achieved with written brochures and pamphlets. A thorough review of the literature finds that this information is written at a grade level too high for most patients to

comprehend. For therapists that treat the old and very old, it is noteworthy that characteristically people over 65 years of age and older are increasingly challenged to understand health information and self-management of chronic diseases (Gazmararian et al., 2003; Wolfe et al., 2010).

The findings of this study continue to question the gaps in methods of education. Adequate health literacy levels on the S-TOFHLA, an assessment that requires reading comprehension, suggest that intervention programs developed by therapists and clinicians need to address all methods of education. If a large percentage of patients can read and comprehend written information but lack listening and speaking skills, a verbal explanation of home exercise programs will not be effective and adherence to disease prevention and treatment protocol will be limited.

This study provided insight into the health literacy level of 50 patients from an outpatient clinic. Based on the findings, the majority of the participants scored at an Adequate level, which should allow them to read and comprehend education materials written at the tenth grade level. While this level of health literacy as assessed with reading materials was unexpected, it did provide a baseline for patient education modification.

Implications for Practice

This study adds to the evidence of low health literacy in an underinsured population and the importance of modifying education techniques and materials to meet the needs of those patients found to have low health literacy. Considering a universal precautions approach to written health information should provide understandable information for all

patients. Future studies should attempt to examine this diverse population with a larger database and a health literacy assessment that includes numeracy items in order to determine the implication of this distinct characteristic.

CHAPTER IV

CLINICIAN KNOWLEDGE AND EXPERIENCE OF HEALTH LITERACY
AND HEALTH LITERACY INTEGRATION IN A LARGE
URBAN HOSPITAL SYSTEM

Study II

Statement of the Problem

One of the findings in previous research highlights the lack of awareness of low health literacy among clinicians and health care workers (Garcia, Hahn, & Jacobs, 2010; Huang, Tobin, & Tompane, 2012; Levasseur & Carrier, 2012). Occupational therapists interactions with patients during therapeutic intervention include written home exercise programs as well as verbal exchange to promote the patient's knowledge of self-management and to meet the objectives of therapy (Costa, 2008). In current accreditation standards, the Joint Commission for Accreditation in Healthcare (2007) calls for clinicians and organizations to acknowledge patient's health literacy and cultural diversity. It is the occupational therapist's professional responsibility to meet the challenges of low health literacy. This includes awareness of the prevalence and outcomes of low health literacy and specific intervention techniques for treatment.

Statement of the Purpose

For the second study, a focus group was conducted that included eight occupational therapists from varied practice areas of a publicly funded hospital system. A semi-

structured interview guide included questions about the concept of health literacy, the ways in which health literacy impacts patients, and integrating health literacy into practice. The research question was: What is the health literacy experience and knowledge of occupational therapists?

Background and Significance

Focus Group

The focus group is a format for obtaining information using qualitative research methods. It is a form of group interview that explores attitudes, experiences and observations of the participants (Patton, 2002). The goal of the focus group was to explore OTs' knowledge and experience with health literacy. Health literacy is approached differently depending on the environment and context (Baker, 2006).

The members of the focus group represented different practice areas including inpatient acute, inpatient rehabilitation, outpatient neurology, outpatient hands, and psychiatry. Although from diverse treatment areas and experience, the therapists discussed similar understanding of health literacy and how it impacts their practice.

Health Literacy Awareness

Research has reported a lack of health professionals' awareness of health literacy across different environments and populations. Studies of physician and health care workers find physicians often just assume their patients understand what is being said. This can be a lack of provider awareness combined with the patient's reluctance to admit they do not understand (Parker, 2000).

Several studies explored educational programs to increase awareness of low health

literacy and best practice methods (Coleman, 2011). The American Medical Association created such a program that included a manual entitled *Health Literacy and Patient Safety: Manual for Clinicians*. The manual, accompanied with patient videos, reviews basic health literacy information and offers suggestions and resources for physicians and non-physicians (Weiss, 2007).

Prevalence of Low Health Literacy

Information gained in Study I revealed that 62% of the sample had Adequate health literacy. The White/Other sample scored the greatest percentage of Adequate health literacy while the Hispanic participants scored highest in the Inadequate range. The ethnicity categorization of the sample included White/Other, 12%; Hispanics 52%; and Black 36%. Fifty-two percent reported income below the poverty line. The ethnicity and income totals are very similar to the demographics of the study site. It is known from the 2003 NAAL report (Kutner et al., 2006), that minority groups and those living in poverty are more likely to have low health literacy. When therapists know the typical occurrence of low health literacy in their treatment population, it facilitates modifications to written and verbal educational instruction.

Practice Specific Intervention

Outpatient neurorehabilitation. In outpatient neurorehabilitation, occupational therapists provide specialized services for patients with neurological problems such as stroke, traumatic brain injury (TBI), spinal cord injury (SCI), Parkinsons disease, amyotrophic lateral sclerosis (ALS), spasticity and multiple sclerosis (MS). Depending on the diagnosis, health literacy challenges include residual or progressive cognitive

limitations and deficits including memory loss, vision and speech disorders (Wolfe et al., 2010; Costello & Halper, 2004; Ganzer, Insel, & Ritter, 2012; Johnston, Diab, Kim, & Kirshblum, 2004).

As in all practice areas, the mode of education delivery in neurorehabilitation is modified according to health literacy needs. Studies specific to stroke, MS, and SCI have reported learning deficits, language discordance, and limited prior knowledge as factors in low health literacy. This was reported in a large study in Central Harlem that included 1023 participants in a high-risk stroke population. The majority of the sample were Black and Hispanic women. Willey, Williams, and Boden-Albala (2009) reported only 53.7% were able to correctly identify the brain as the site of a stroke. The Hispanic sample was found to have overall lower scores when identifying stroke symptoms and risk factors. This study recommended education be designed considering culture and ethnicity. In a study of MS patients, Chiovetti (2006) suggests recalling and processing information and instructions can be especially challenging. As explained in this study, MS education is evolving and requires multifaceted strategies for intervention and management. Health literacy for neurorehabilitation patients includes educating patients and caregivers to increase their knowledge of treatment options and methods for self-management to improve quality of life with extremely complex, transforming diagnoses.

Outpatient hand clinic. The injuries and diagnoses seen in an outpatient hand clinic are varied. They include chronic conditions such as carpal tunnel syndrome and lateral epicondylitis as well as emergent tendon and fracture diagnoses. The patient's health literacy impacts his ability to follow a specific treatment protocol, splint wear and care,

activity modification, and home exercise program (McKee & Rivard 2011). In a recent study of outpatient orthopedic patients (Kadakia et al., 2013), the majority were found to lack basic comprehension of surgical intervention including what specific bone was fractured, weight-bearing status and what fracture recovery time was. Education modification that combined pictures with narrative and text is a technique found to increase patient comprehension (Tsahakis et al., 2014). Clear communication and teach-back methods are imperative to assure vital patient comprehension in an outpatient hand clinic (Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005).

Inpatient acute. In large urban trauma hospitals, inpatient acute therapists treat a wide range of diagnoses. Patients require evaluation and concise treatment plans to ensure their return to function once discharged from the hospital. Acute care therapists must address their patient's physical, cultural, psychological, and spiritual well-being in a very short hospital stay. Health literacy in an acute care setting is strongly influenced by the situation (Roberts & Robinson, 2014). Traumatic illness or accident that requires surgery or complex medical care is confusing and frightening for the patient. The patient is inundated with information and instruction for treatment and self-management. Physician explanation of the diagnosis and disease is often confounding and hard to understand. Working within the acute care system, the therapist is responsible to help the patient understand his injury or illness and provide a plan to return to functional activities. To accomplish this, the OT must address premorbid functional limitations as well as functional decline often seen from admission to the hospital (Brown et al., 2014).

Inpatient rehabilitation. In inpatient rehabilitation, therapists are treating patients

returning to the life and family they had before injury or illness. Adequate health literacy is essential as patients need to understand the process of rehabilitation and what is expected to be successful.

Cerebral vascular accident (CVA), or stroke, is the most frequent neurologic rehabilitation diagnosis (Centers for Disease Control and Prevention, 2009) seen in inpatient rehabilitation. Stroke rehabilitation is complex and treatment plans require daily assessment and frequent modification depending on the patient's progress. Stroke rehabilitation and information retention has been reported to be better with adequate health literacy and higher education (Willey et al., 2009). In a study by Latham et al., (2006), data were collected from 182 OTs treating stroke patients in one of six inpatient hospitals. It was reported that the hospital stays averaged less than three weeks and included cognitive and perceptual education and training. As noted above, neurorehabilitation health literacy challenges include cognitive limitations and deficits of memory loss, vision and speech disorders (Costello & Halper, 2004; Ganzer et al., 2012; Johnston et al., 2004; Wolfe et al., 2010). In the inpatient rehabilitation unit, the therapist will use a variety of educational tools and methods to challenge these new and developing barriers to health literacy.

Mental health. When the patient's mental health is affected, health literacy can be incongruous with psychiatric diagnoses. The ability to understand illness and make decisions for treatment will be diminished when a patient experiences a mental illness. In a study by Jorm (2015), he proposed the concept of mental health literacy. The definition, "knowledge and beliefs about mental disorders which aid their

recognition, management or prevention” (p. 1166) involves knowing and recognizing mental illness, available treatments and approaches for self-management. There is a correlation between low health literacy and psychiatric disorders. Lincoln, Espejo, Johnson, Paasche-Orlow, Speckman, Webber, and White (2008) reported an association between REALM low health literacy scores and substance abuse disorders, psychotic disorders, or posttraumatic stress disorder (PTSD).

Neurocognitive deficits are an obstacle to function. To address this barrier, psychoeducation is used to explain diagnoses, increase medication adherence, and lower readmission. In psychiatry and mental health, education has also been found to be written at a high literacy level. Broussard, Radkins, and Compton (2014), studied the development of manuals for minority schizophrenic patients with low health literacy. Their material used a comic book like format written at a fifth grade reading level to inform and educate patients and care givers. They found this method was well received and provided information that was entertaining and easily understood.

Inpatient mental health therapists provide much needed education to patients with neurocognitive deficits and accompanying psychotic disorders. To do so successfully, they must be creative and consider new and innovative OT treatment methods.

Methodology

Research Design

A focus group was conducted for Study II. The focus group is a format for obtaining information using qualitative research methods. It is a form of group interview that

explores attitudes, experiences and observations of the participants (Patton, 2002). Study II served as another data collection source for the health literacy strategies manual.

Participants

The focus group participants of eight occupational therapists (N=8), were recruited from different practice areas of a large urban hospital. A flyer was posted in the OT departments describing the study and calling for focus group volunteers. The volunteers responded by phone and a day and time were established. The participants signed informed consent forms and completed a brief demographic questionnaire (see Appendix E). The focus group members included therapists with varied years of employment from different ethnic backgrounds. Additional details of the demographic questionnaire can be found on Table 4.

Table 4

Focus Group Participants

#Participant	# years worked	Gender	Age	Ethnicity	Area of Practice	Familiarity with term
001	3	Female	29	Asian	Outpatient Hands	Somewhat
002	1	Female	30	Asian	Acute	Somewhat
003	2	Female	26	Indian	Outpatient Neuro	Yes
004	16	Female	52	White	Acute/Outpatient Hands	Somewhat
005	38	Female	63	Black	Inpatient Psych	Somewhat
006	2	Female	28	Hispanic	Acute	Somewhat
007	17	Female	60	Hispanic	Inpatient Rehab	Yes
008	19	Male	44	Asian	Inpatient Rehab	Yes

Collection Procedures

The focus group process included an interview guide consisting of eight questions (see Appendix C). The semi-structured interview guide was developed to explore the

knowledge and experience of the therapists when treating patients with low health literacy. The Institutional Review Board at Harris Health System and Texas Woman's University approved the process and questions. The first four questions probed the therapists knowledge of health literacy. The next two questions addressed identification of patients with low health literacy and the last two questions focused on therapists perspective of the role of occupational therapists when treating patients with low health literacy. The PI, acting as moderator, explained the purpose of the study to the participants. A research assistant was present to observe and take notes concerning body language and other environmental influences. The research assistant assisted as necessary with logistics of the focus group and gave an outside perspective of the process. The focus group discussion was audiotaped for analysis. The recordings were transcribed and the transcription was processed using line-by-line coding (Creswell, Plano Clark, Gutmann, & Hanson, 2003; Patton, 2002).

Data Analysis

The PI transcribed the audio tapes. Initially, transcriptions were coded with line-by-line coding (Creswell, 2013; Patton, 2002) and labeled into general categories. These categories were combined and/or subdivided in an effort to identify common themes and ideas. Analysts triangulation, (Patton, 1999) was achieved as data were coded by the research assistant and committee chair to arrive at common codes and themes.

Results

Six themes emerged from the focus group (see Table 5). The themes are divided into two major categories, the therapists' perspective on health literacy and the therapists'

perspective of patients with low health literacy. The discussion reflected the therapists' knowledge and experience of health literacy. It included their awareness of health literacy and factors specific to their practice areas.

Following a group discussion of the definition of health literacy, six themes emerged from the focus group, with integrating health literacy into OT practice as the over-arching theme. The participants identified challenges of low health literacy as they were impacted by education, culture, practice areas, and language discordance. The following discussion highlights these themes.

Health Literacy Defined

Participants described health literacy as general knowledge of health and the healthcare system. The notion of maintenance and compliance to medication was discussed as a part of the definition. A participant also spoke of health literacy as the patient having insight and being able to communicate his needs. She included the ability to maneuver or navigate a physical setting like a hospital or clinic. A contrasting observation suggested that health literacy was a grasp of the medical condition but not necessarily a connection to a healthcare system or accessibility.

Participants identified health literacy as the patient is understanding of his health. This is in part the commonly accepted definition of health care that includes "...the degree in which the individual has been able to obtain and understand information and to be able to make informed decisions" (Neilsen-Bohlman et al., 2004, p. 4).

Culture

The focus group recognized and addressed the significant role of culture in health literacy. There was a discussion of the effect of cultural differences and what part they played in patient compliance and attitude toward therapy. Health literacy and culture were connected by the patient's language, traditions, and beliefs in medicine and health. A participant commented that the challenge of treating a patient from another culture may include strong family relationships and how much the patient's family believes they should do everything for the patient while he is sick.

Education

There was also a discussion about the patient's lack of education and how that impacted health literacy. One participant commented that what has to be taught and explained needs to be done using plain language, not using medical jargon. The use of simple language and pictures is a technique reported by several in the group as a way to manage low health literacy. Participants also spoke of using smart phones and iPads to assist the patient with recall and comprehension.

Health literacy education for the therapist was discussed. The general agreement was that it was not formally taught in school. They explained that their students were introduced to techniques for low health literacy on their fieldwork.

Language Discordance

The education theme also dealt with understanding what was being told to the patient. Participants described communication difficulties due to culture, specifically language, as well as literacy. When doctors explained diagnosis and treatment information using

medical jargon and terminology, it was frequently left to the therapists to explain the details to the patient. A participant commented that doctors often talked to the acute patient when he was sleepy or medicated. This meant the same information had to be repeated to the patient once he was fully awake and listening. In the acute care setting, the patient was described as being overwhelmed by much of what was going on around him. Language discordance invariably led to greater confusion and anxiety.

It was agreed upon by the group that explanation through an interpreter was better than using family members or struggling to help the patient understand using hand gestures. However, some participants felt translators used their own discretion in how much and in what way to interpret what was being said.

Practice Area Challenges

When addressing low health literacy, participants commented on challenges specific to their own practice area. The outpatient neurorehabilitation therapist stated that her evaluations with patients with low health literacy took longer to complete due to the need for explanation of basic stroke facts. The stroke patient may have come from an inpatient setting but would not recall the information. The inpatient acute therapists agreed that new patients were often very ill and overwhelmed by their diagnosis and the process of rehabilitation. One therapist commented that she would present patient education in multiple ways and repeat it several times. The psychosocial factors evident in the mental health patient population were discussed. It was reported that health literacy was impacted by confusion and lack of insight into their illness.

Inpatient rehabilitation therapists spoke of patients with low health literacy as being more often non-compliant with therapy and reluctant to change their lifestyle and take responsibility for their well-being. It was agreed that patients response to therapy can depend on the support they have from family and friends. In addition, patients that have support of others with similar injury or diagnosis seemed to be more successful in their efforts.

Strategies

There was a discussion about the advantage of looking at successful patients. What accounts for the patients that have progressed and done well in their rehabilitation program? One participant suggested a questionnaire or survey of those patients active in current follow-up groups. It was suggested that discovering the basis for patient success would encourage other programs to build in similar structure and design to improve patient outcomes.

Discussion

The following discussion section will answer the research question, What is the health literacy experience and knowledge of occupational therapists? It will include discoveries, clinical implications, and future directions.

The focus group of eight OTs offered a unique perspective of health literacy. Most of the participants correctly described health literacy and basically understood the challenges of low health literacy. Challenges to treating patient with low health literacy included lack of education, cultural differences and language discordance. The lack of education was seen as a barrier to keeping appointments, medication compliance, and

following a home exercise program. To overcome these barriers, the therapists would use plain language when instructing the patient about his diagnosis and role of therapy. Some were reluctant to use traditional handouts and choose instead to use a “hands-on” practical approach.

Health literacy education for the therapist was not available in OT school. The coursework did not include health literacy. One participant did comment that in a recent advanced degree program, they had discussed learning styles and the best way to provide education. For the therapists, culture was a significant factor influencing health literacy as majorities of their patients are from a minority group. The hospital system where each of these therapist works has a large minority population including Hispanic, Vietnamese, and East Indian patients. Each of these minority groups brings a different set of traditions and beliefs to the healthcare arena. The challenges included working with the patient and his extended family members and considering their various traditions and beliefs. In some practice areas, the family dynamic was seen as a hindrance. Often families would try to do all the work for the patient. In other instances, the family served as motivation and greatly encouraged the patient. Different cultures usually meant the patient used a language other than English. This was typically addressed with an interpreter. Interpreter services were welcomed but not always found to be accurate in their explanations. Language discordance also existed when the language used included medical jargon that could not be understood by the patient. It was suggested that all communication be in plain language and even accompanied by pictures as needed.

An interesting discussion followed the end of our focus group. One therapist commented that it would be useful to consider why some patients are successful and others are not. This would allow a valuable examination of the successful patient.

Implications for Practice

The focus group results would seem to have application to many patient groups. The findings from Study II were applied in Study III for the development of an educational strategies manual for OTs. Depending on their practice areas, the therapists had different ideas and experiences with patients identified as having low health literacy. However, the general agreement was that all patients' health literacy needs should be addressed and that it is the therapists' responsibility to recognize and address barriers of low health literacy. As was discussed in the focus group, a future study of those patients that have been successful might reveal valuable information and increased awareness of what produces optimal health outcomes.

Further consideration of the focus group emerging themes suggest they agree with the literature identifying specific ways to integrate health literacy into OT practice (Levasseur & Carrier, 2012). The therapists interviewed demonstrated an awareness of health literacy and the need to modify OT interventions to address low health literacy. Implications for practice would include developing educational efforts at the departmental level for therapists and staff to initiate ways to further the discussion of health literacy including how best to provide services for all patients, including those with low health literacy. Additionally, finding ways to increase collaboration with

physicians, nursing and other therapeutic disciplines would improve organizational procedures for patients with low health literacy.

Table 5
Themes from Focus Group

THEME	RESPONDENTS QUOTE	THERAPIST PERSPECTIVE ON HEALTH LITERACY	THERAPIST PERSPECTIVE OF PATIENT with LOW HEALTH LITERACY
Health Literacy Defined	<i>"It is general knowledge of the health care system as well as their own health."</i>	Knowledge of health, health care system, maintain health including medicine compliance	Progress is slow or minimal Participates less
Cultural Impact	<i>"I think in some cultures there is a passivity and patients expect family members to do the exercises for them."</i>	Hard to encourage patient when family members doing much of their ADLS, can be poor carryover	Passive attitude toward rehabilitation; attitude toward therapy
Practice Area Challenges inpatient acute	<i>"(patient's response)...right now I have more important things to do."</i>	Daily participation is difficult; Suggest not focus on hand outs, but daily activity	Patient is dealing with acute medical issues and pain
outpatient rehabilitation	<i>"It is our job to make sure they know it is not just going to get better,"</i>	Therapists explain process of therapy; Use teach-back	Injury seen as temporary problem; Need help to maneuver clinics
inpatient rehabilitation	<i>"How much ownership do they really have over their outcome?"</i>	Problem when patient does not recognize the need for a lifestyle change; older patients do not see the need to change	Personal ownership limited
mental health factors	<i>"Give them the freedom to ask questions and to make them feel comfortable."</i>	Present material in a respectful way to limit any stigma or shame	Psychosocial factors, depression, not receptive to HEP
Language Discordance	<i>"Sometimes we as therapists have to translate it so they understand."</i>	Remember to use "street" language, limit medical jargon, Explain doctor's discussion with patient;	Interpreter using language of patient's own country;
Education	<i>"..., I don't think they fully believe me. Like I haven't quite sold them on the idea of why it is important."</i>	Therapists do not get education about health literacy in school, some OTD program, styles of learning; use pictures, smart phones, iPad	Consider lack of education vs. behavioral aptitude, failure to comply due to inability to understand instructions; pictures
Strategies to overcome low health literacy	<i>"Let's look at the successes."</i>	Consider what we do right with the patients that succeed, advocacy of therapist? Family support?	Groups, Healthy Hearts ,weight management, stroke

CHAPTER V
DEVELOPMENT OF EDUCATION STRATEGIES
MANUAL FOR OCCUPATIONAL THERAPISTS

Study III

Statement of the Problem

Occupational therapists treat patients in every stage of their return to function and ways of doing. Patients may be healing from an injury or illness, coping with the residual limitations of a neurological incident, or beginning to recognize and accept their life changes due to mental illness. There is a vast amount and variety of written and verbal information shared in the therapeutic process. Due to low health literacy, many patients struggle to understand written information as well as the verbal exchange (Billek-Sawhney & Reicheuter, 2005; Costa, 2008; Levasseur & Carrier, 2010, 2012). To address this low health literacy, the manner in which patients are educated and informed may need to be adapted. As practitioners, it is our responsibility to be knowledgeable of techniques and methods to effectively communicate with patients impacted by low health literacy (Coleman, 2011; Kripalani & Weiss, 2006; Nielsen-Bohlman et al., 2004). This could include finding simpler words when instructing patients, using pictures and drawings to define new concepts, and asking the patient to explain the instructions in his own words (Houts, Doak, Doak, & Loscalzo, 2006 ; McCarthy et al., 2012).

Statement of the Purpose

For the third study, an education strategies manual was created. The manual incorporated health literacy patient education strategies for occupational therapists. The manual information was based on results of the health literacy assessments and handout analysis in Study I and thematic data from the focus group in Study II. It provides guidelines for treating patients with low health literacy. The research question was: What content is needed for an education manual of treatment strategies and guidelines for occupational therapists treating patients with low health literacy?

Background and Significance

Research has reported a lack of health professionals' awareness of health literacy across different environments and populations. Studies of physician and healthcare workers find physicians often just assume their patients understand what is being said. This can be a lack of provider awareness combined with the patient's reluctance to admit he does not understand the provider's explanation (Parker, 2000). Several studies have explored educational programs to increase awareness of low health literacy and best practice methods (Coleman, 2011). These studies describe efforts to increase health care professionals' knowledge of health literacy. Green, Gonzaga, Cohen, & Spagnoletti (2014) completed a pre-post survey of 31 internal medicine residents after a training program that included lectures, real and standard patient meetings, videos, and a self-assessment skills checklist. They found health literacy knowledge was increased as well as an increase in consideration of the health literacy of patients. Various healthcare workers were highlighted in a similar study that included a

pre-post test after a 90 minute instruction in health literacy including communication techniques. This instruction increased the perceived knowledge of health literacy and increased the staff's intention to focus on patients' health literacy (Mackert, Ball, & Lopez, 2011). Pharmacy, nursing, and dietetic students were also included in studies to increase knowledge of health literacy (Cotugna & Vickery, 2003; McCleary-Jones, 2012; Sicut & Hill, 2005). These studies found formal instruction increased the knowledge of health literacy in their respective professions.

Health literacy education for healthcare professionals was also emphasized in the National Action Plan (*National Action Plan* 2010). The National Action Plan published in 2010 was based on the Department of Health and Human Services Agency for Healthcare Research and Quality systematic review of research to examine the effect of health literacy. Baur (2011) described the contribution of the National Action Plan (NAP) and the resulting framework to approach the problem of low health literacy. One key goal of the NAP was professional education and collaboration with emphasis on patient- clinician communication (*National Action Plan* 2010).

To address the goals of the NAP, occupational therapists are charged with creating and modifying patient materials to provide clearly understood information. Communication using plain language and culturally relevant language is imperative to the therapeutic process. The requirement to develop or modify material to meet the needs of all literacy levels has been identified as a specific way to integrate health literacy into OT practice (Levasseur & Carrier, 2012).

Other national programs intended to address low health literacy have also emphasized the need for health literacy education for health professionals. The IOM publication “The Prescription to End Confusion” (Nielsen-Bohlman et al., 2004) speaks to health care communication and the importance of professional education in health literacy. Developing health literacy curricula or continuing education for health professional schools is considered an approach to address all phases of professional development. Manuals and guidelines have been developed to inform professionals about health literacy and ways to integrate health literacy into their practice but none address specifically OT (see Table 3). The American Medical Association created a patient safety program which included such a manual entitled *Health Literacy and Patient Safety: Manual for Clinicians*. The manual, accompanied with patient videos, reviews basic health literacy information and offers suggestions and resources for physicians and non-physicians (Weiss, 2007).

To recognize the significance of health literacy in occupational therapy practice, the therapist must be knowledgeable and aware of the consequences and implications of low health literacy. The manual created for this study is specifically designed to educate and inform occupational therapists about health literacy. It includes experiential activities and case studies based on the Occupational Therapy Practice Framework (OTPF). As an OT strategies education manual, it is meant to be a fluid document that can be updated and augmented as organizational guidelines and options change and evolve.

Table 6

Examples of Manuals and Guides for Health Literacy

Manual/Guide	Source	Purpose	Topic
Clear Communication Initiative	National Institute of Health (NIH)	Provide accessible information that is culturally competent Using plain language	Communication Guidance ("Clear Communication", 2015)
Pink Book	National Cancer Institute and NIH	Planning, implementing and evaluating clear communication	Communication Guidance ("Making Health Communication Programs Work", 2004)
Clear Communication Index	Centers for Disease Control	Plan and assess public materials using research-based tools	Public Communications materials (Baur & Prue, 2014)
Addressing Patient's Health Literacy Needs	Joint Commission Resources	Communication techniques, Health literacy organization priorities	Public Communications materials ("Comprehensive Accreditation Manual for Hospitals", 2007)
Say It Right the First Time: Using Plain Language to Address Health Literacy	County of Los Angeles Public Health	Improve written and oral communication of county staff	Public Communications materials ("Say it Right the First Time", 2013)
Toolkit for Making Written Material Clear and Effective	Centers for Medicare and Medicaid Services	11-part toolkit to create easily understood printed material	Material Assessment (McGee, 2010)

The Federal Plain Language Guidelines	The Plain Language Action and Information Network (PLAIN)	Provide updated communication guidelines	Standards and Guidelines (“Federal Plain Language Guidelines”, 2011)
National Culturally and Linguistically Appropriate Services (CLAS) Standards	Department of Health and Human Services, Office of Minority Health	Assist organizations in providing culturally sensitive information	Internet Design Guidelines (“National Standards”, 2001)
Health Literacy Guide	Department of Health and Human Services	Web design and public health communication	Web Design Guidelines (“Health Literacy Online”, 2010)

Methodology

Research Design

The purpose of Study III was to develop a health literacy education manual with treatment strategies for occupational therapists. This treatment guide is applicable to most patients, especially patients those impacted by low health literacy.

Data Collection Tools

Tools included current literature that defined strategies for communicating and treating patients with low health literacy. This included techniques to clarify written and oral communication, patient check lists and experiential exercises. Results from Study I & II were also an essential part of the data collection tools. Study I revealed patient health literacy levels and demographics that demonstrate low health literacy and subsequent communication needs. Results of Study II reported therapists' insights into patient education from various practice areas.

Data Analysis

Using current literature, an education manual was created to provide guidelines for patient-centered treatment plans with strategies for communication. Members of the focus group were asked to review the manual and to provide feedback. Six of the eight participants responded. Changes were made to the manual template based on their feedback.

Results

The manual is comprised of eight chapters (see Appendix F). These included:

Chapter One, Introduction and Significance of Health Literacy

Chapter Two, Assessing Patient Health Literacy

Chapter Three, Strategies for Better Communication

Chapter Four, Teach-Back Techniques

Chapter Five, Strategies for Written Materials

Chapter Six, Internet Information

Chapter Seven, Goals for a Health Literate Organization

Chapter Eight, Accessibility to Clinic or Hospital

Case Studies, Experiential Activities

Manual Feedback

The manual was reviewed by six members of the focus group. Through email correspondence, the members of the focus group were asked to review the manual and offer comments and/or questions about the content. The overall impression of the manual reported having a good flow and being informative.

Focus group respondents quotes:

“The manual is very informative, especially with instructions provided on ensuring that patient receive information they can understand as well as determining reading level. It is divided into chapters that flow nicely from one to the next in terms of content.”

“Great explanation for the need to address health literacy, especially...with our diverse population.”

The experiential activity was considered useful and the manual was seen as providing helpful information to have when teaching patients.

Focus group respondent quote:

“Resources and experiential exercise were useful /helpful summarizing up the purpose of the manual and gives the therapists easy access to reliable resources.

The feedback also included questions about content.

Focus group respondent quote:

“I was a little confused about the universal precautions toolkit and also attribute number five of a health literate organization.”

The manual addressed concerns and themes expressed during the focus group. Much of the manual content was determined by discussion with focus group therapists.

Focus group respondent quote:

“ I definitely feel like in acute care there are some patients that are overwhelmed with their diagnosis and everything coming at them and all these medicines they are taking. And then I come in and say, “Did you do your exercises? “ And they are like “who are you?”

This concern could be addressed with the following communication strategy: If the patient is not feeling well enough to participate, assure the patient and family or friends that you will be back to continue the conversation. Be sure the patient has a way to contact you.

Focus Group respondent quote (referring to physician communication):

“They typically talk a little bit higher than they should and sometimes like we, as therapists have to re...almost have to translate it to them so they understand.

You can see those lightbulbs come on. Like “oh, okay.”

This concern could be addressed with the following communication strategy: As the doctor explains their diagnosis and or procedures, take note of the patient’s response. Do they ask pertinent questions? Are their answers and comments appropriate? Patients with low health literacy do not ask as many questions and do not understand their physician’s explanation (Schillinger et al., 2003). As the therapist, you may determine the patient’s comprehension by their comment or follow-up question.

Discussion

The following discussion section will answer the research question: What content is needed for a patient education manual that provides guidelines for occupational therapists? It will include discoveries, clinical implications, and future directions.

The manual was created to include evidence-based health literacy information. Current research and published guidelines were reviewed to determine information applicable to the needs of occupational therapists in varied practice areas.

As an OT education manual, the intent is for it to be a fluid document that can be updated and augmented as organizational and professional parameters and options change and evolve. The manual addresses communication strategies applicable to almost every setting and practice area.

A review by members of the focus group from Study II suggested portions of the manual to be modified and clarified for better understanding. Each focus group member who responded was contacted to discuss suggestions. Changes and modifications were incorporated into the current manual.

Implications for Practice

The Health Literacy Manual of Patient Education Strategies is designed to be used for occupational therapists working in a large urban hospital with a varied population. It is an instructional manual to increase the knowledge and awareness of health literacy and to identify the ways in which low health literacy affects patient outcome. The manual is to be used as a guide for improving communication between the occupational therapist and patient. It includes resources for additional information and references. The manual is designed to grow and expand as the clinicians use it and add resources specific to their patient population. However, information in the manual is applicable across most practice areas. It is suggested that the manual be introduced to the therapists during a bimonthly OT topics meeting. Once introduced to the therapists, they should be encouraged to use the information in round table discussions, during staff meetings and as an addition to new employee orientation. The included experiential activities are designed to be used in group discussions appropriate for staff development. Future research should attempt to determine the efficacy and effectiveness of this manual including content and method of delivery.

CHAPTER VI

CONCLUSION AND SYNTHESIS

Introduction

This chapter includes a summary of the findings of Studies I, II, and III. It also includes implications for occupational therapy practice, limitations, and lessons learned.

The literature reviewed for this study found low health literacy resulted in patients' decreased participation in preventative health measures, greater chronic disease, and more frequent hospitalization (AHRQ, 2004). Furthermore, patients with low health literacy have difficulty comprehending written information and verbal communication with providers. It has been found that professional education increased the recognition of health literacy and emphasized the importance of considering low health literacy in the clinical interaction with patients (Coleman, 2011).

Summary of Study I

In Study I, a health literacy assessment of outpatient hand clinic patients was completed. Using the S-TOFHLA, the results reported were 62% Adequate, 20% Marginal, and 18% Inadequate health literacy. Analysis of the demographics revealed that low literacy was greater in the Spanish-speaking and minority member patients. This was consistent with findings in health literacy literature.

The second part of Study I examined OT handouts, determining reading levels and areas that should be modified for ease of comprehension. Comparing the health

assessment findings to reading levels of handouts found that 38% of patients would not be able to entirely understand the concepts introduced.

Summary of Study II

In Study II, a focus group of eight therapists from various practice areas was asked to respond to questions about health literacy. This group interview discussed patient education and instruction. During the interview, the focus group discussed their individual perspectives and experience with health literacy. The focus group members work in different practice areas and each area revealed different challenges and distinct approaches to patient communication. However, collectively, the group agreed that as therapists they should consider the implications of health literacy and the impact, in particular, of low health literacy.

Summary of Study III

Study III was the planning and development of an education strategies manual for occupational therapists. The manual was developed to review the definition of health literacy and offer tactics when treating low health literacy. Strategies include methods to modify written material as well as techniques to clarify verbal communication. The manual also provides resources and experiential activities.

PEOP–HL, Conceptual Model Adapted for Health Literacy

The adapted Person- Environment-Occupation-Performance (PEOP) model, as described in the Introduction, has been further modified based upon the findings from Studies I and II. It is now titled the PEOP-HL model and is applied to the study of health literacy with an emphasis on the interaction of health literacy skills and unique

environmental factors. This model was initially developed to describe the relationship between the person, environment and the occupation or skills needed for optimal occupational performance (Christensen & Baum, 2005). It has been suggested that the PEOP model was a good fit as a health literacy model and was adapted by Smith and Hudson (2012) to address health literacy factors that relate to the occupation performance of health care management.

In this study, the PEOP-HL model further adapts the work of Smith and Hudson (2012) emphasizing the significant role of the environment and how it affects the level of health literacy. Examining the model, the Person (P) construct includes those intrinsic factors that impact health literacy. These include the person's culture, age and cognition. Other Person factors specific to health literacy include English as a second language, extent of education and the poverty level. These features have been identified as barriers to health literacy (Kutner et al., 2006).

The Environment (E) is defined as an overarching element when determining health literacy. The Environment plays a key role in moderating the level of health literacy. For example, the health literate patient may be completely familiar and knowledgeable when visiting a community health clinic for routine lab tests. The surroundings and staff are familiar and the patient can easily maneuver the trip from his home to the clinic and the appropriate waiting room. However, when faced with an acute injury or illness, this same patient may not demonstrate *Adequate* health literacy. The patient may find himself in the environment of an acute care hospital surrounded by staff he does not know along

with experiencing pain and confusion. This temporal, physical, and social change in the environmental context will significantly impact the patients health literacy.

Occupation (O) includes activities and skills needed to make health care decisions. Can the patient read informational handouts and understand the healthcare providers explanation? Are his numeracy skills such that he can decipher and manage medicine? Many healthcare activities require skills and abilities that may require the therapist to modify the environment such as: (1) confirm explanation with teach-back; (2) improve comprehension through modified handouts; and (3) inform with cultural consciousness.

The Performance (P) outcome is dependent on the interaction of person, environment, and occupation factors. In this further modified model, educational strategies such as teach-back techniques and recognition of low health literacy will promote positive performance outcomes (see Figure 2).

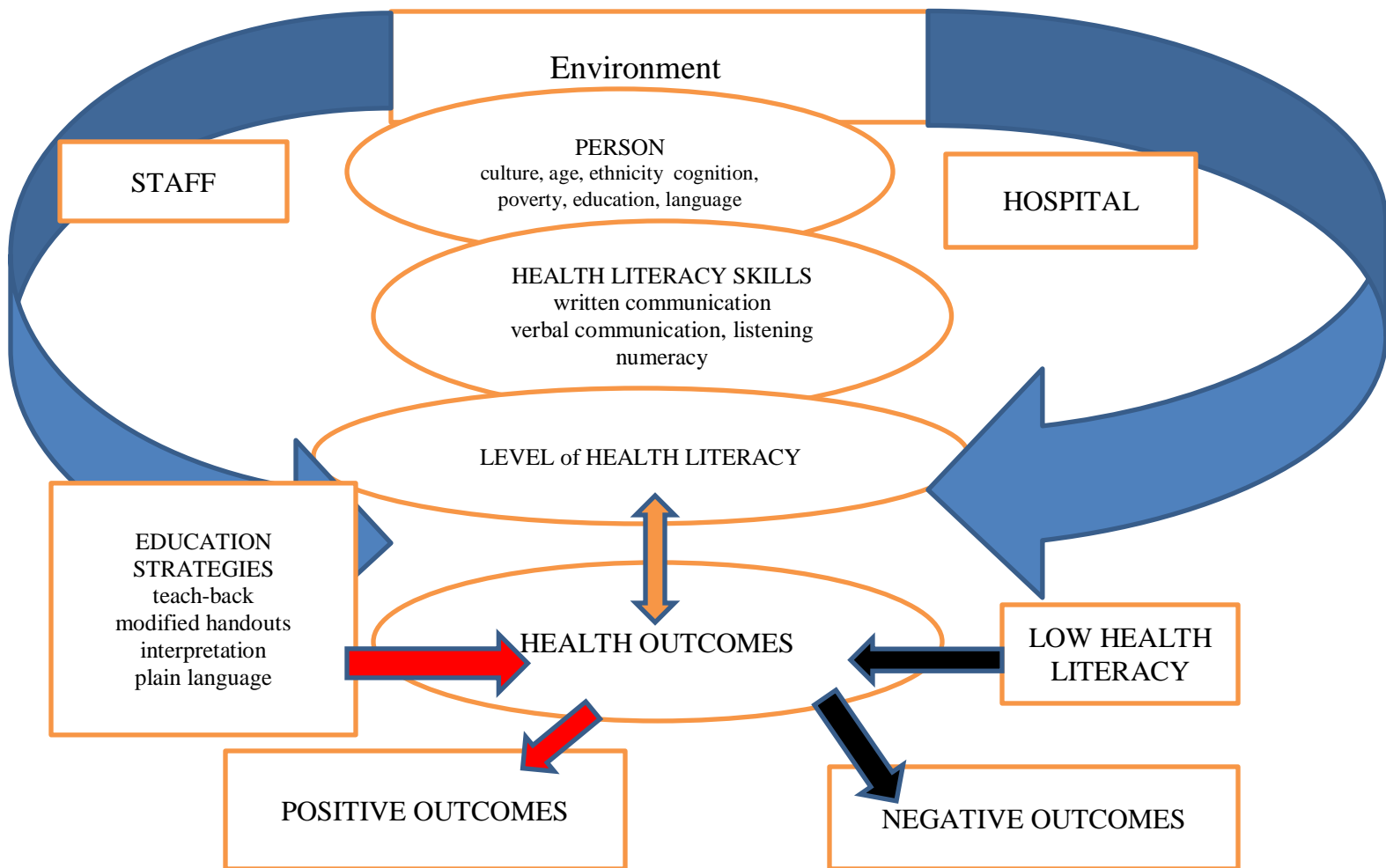


Figure 6. *PEOP-HL adapted model of health literacy.*

Implications for Practice

The results of Study I, II, and III are applicable to OT practice. Health literacy affects each patient in every practice area and should be considered when preparing individual treatment plans. Health literacy is not just specific to the person, but also to the situation and environment. For the patient experiencing an acute care injury or illness or a patient beginning rehabilitation, consideration of low health literacy is crucial to successful therapeutic outcomes.

Limitations

The participants in Study I were drawn from a publicly funded health system that serves uninsured and underinsured patients. This includes a higher number of minorities and people from a low socioeconomic status. This may affect the results as research has found that populations with these characteristics are disposed to low health literacy. In Study I the PI issued the assessment and questionnaire to the study participants. As some of the participants were returning patients, the PI had a previous relationship that may have created a bias in patient participation.

In the second part of Study I, the handouts collected were those used at the time of data compilation. These do not reflect every patient handout and information material available. Another limitation is that the handouts were not analyzed for layout and design.

Study II used a focus group design and interviewed eight OTs to determine and discover knowledge and experiences of health literacy. The amount of input was limited to only one group meeting.

In Study III, the manual lacks a pre-post test. This could have determined if the use of the manual increased practitioners' health literacy knowledge and their inclination to consider health literacy.

Lessons Learned

The results of Study I reported a greater number of patients with *Adequate* health literacy than expected. This indicated that a larger percentage of the participants were able to read and comprehend written material at or above the sixth grade level.

Considering the results of this health literacy assessment and the ability of patients to read and comprehend written material, it suggests that consideration of patient-provider verbal communication is also an important element to emphasize in patient care. To clarify verbal instructions and information, plain language should be used with techniques designed to confirm new information such as the teach-back technique.

In my own practice, I have become more aware of patient comprehension of verbal instruction. I have begun to integrate teach-back into every session. Also, the practice of reviewing and modifying patient education and information handouts is ongoing in my department.

Future Directions

The field of health literacy is shifting from investigating the patient's health literacy to a broader investigation of providers and institutions (Rudd, 2011). Considering the results from Study I, efforts should be made to modify patient handouts and instructions already being used to provide material at or below a sixth grade reading level.

Communication between the patient and provider and the patient and institutions needs to

be the focus of future studies. Other future areas of research include studying both the physical environment and the impact of healthcare circumstances that may be demanding and stressful not only for clients but also for staff.

A follow-up with the focus group from Study II could be useful in determining how the health literacy manual is being utilized. Ongoing reviews of the manual from Study III would be beneficial to assure applicable material. Current topics of health literacy and techniques for integrating health literacy could be shared periodically through electronic mail.

Conclusion

The research question for Study I was: Are required hospital documents written at an appropriate reading level for patient comprehension? The research question for Study II was: What is the health literacy experience and knowledge of occupational therapists? The research question for Study III was: What content is needed for an education manual of treatment strategies and guidelines for occupational therapists treating patients with low health literacy?

In Study I it was found that 62% of patients read and understood material written at the tenth grade level. A survey of written material revealed the majority were written at or above the tenth grade level. This material was not appropriate for 38% of patients. The remainder of material should be modified to meet the literacy baseline.

The focus group interview in Study II found that therapists had some prior knowledge of health literacy. Each therapist shared their own experiences with low health literacy patients. It was evident that practice areas had specific challenges and confirmed findings

from literature that health literacy is a dependent on the patient and their current circumstances.

The education strategies manual was developed using evidence gathered from the current research. The manual introduced the concept of health literacy and suggested strategies to use when treating patients with low health literacy. The strategies and guidelines to treat low health literacy have been established over the last decade. Using the OTPF, experiential activities provide opportunity for the therapists to identify low health literacy and the ways that it affects the patient's occupational performance.

Considering the results of all three studies, it is evident that health literacy is a combination of the patient's skills and current environmental factors. As occupational therapists, we should use our skills to analyze and address patients' occupational demands impacted by low health literacy. In client-centered therapy, our challenge is to provide easy to understand instructions for both written and verbal communication that will encourage health promotion and healthier outcomes. In addition, as advocates for our patients, we must increase our own awareness of the healthcare environment including the temporal, social, and physical demands that will, in turn, have a positive effect on the health literacy levels of our clients.

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APPENDIX A

S-TOFHLA Health Literacy Assessment

S-TOFHLA Health Literacy Assessment

LITERACY in HEALTH CARE

Test of Functional Health Literacy in Adults

Short Test of Functional Health Literacy in Adults (S-TOFHLA)

S-TOFHLA Large Print Version English

page 2

Short Test of Functional Literacy in Adults S-TOFHLA READING COMPREHENSION

HAND PATIENT THE READING COMPREHENSION PASSAGES TO BE
COMPLETED. FOLD BACK THE PAGE OPPOSITE THE TEXT SO THAT THE
PATIENT SEES ONLY THE TEXT.

PREFACE THE READING COMPREHENSION EXERCISE WITH:

"Here are some other medical instructions that you or anybody might see around the
hospital.

These instructions are in sentences that have some of the words missing. Where a word is
missing, a blank line is drawn, and 4 possible words that could go in the blank appear just
below it. I want you to figure out which of those 4 words should go in the blank, which
word makes the sentence make sense. When you think you know which one it is, circle
the letter in front of that word, and go on to the next one. When you finish the page, turn
the page and keep going until you finish all the pages."

STOP AT THE END OF 7 MINUTES

PASSAGE A: X-RAY PREPARATION

PASSAGE B: MEDICAID RIGHTS AND RESPONSIBILITIES

S-TOFHLA • Large Print Version, English 14 point font

page 3

PASSAGE A

Your doctor has sent you to have a _____ X-ray.

a. stomach b. diabetes c. stitches d. germs

You must have an _____ stomach when you come for _____.

a. asthma b. empty c. incest d. anemia

a.

is. b. am. c. if. d. it.

The X-ray will _____ from 1 to 3 _____ to do.

a. take b. view c. talk d. look a. beds b. brains c. hours d. diets

page 4

THE DAY BEFORE THE X-RAY.

For supper have only a _____ snack of fruit, _____ and jelly,

a. little b. broth c. attack d. nausea a. toes b. throat c. toast d. thigh

with coffee or tea.

After _____ you must not _____ or drink

a. minute, b. midnight, c. during, d. before, a. easy b. ate c. drank d. eat

anything at _____ until after you have _____ the X-ray.

a. ill b. all c. each d. any a. are b. has c. had d. was

page 5

THE DAY OF THE X-RAY.

Do not eat_____

a. appointment. b. walk-in. c. breakfast. d. clinic.

Do not_____, even_____

a. drive b. drink, c. dress, d. dose a. heart. b. breath. c. water d. cancer.

If you have any_____, call the X-ray_____ at 616-4500.

a. answers, b. exercises, c. tracts, d. questions a. Department b. Sprain c. Pharmacy

d. Toothache

page 6

PASSAGE B

I agree to give correct information to_____ if I can receive Medicaid.

a. hair b. salt c. see d. ache

I _____ to provide the county information to_____ any

a. agree b. probe c. send d. gain a. hide b. risk c. discharge d. prove

statements given in this_____ and hereby give permission to

a. emphysema b. application c. gallbladder d. relationship

the_____ to get such proof. I _____ that for

a. inflammation b. religion c. iron d. county a. investigate b. entertain c. understand d.

establish

Medicaid I must report any_____ in my circumstances

a. changes b. hormones c. antacids d. charges

page 7

within_____ (10) days of becoming_____ of the change.

a. three b. one c. five d. ten a. award b. aware c. away d. await

I understand_____ if I DO NOT like the_____ made
on my

a. thus b. this c. that d. than a. marital b. occupation c. adult d. decision

case, I have the_____ to a fair hearing. I can_____ a

a. bright b. left c. wrong d. right a. request b. refuse c. fail d. mend

hearing by writing or _____ the county where I applied.

a. counting b. reading c. calling d. smelling

If you_____ TANF for any family_____, you will
have to

a. wash b. want c. cover d. tape a. member, b. history, c. weight, d. seatbelt

page 8

_____ a different application form. _____ we will use

a. relax b. break c. inhale d. sign a. Since, b. Whether, c. However, d. Because,

the_____ on this form to determine your _____

a. lung b. date c. meal d. pelvic a. hypoglycemia. b. eligibility. c. osteoporosis. d.

schizophrenia.

S-TOFHLA Health Literacy Assessment, Spanish Version

LITERACY in HEALTH CARE

Test of Functional Health Literacy in Adults

Short Test of Functional Health Literacy in Adults (S-TOFHLA)

S-TOFHLA Large Print Version Spanish

Page 2

Short Test of Functional Literacy in Adults S-TOFHLA READING COMPREHENSION

HAND PATIENT THE READING COMPREHENSION PASSAGES TO BE
COMPLETED. FOLD BACK THE PAGE OPPOSITE THE TEXT SO THAT THE
PATIENT SEES ONLY THE TEXT.

PREFACE THE READING COMPREHENSION EXERCISE WITH:

“Estas son ALGUNAS instrucciones medicas que UD. O cualquier
persona puede encontrar aqui en el hospital. En cada fase faltan algunas
palabras; donde falta la palabra, hay un espacio en blanco y luego hay 4
posibles palabras para escogar. Quisiera que Ud. Lea la frase y decida cual
de estas cuatro palabra es la palabra que falta en la frase, o que leda major
sentido ala frase. Cuando Ud. decida cual es la palabra correcta para aquel
espacio, marque con un circulo la palabra que Ud. ha escogido y siga
leyendo. Cuando termine la pagina, continue en la pagina siguiente hasta
terminar todas.”

STOP AT THE END OF 7 MINUTES
PASSAGE A: X-RAY PREPARATION
PASSAGE B: MEDICAID RIGHTS AND
RESPONSIBILITIES
S-TOFHLA • Large Print Version, Spanish 14 point font

Page 3

LECTURA A

Su doctor le ha _____ a sacarse Rayos X del_____.

- | | |
|----------------|---------------|
| a. distinguido | a. estomago |
| b. mandado | b. caminar |
| c. corrido | c. vestido |
| d. formalmente | d. comunmente |

Cuando venga por los _____ debe de tener el estomago_____.

- | | |
|-----------|-------------|
| a. libros | a. volar |
| b. fiel | b. cabeza |
| c. RayosX | c. vacio |
| d. dormir | d. contento |

Este examende Raoyos X _____ de 1 a 3 _____.

- | | |
|---------------|------------|
| a. durara | a. millas |
| b. cantara | b. luz |
| c. permanente | c. Rayos X |
| d. silla | d. horas |

El dia antes de _____ radiographia, cene solamente
alguna_____.

- | | |
|----------|----------------|
| a.del | a. bailar |
| b.alguna | b. inteligente |
| c. la | c. fruta |
| d. boton | d. receta |

pan con mermelada, y _____o te. Despues de

- a.lentes
- b.cafe
- c. cantar
- d. pensamiento

Page 4

la _____, nom debe comer
ni _____absolutamente

- | | |
|---------------|----------------|
| a.taciturno | a. beber |
| b. vehiculo | b. nadir |
| c. medianoche | c. cabello |
| d. poder | d.conocimiento |

nada hasta despues _____que la hayan tomado la _____.

- | | |
|-----------|----------------|
| a.sentar | a. radiografia |
| b. cansar | b. calcomania |
| c. de | c. advertencia |

d. contra

d. estrujar

El dia de la radiografia, no_____. No beba nada,
ni_____.

a. facta

a. agua

b.desayune

b. hierba

c. observe

c. avaro

d. estruendo

d.maleta

Si Ud. tiene alguna _____, llame al depaertmento de Rayos X al numero
(310) 222-2821.

a. pregunta

b. respuesta

c. caliente

d. doctor

Page 5

LECTURA B

Yo acepto dar informacion correcta para ver si puedo recibir Medi-Cal.

Yo acepto proveer _____al condado para verificar_____

a. informacion

a. desde

b.positivo

b. cualquier

c. procurar

c. fascinante

d. vision

d. bien

declaracion dada en esta_____y por consiguiente
doy_____

a. solicitud

a, boletos

b. periodico

b. permiso

c. fantastic

c. mirar

d. amplitude

d. con

al condafo para obtener_____informacion. Yo entiendo que

a. dicha

b. noticias

c. estar

d. testarudo

_____la responsabilidad de_____a Medi-Cal dentro

a. una

a. comentar

b. desigualdad

b. papel

c. ganas

c. notificar

d. tengo

d. desalmado

Page 6

de _____periodo de diez dias_____de
enterarme

a.un

a. recipient

b. a

b. entonces

c. tiempo

c. despues

d. llamar

d. formula

de un _____en mi situacion. Yo _____que si no estoy

a. canto

a. saco

b. cambio

b. letra

c. girar

c. entiendo

d. mes

d. de

_____con la decision tomado_____mi solicitud, yo

a.estudiando

a. arriba

b. satisfecho/a

b. sobre

c. leccion

c. pensado

d. sin

d. pronto

tengo_____a una aufiencia con_____condado. Yo

a. derecho

a. el

b. prosperidad

b. estos

c. salir

c. incredible

d. valor

d. hospital

puedo pedir_____audiencia escribiendo o
_____a la

- | | |
|--------------|-------------|
| a.estipular | a. candado |
| b. confianza | b. honesto |
| c.donde | c. llamando |
| d. una | d. llorando |

Page 7

oficina del_____donde entregue mi solicitud.

- a.condado
- b. escuela
- c. ver
- d. altivo

_____Ud. quiere TANF/Welfare para_____

- | | |
|-------------------|---------------|
| a.A | a. deber |
| b.Corriendo | b. cualquier |
| c. Descididamente | c. escritorio |
| d. Si | d. vacilar |

miembro de su familia, tiene que llenar otro tipo de solicitud.

S-TOFHLA: Reading Comprehension

Scoring Key

Spanish: 14 Point Font

Passage A	Passage A	Passage B	Passage B	Passage B
A1 b	A10 c	B17 a	B24 a	C34 a
A2 a	A11 a	B18 b	B25 c	C35 d
A3 c	A12 c	B19 a	B26 b	C36 b
A4 c	A13 c	B20 b	B27 c	
A5 a	A14 b	B21 a	B28 b	
A6 d	A15 a	B22 d	B29 b	
A7 c	A16 a	B23 c	B30 a	
A8 c			B31 a	
A9 b			B32 d	
			B33 c	

APPENDIX B

Demographic Survey

Demographic Survey

1. What is your gender?

Male

Female

Rather not say

2. What is your age?

Under 18 years

18 to 24 years

25 to 34 years

35 to 44 years

45 to 54 years

55 to 64 years

65 or older

Rather not say

3. What is your race?

American Indian or Alaskan Native

Asian

Black or African-American

Latino or Hispanic

Native Hawaiian or other Pacific Islander

White/Caucasian

From multiple races

Other (specify)

Rather not say

4. What is your employment status?

Employed full time

Employed part time

Unemployed

Retired

Student

Rather not say

5. What is the highest level of education you have completed?

Less than high school

Completed some high school

High school graduate

Completed some college

Associate degree

Bachelor's degree

Completed some postgraduate

Master's degree

Ph.D., law or medical degree

Other advanced degree beyond a Master's degree

Rather not say

6. Approximately what is your household income?

\$0 - \$9,999

\$10,000 - \$19,999

\$20,000 - \$29,999

\$30,000 - \$39,999

\$40,000 - \$49,999

\$50,000 - \$59,999

\$60,000 - \$69,999

\$70,000 - \$79,999

\$80,000 - \$89,999

\$90,000 - \$99,999

\$100,000 - \$149,999

\$150,000 or more

Rather not say

Demographic Survey, Spanish

Encuesta Demográfica

Code No. _____

Por favor marque con un circulo la respuesta correcta.

1. ¿Cuál es su género?

Hombre

Mujer

Prefiero no contestar

2. ¿Cuál es su edad?

Menor de 18 años

18 a 24 años

25 a 34 años

35 a 44 años

45 a 54 años

55 a 64 años

65 o más años

3. ¿Cuál es su raza?

Nativo americano o nativo de Alaska

Asiático

Negro o afro-americano

Latino o hispano

Nativo de Hawái o de otras islas del Pacífico

Caucásico o blanco

De varias razas

Otro (especificar)

Prefiero no contestar

4. ¿Cuál es su estado laboral?

Trabajando a tiempo completo

Trabajando (tiempo parcial)

Desempleado

Jubilado

Estudiante

Prefiero no decir

5. ¿Cuál es el nivel de educación más alto que usted terminó?

Menos que escuela secundaria

He estudiado algo de preparatoria.

Me gradué de la preparatoria

He estudiado algo de la universidad pero nunca me gradué.

Grado Técnico, Título Técnico, o Grado Superior (Título de dos años)

Título de Licenciado

He asistido algunas clases de postgrado
Una Maestría
Doctorado, Diplomado en Derecho (abogado) o Medicina (médico)
Otro título más avanzado que maestría.
Prefiero no decir

6. ¿Aproximadamente cuantos son los ingresos de su hogar?

\$0 - \$9,999
\$10,000 - \$19,999
\$20,000 - \$29,999
\$30,000 - \$39,999
\$40,000 - \$49,999
\$50,000 - \$59,999
\$60,000 - \$69,999
\$70,000 - \$79,999
\$80,000 - \$89,999
\$90,000 - \$99,999
\$100,000 - \$149,999
\$150,000 o more
Prefiero no decir

APPENDIX C

Interview Guide for Focus Group/Study II

Interview Guide for Focus Group/Study II

General Questions:

1. Tell me what you know about health literacy?
2. Have you seen a lack of health literacy demonstrated with your patients?
3. What do you think it means for patients to have low health literacy?
4. What would you say the prevalence is of low health literacy in your setting?

Patient Groups:

5. What groups of patients are more likely to be low health literate? How have you seen that demonstrated?
6. What do you think are the health outcomes associated with low health literacy?

Approach/ Techniques:

7. What is a technique to use to be sure your patient understood your instructions?
8. What are some techniques to create an environment to reduce or prevent patient embarrassment or discomfort about their low health literacy?

APPENDIX D

Focus Group Demographic Questionnaire/Study II

Focus Group Demographic Questionnaire/Study II

Code No. _____

1. How long have you worked as an occupational therapist? _____
2. What area do you work in now (inpatient/outpatient)? _____
3. Are you familiar with the term 'Health Literacy'? _____

APPENDIX F

EDUCATION STRATEGIES MANUAL

HEALTH LITERACY

PATIENT EDUCATION

STRATEGIES

for the

OCCUPATIONAL THERAPIST

F. Kay Brown, August 2016

“Patients have the right to understand health care information that is necessary for them to safely care for themselves, and the right to choose among available alternatives. Health care providers have a duty to provide information in simple, clear and plain language, and to check that patients have understood the information before ending the conversation.”

(Weiss, 2007)

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INTRODUCTION

This manual is created to assist the occupational therapist in patient centered communication. Clear communication has been shown to improve clinical outcomes with all patients, including those with low health literacy (LHL).

Health literacy has been defined as “the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment.” (Neilsen-Bohlman, Panzer& Kindig, 2004)

According to the National Assessment of Adult Literacy Survey (NAALS), 2003, 14% of Americans cannot understand basic literacy. It found that those persons most affected with LHL included the elderly, those living in poverty and patients with English as a second language. The NAALS 2003 reported health literacy by dividing it into 4 categories; proficient, intermediate, basic and below basic (Kutner, M., Greenberg, E., Jin, Y. & Paulsen, C.,2006).

Table 1 *Categories of Health Literacy*

Proficient	13%	Complex	Read and understand all text and numeric information
Intermediate	44%	Challenging	Read and understand medicine labels, determine correct dosage of medicine
Basic	29%	Everyday	Reading basic pamphlets, newspapers
Below Basic	14%	Concrete	Read short set of instructions, elementary literacy

As allied health professionals, occupational therapists have the responsibility to ensure the highest quality of care for all our patients. Each practice area is unique and each

physical facility presents its own distinct barriers and limitations to health literacy. The goal of this manual is enhance clinical outcomes for patient by providing recommendations and information that will increase productive patient-clinician communication.

CHAPTER ONE

Health Literacy and Occupational Therapy

Therapists routinely issue written information to their patients to support their home programs. The patient's ability to benefit from this information depends on their level of understanding. The degree of basic literacy skills will affect the extent of their comprehension.

Skills included in health literacy include reading and verbal comprehension, numeracy, and organization. These skills are dynamic and change depending on the patient's age, health, education, previous experience and culture. As occupational therapists, an important part of our job is to ensure the patient has understood their role in the rehabilitation process. In order to do this, written materials and verbal communication should match the patient's level of comprehension. Encouraging self-management of healthcare can only be possible if the patient is offered information that is clear and appropriate for their level of understanding.

The American Occupational Therapy Association (AOTA) supports health literacy. This is reflected in official documents and guidelines. These include the following: (1).

AOTA's Accreditation Council for Occupational Therapy Education (ACOTE®), recognized as the accrediting agency for occupational therapy education by both the United States Department of Education (USDE) and the Council for Higher Education Accreditation (CHEA), has included health literacy in its latest accreditation standards.

Standard B.5.18. Demonstrate an understanding of health literacy and the ability to

educate and train the client, caregiver, family and significant others, and communities to facilitate skills in areas of occupation as well as prevention, health maintenance, health promotion, and safety.

(AOTA, 2015, p.26)

(2). AOTA Societal Statement

Occupational therapy can promote health through the development and use of health education approaches and materials that are understandable, accessible, and usable by the full spectrum of consumers. Occupational therapy practitioners can assist in ensuring that all health-related information and education provided to recipients of occupational therapy or other health related service match that person's literacy abilities; cultural sensitivities; and verbal, cognitive, and social skills.

(AOTA, 2011, p.1)

(3.) CAOT Position Paper

The Canadian Association of Occupational Therapists (CAOT) acknowledges that health literacy is a resource for daily living. Health literacy influences life's occupations as it enables optimal access to and utilization of relevant and meaningful health information and services, and allows informed health decision making and action. Occupational therapists are in a privileged position to enable clients' health literacy through their professional expertise and focus on supporting clients in occupations that are meaningful to them. CAOT recognizes the major impact of health literacy skills on health for individuals, families, groups, communities, organizations, and populations and supports increasing health literacy skills as a mean to achieve a just and inclusive society.

(CAOT, 2013, p. 1)

CHAPTER TWO

Assessing Patient Health Literacy

How much does my patient understand?

It is difficult to know if your patient has low health literacy. You cannot tell by looking at the patient. There are many formal health assessments and screening. These include word recognition, reading and numeracy. Due to time constraints, short forms and screenings should be considered for clinical use. (see Table 2 for examples)

Table 2 *Assessments and screening tools*

Instrument	Description	Validation	Administration time
Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis, et al. 1993)	Word recognition, 66 words, short version	English/Spanish	5 minutes, short form, 2-3 minutes
Test of Functional Health Literacy (TOFHLA) (Parker, 1995)	Prose passages, numerical questions, short version	English/Spanish	22 minutes, Short form, 7 minutes
Newest Vital Sign (NVS) (Weiss, et al., 2005)	Question from nutrition label, screening	English/Spanish	3 minutes
Self-Report Question (Chew, 2003)	1-3 questions, screening	English/ Spanish	<3 minutes
Short Assessment of Health Literacy(SAHL) (Lee, et al., 2010)	Word recognition, 18 words, recognize word with related meaning	English/Spanish	2-3 minutes

Red Flags:

Because you cannot tell by looking, it is important to learn the signs of low health literacy. Frequent red flags:



* Mrs. Jones reports she doesn't have her glasses to read the handout.

*Mr. Nguyen can only identify his pills by color and shape, not label information.



* Ms. Anderson is not compliant with medicine, dosage, and frequently crushes pills that are meant to be taken whole.



*Mr. Garcia cannot complete his registration forms.

*Mrs. Burris misses numerous appointments, or may come to appointments on the wrong day.

*Aaron cannot explain his diagnosis or prognosis. He has had surgery but cannot explain the reason for surgery.



*Ms. Tan cannot demonstrate her exercises as instructed. She cannot correctly apply her splint as instructed.



*Mr. Funtanella has trouble accurately reporting his medical history.

CHAPTER THREE

Strategies for Better Communication

Consider why it is hard to communicate:



- Is the patient afraid? The health care system can be very intimidating.

- Is the patient embarrassed because they don't really understand their diagnosis?



➤ Useful Tips:



- As time permits during your treatment session, discuss with the patient 1-3 main aspects of their diagnosis including how they will be expected to manage the diagnosis. With the patient's permission, discuss information with the patient and trusted friends or family members, always using the patient's native language.



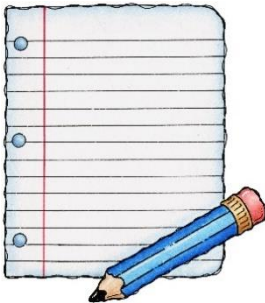
- If the patient is not feeling well enough to participate, assure the patient and family or friends that you will be back to continue the conversation.
- Be sure the patient has a way to contact you if further questions arise

Encourage the patient to ask questions:

- Assure the patient that there are no bad or stupid questions.

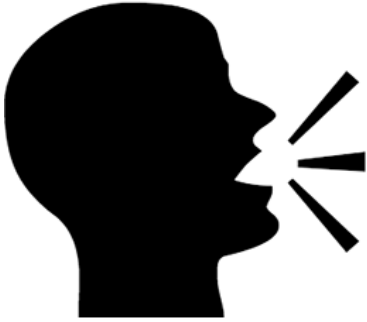


Explain the only way to better understand information about their diagnosis or treatment is to ask questions.



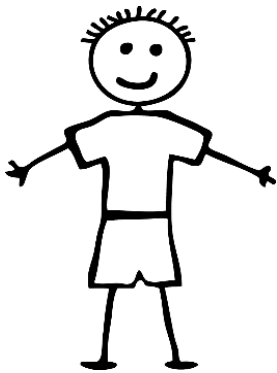
- Encourage patient to question their therapists and their doctors.
- Provide pen and paper so patient can write their questions down before seeing the doctor.
- As the doctor explains their diagnosis and or procedures, take note of the patient's response. Do they ask pertinent questions? Are their answers and comments appropriate?
- Provide information to patient including printed pamphlets, websites, contact for local groups or associations (Heart Association, StrokeAssociation, Cancer Society and Local support groups available for Stroke, Low Vision, Spinal Cord Injury).

- Always remember to follow proven methods for better verbal communication.

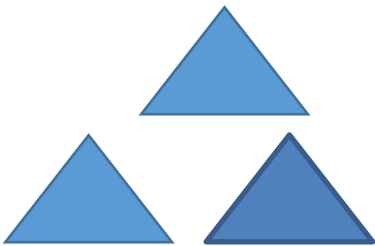


S-L-O-W, speak slowly

DO NOT use medical jargon, plain language is always better when explaining to patients, If you use a medical term, then always explain terminology



- PICTURES, use pictures or drawings when explaining information

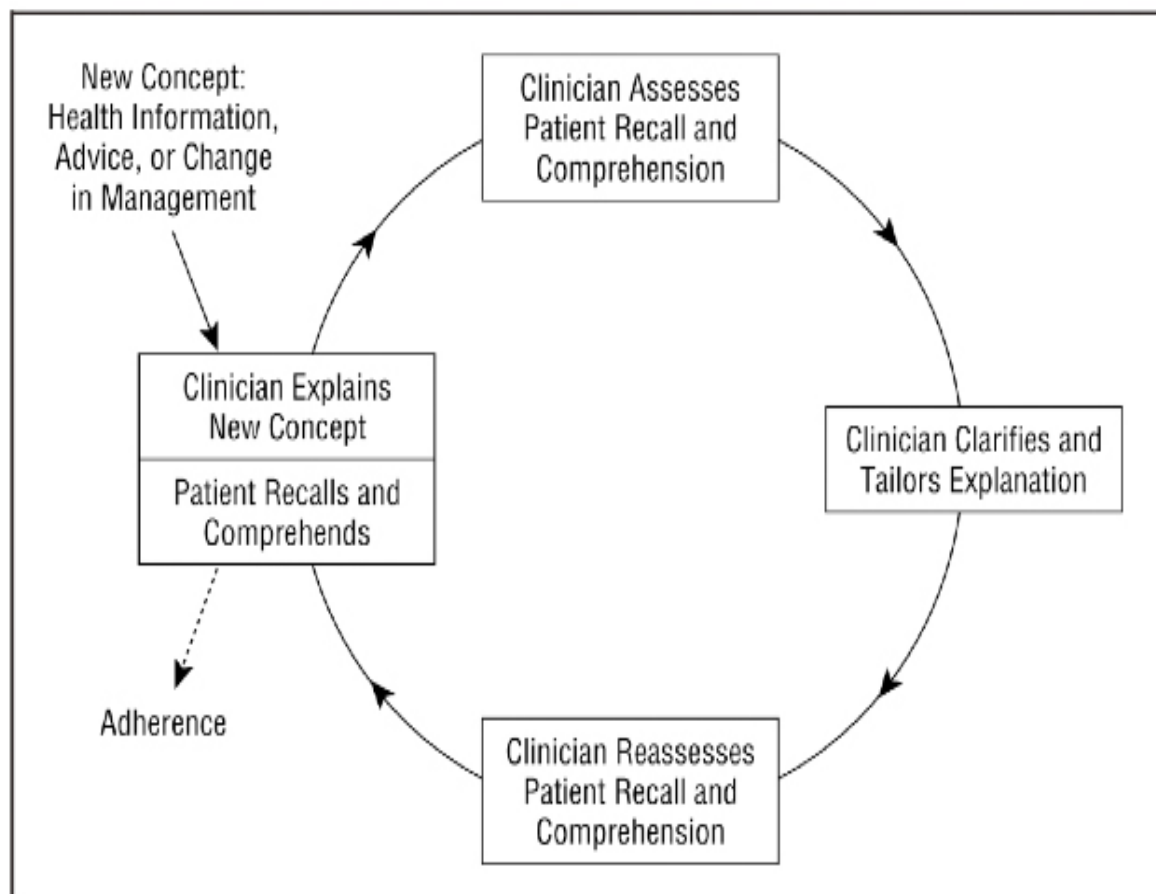


LIMIT TALKING POINTS, keep discussion brief, discuss the 3 most important things first

CHAPTER FOUR

TEACH-BACK Technique

How can you be sure the patient understands what you are trying to teach them? One method that is very useful is called the *teach-back technique*. This technique has been called an *interactive communication loop*. It is an approach to determine what your patient understands and will also help you, the therapist; better understand your patient's questions or concerns. (Arch Intern Med 2003 Jan 13; 153(1): 83-90)





Suggestions for Using Teach-back Successfully

1. Your voice and attitude should have a caring tone, **no shame**
2. Always make eye contact.
3. Always use plain language.
4. Ask the patient to explain or repeat back your instructions or information using their own words.
5. To confirm comprehension, use open-ended questions.
6. Do not use questions that can be answered with “yes or no”.
7. Begin the encounter by assuring the patient that the responsibility to explain clearly is on you, the therapist.
8. If the patient cannot teach back correctly, explain AGAIN and re-check.
9. Printed materials should be easy for patients to read and understand
10. Include your patient response to teach-back in your notes.

Teach-Back Examples

“I want to be sure I explained everything clearly. Can you please explain it back to me so I can be sure I did?”

“I want to be sure I did a good job of showing you how to use the Call Light. Can you show me how you will use it if you need help getting out of bed?”

“I’ve given you a lot of information. We should probably review what we have discussed. Why don’t you start?”

“What will you tell your wife about your condition?”

“Tell me what you will do and how you will do it when you get home?” (Teach Back Toolkit, Health Literacy Iowa, 2013)

CHAPTER FIVE

Written Materials

It has been shown that there is a discrepancy between written patient education and the



patient's literacy level.

Research has

reported that most materials including internet information are written above the reading level of most patients.

How can we as therapists be sure our written material is appropriate for our patient?

- Check for reading level by using a formula for reading levels
- Flesch-Kincaid is a readability tool that is readily available on Microsoft word.

Instructions for finding readability statistics in WORD:



1. Click the **Microsoft Office Button**, and then click **Word Options**.
2. Click **Proofing**.
3. Make sure **Check grammar with spelling** is selected.
4. Under **When correcting grammar in Word**, select the **Show readability statistics** check box.

(Microsoft,
2015)

If material cannot be tested through Word, another formula for determining reading level is the SMOG Readability Formula. (McLaughlin, 1969)

SMOG

To calculate the SMOG (Simplified Measure of Gobbledygoop) reading grade level, begin with the entire written work and follow these four steps:

1. Count off 10 sentences near the beginning, in the middle, and at the end of the text.
2. From these 30 sentences, circle all of the words containing three or more syllables (polysyllabic), including words that are repeated. Count the number of words circled.
3. Find the square root of the total number of polysyllabic words counted.
4. Add a constant of 3 to the square root. This number equals the SMOG grade, or the reading grade level of the document

A few additional guidelines will help to clarify these directions:

- A sentence can end with a period (.), exclamation point (!), or a question mark (?).
- If a word is Hyphenated, count it as one word.
- Numbers should also be counted, the number can be written out or in numeric form.
- Proper nouns should also be counted.

Many of the pamphlets or paperwork issued to the patient are short and do not contain 30 words. Follow these instructions to test a text that has fewer than 30 sentences:

1. Count all of the polysyllabic words in the text.
2. Count the number of sentences.
3. Find the average number of polysyllabic words per sentence as follows:

$$\frac{\text{Number of words}}{\text{Number of sentences}} = \text{Average}$$

Average= Total # of polysyllabic words /Total # of sentences

4. Multiply that average by the number of sentences.
5. Add that figure on to the total number of polysyllabic words.
6. Find the square root and add the constant of 3.

The quickest way to determine the SMOG grading test is by using the SMOG conversion table. Count the number of polysyllabic words in 30 sentences and look up the corresponding rate level on the chart.

The following is an example of how to use the SMOG Readability Formula and the SMOG Conversion Table for educational material on pancreatic cancer



Pancreatic Cancer

What is pancreatic cancer? To understand **pancreatic** cancer, it helps to know about the pancreas and what it does.

The normal pancreas

The pancreas is an organ located behind the stomach. It is shaped a little bit like a fish with a wide head, a **tapering** body, and a narrow, pointed tail. In adults it is about 6 inches long but less than 2 inches wide. The head of the pancreas is on the right side of the **abdomen** (belly), behind where the stomach meets the **duodenum** (the first part of the small **intestine**). The body of the pancreas is behind the stomach, and the tail of the pancreas is on the left side of the **abdomen** next to the spleen. The pancreas contains 2 different types of glands: **exocrine** and **endocrine**.

The **exocrine** glands make pancreatic “juice,” which is released into the **intestines**. This juice contains enzymes that help you digest the food you eat. Without these, some of the food would just pass through your **intestines** without being absorbed. (10)

The enzymes are released into tiny tubes called *ducts*. These tiny ducts merge to form larger ducts, which empty into the **pancreatic** duct. The **pancreatic** duct merges with the common bile duct (the duct that carries bile from the liver), and empties the **pancreatic** juice into the **duodenum** (the first part of the small **intestine**) at the **ampulla** of Vater. More than 95% of the cells in the pancreas are in the **exocrine** glands and ducts. A small **percentage** of the cells in the pancreas are **endocrine** cells. These cells are in small clusters called *islets* (or *islets of Langerhans*). The islets make important hormones, such as insulin and **glucagon**, and release them directly into the blood. **Insulin** reduces the amount of sugar in the blood, while **glucagon** increases it.

Benign and precancerous growths in the pancreas

Not all growths in the pancreas are cancer. Some growths are simply benign (not cancer), while others might become cancer over time if left untreated (known as **precancers**). (10) Because people are getting imaging tests such as CT scans more often than in the past (for a number of reasons), these types of pancreatic growths are now being found more often. (10)

Serous cystic neoplasms (SCNs) (also known as *serous cystadenomas*) are tumors that have sacs (cysts) filled with watery fluid. SCNs are almost always benign, and most don’t need to be treated unless they grow large or cause symptoms. **Mucinous cystic neoplasms** (MCNs) (also known as *mucinous cystadenomas*) are slow-growing tumors that have cysts filled with a jelly-like substance called *mucin*. These tumors usually start in the body or tail of the pancreas. While they are not cancer, some of them can progress to cancer over time if not treated. Whether these tumors need to be removed or can just be followed closely over time depends on several factors, such as their size, rate of growth, how they look on imaging tests, and if they are causing symptoms. **Intraductal papillary mucinous neoplasms** (IPMNs) are benign tumors that grow in the **pancreatic** ducts. Like MCNs, these tumors make mucin, and they can sometimes become cancer over time if not treated. (American Cancer Society, 2015).



Calculations:

Total number of polysyllabic words=37

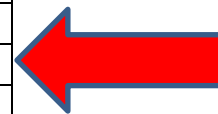
Nearest Perfect Square=36

Square root=6

Constant=3

SMOG Conversion Table SMOG Conversion Table

Total Polysyllabic Word Count	Approximate Grade Level
0-2	4
3-6	5
7-12	6
13-20	7
21-30	8
31-42	9
43-56	10
57-72	11
73-90	12
91-110	13
111-132	14
133-156	15
157-182	16
183-210	17



According to the SMOG calculation, this sample article from the American Cancer

Society is written at a 9th grade level. Education and instructions for patients should **be**

written at or below a 6th grade level to assure most patients will comprehend the information.

Writing at a **lower grade level** is included in ways to improve written communication for patients. In addition, written material including forms should be published in a **larger font**, especially if your patients are older adults. As mentioned before, use **plain language**, simple terms that can be explained easily. See the following list for suggestions to prepare clear language text:

1. Use plain language.
2. Prepare text at or below 6th grade reading level.
3. Use large serif font, at least a 14 – point (Times Roman, 14 point).
4. Incorporate white space in document, your patient shouldn't have to read lines and lines of words.





5. Use pictures or drawings to demonstrate information.
6. Always prepare content in the spoken language of the patient.
7. Consider your patient's culture and social norms when preparing information.
8. Include reputable resources for additional information.
9. Include chunks of material, do not exceed 3 key points.



10. Information should be formatted in short sentences and short paragraphs.
11. Use headings to divide material.
12. Simple charts or bulleted lists are easier to read than lines of texts.

CHAPTER SIX INTERNET

How can we help our patients find information that is accurate and understandable?

In addition to pamphlets and handouts, patients use of the internet for medical information has increased. Studies have shown that a majority of internet searches are for specific medical conditions. As therapists, it is our responsibility to guide our patients to reputable, trusted websites for valid information. The National Institute of Health (NIH) has published recommendations when evaluating health information from the internet.



Content

Is the content serious?

Who is the author?



Is the site connected to an organization?

Accuracy

Is the page edited?

Does the site reference other resources?

Is a bibliography included?

Updated

Is this internet site updated regularly?

When was it created?

Does it offer links to other current webpages?

Fact-Based

Is information factual?

Is it straightforward and without advertising?



What is the purpose of the site? Is it popular, clinical, or scholarly?

(U.S. Department of Health and Human Services, 2014)

CHAPTER SEVEN

What Can We do as an Organization?

The field of health literacy has recognized that providing and supporting health literate information and access to the health system is not just up to the patient, and the clinician but now the organization as a whole. Health organizations must share the responsibility to make healthcare systems less complicated and to find ways to reduce the demand on patients and consumers. The Institute of Medicine (2012) has established 10 attributes of a health literate healthcare organization. These attributes are described as **building blocks in the foundation** of a health literate clinic or hospital.



TEN ATTRIBUTES of a HEALTH LITERATE ORGANIZATION

1. Leadership, or management, must make health literacy a **priority**
2. Conduct **assessments**: How can the organization best meet the needs of those with low health literacy?
3. **Train** the staff in techniques to address health literacy limitations. This includes physicians, clinicians, cafeteria staff, environmental services staff, etc.
4. **Seek input** from patients and consumers. They can identify the barriers.
5. Consider health literacy and practice **universal precautions** with every patient.

6. Practice use of **specific strategies** for verbal and written communication.
7. Design systems to be **accessible** to all patients, including website, e-chart portals, appointments, lab work, test results.
8. **Create all printed and audiovisual material** in easy-to-read style, provide translation as needed.
9. **Address medications and patient self-management**, especially in high-risk
10. **Clearly explain costs and charges** for services including self-pay or costs not covered by health plan.

(Brach et al.,2012)



CHAPTER EIGHT

Is your hospital or clinic accessible to patients?

Are there clear directions to the physical location?

(website, phone directions, google?)



Once the patient arrives, are the directions to the clinic or department clearly posted?

Is the signage in *simple* language?

Is the signage in more than one language?



Is there staff to greet patients if they require assistance?



Resources

Centers for Disease Control and Prevention.
<http://www.cdc.gov/healthmarketing/healthliteracy/>

Centers for Medicare & Medicaid Services.
<http://www.cms.gov/WrittenMaterialsToolkit/>

Consumer Health: Health Literacy. <http://nnlm.gov/outreach/consumer/hlthlit.html>

Food and Drug Administration: Medicines in My Home. :
<http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/UnderstandingOver-the-CounterMedicines/ucm092139.htm>

Health Resources and Services Administration (HRSA): Health Literacy. :
<http://www.hrsa.gov/healthliteracy/>
Health Resources and Services Administration (HRSA): Cultural Competence Resources
for Health Care Providers. <http://www.hrsa.gov/culturalcompetence/>

MedlinePlus: Easy-to-Read.
http://www.nlm.nih.gov/medlineplus/easytoread/easytoread_a.html

MedlinePlus: Health Information in Multiple Languages
<http://www.nlm.nih.gov/medlineplus/languages/languages.html>

MedlinePlus: Health Literacy <http://www.nlm.nih.gov/medlineplus/healthliteracy.html>

National Institutes of Health (NIH): Clear Communication: An NIH Health Literacy
Initiative.
<http://www.nih.gov/clearcommunication/>

Partners in Information Access for the Public Health Workforce. Healthy People 2010.
Goal 11: Health Communication http://phpartners.org/hp/health_comm.html

U.S. Department of Health and Human Services. Scope of the Problem: Health Literacy.
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EXPERIENTIAL EXERCISES

How can YOU integrate Health Literacy into YOUR practice?

Each area of practice will demonstrate different barriers and limitations. Discuss the case studies with co-workers and determine how best to address possible low health literacy.

CASE STUDIES:

- 1. Inpatient Mental Health**
- 2. Inpatient Rehabilitation**
- 3. Inpatient Geriatrics**
- 4. Inpatient Acute**
- 5. Outpatient Hand Clinic**
- 6. Outpatient Neurological Rehabilitation**

Inpatient Mental Health

Patient: 53 year old White male with history of bipolar disorder type 1 and substance abuse with suicidal ideation, mania and psychosis. Currently homeless.

Education/Vocation: Pt completed 12th grade, work history is sporadic, mostly odd jobs

Goals: Provide reality orientation, increase ADL's, concentration for cognitive functioning, social interaction coping skills.

Information/patient education: diagnosis education, coping skills and community resources, crisis hotline and leisure resources, community support groups, vocational resources.

Length of time treated: 3 weeks

Areas impacted by health literacy:

- 1.
- 2.
- 3.
- 4.
- 5.

Inpatient Rehabilitation

Patient: 25 year old, Hispanic male with recent Spinal Cord injury, T 4 ASIA A, lives with wife and 2 young children.

Education/Vocation: pt. reports attended school in Mexico, works in construction

Goals: to increase independence in dressing, grooming, and wheelchair mobility

Information/patient education: diagnosis education ASIA level, bowel/bladder management, pressure relief, pressure sore, skin inspection and integrity, sexuality, leisure activities and peer support.

Length of treatment: 2-3 weeks

Areas impacted by health literacy:

- 1.
- 2.
- 3.
- 4.
- 5.

Inpatient Geriatrics

Patient: 75-year-old Black female, deconditioning, right hip fracture. Patient lives with son and his family

Education/Vocation: pt. reports she reads but not well, worked as cook in private home for 35 years

Goals: to increase dressing and grooming independence, mobility, home safety, family training

Information/patient education: Hip precautions, safety techniques in transfers, prognosis

Length of treatment: 3-4 weeks

Areas impacted by Health Literacy:

1.

2.

3.

4.

5.

Inpatient Acute:

Patient: 35-year-old white male, head trauma patient. Lives with girlfriend

Goals: Increase independence with ADL/mobility and demonstrate good safety awareness during out of bed ADLs.

Education/Vocation: No information on education, patient worked in telephone sales

Information/patient education: verbal education on safety and importance of participating in OT,

diagnosis/surgery, family education

Length of treatment: 2-3 weeks

Areas impacted by health literacy:

1.

2.

3.

4.

5.

Outpatient Hand Clinic

Patient: 32-year-old Hispanic female with flexor tendon repair zone II. Pt lives with her husband and teenage son

Education/Vocation: Pt completed Master's degree, works as office manager

Information /patient education: dorsal blocking splint, Kleinert splint, precautions, expectations, exercises, typical expected progression of hand use and return to work if appropriate, information on adhesions/scarring

Goals: to increase ROM and grip strength for independence with ADLS, IADLS.

Length of treatment: 12 weeks, 1-2 x week.

Areas impacted by health literacy:

- 1.
- 2.
- 3.
- 4.
- 5.

Outpatient Neurological Rehabilitation

50-year-old Black male, suffered stroke 3 months ago, R hemiplegia. Patient lives with wife.

Education/Vocation: patient completed high school, not currently working secondary to reported injury to his back 3 years ago

Information/ patient education: monitoring blood pressure, signs of a stroke, stroke prevention, diet, home exercise program, safety with ADLs/transfers

Goals: Independence with ADLs/IADLs, Increase AROM and upper extremity strength in hemiplegic, acquire appropriate equipment to increase independence and safety with ADLs

Length of time: 6-8 months

Areas impacted by health literacy:

1.

2.

3.

4.

5.

Case Studies:

Suggested Answers:

❖ Inpatient Mental Health

Areas impacted by health literacy:

1. written, verbal information,
2. reading level,
3. find virtual environment (website, app) that will provide accurate information,
4. comprehension of medicines and correct schedule of taking them.
5. access to community resources including support groups

❖ Inpatient Rehabilitation

Areas impacted by health literacy:

1. access to community resources
2. easy-to-read information about spinal cord injury
3. All information in Spanish language
4. importance of following skin pressure precautions
5. follow-up with PCP and/or outpatient rehabilitation

❖ Inpatient Geriatrics

Areas impacted by health literacy:

1. all written material in larger font
2. simple language, including important hip precautions
3. transfer technique teach-back
4. medicine (pill) recognition, dosage

5. follow up instructions for outpatient therapy

❖ Inpatient Acute Care

Areas impacted by health literacy:

1. verbal communication strategies
2. teach-back technique
3. family education in simple terms
4. avoid medical jargon to explain injury and prognosis
5. follow up with outpatient clinic at QM.
6. check access information, including clear directions to QM
7. paper or virtual calendar to keep appointments straight.

❖ Outpatient Hand Clinic

Areas impacted by health literacy:

1. drawing or picture of tendons and repair site
2. simple language, no medical jargon
3. instruct in A/PROM, use teach-back technique

❖ Outpatient Neurological Rehabilitation

Areas impacted by health literacy:

1. verbal communication in simple language

2. ADL teach back, IADLS teach back
3. physical and social environment safety
4. family education

Practice Area	Common Diagnosis	Health Literacy	Occupational therapy Practice Framework	Written Communication	Verbal Communication
Inpatient Rehabilitation	Spinal Cord Injury		Environment Demands Physical, social, virtual	Simple language, pictures to describe injury	Community re-entry
Inpatient Acute	Head trauma		Analyze activities	Explanation of diagnosis to family, caregiver	Pt may require directions repeated, simple language, pictures to describe information
Inpatient Geriatric	Hip fracture		Health and wellness	Larger font, short sentences Nutrition, management of medicine	Speak slowly, directly to patient, pictures, drawings, teach back
Inpatient psychiatric	Schizophrenia		Environment Demands Physical	Explanation of diagnosis, important	With respect, calmly, repeat important points Family education

			Social virtual	points only	
Outpatient Neurology	Stroke		Analyze tasks For adaptation	May require picture, or drawing rather than text or numbers	Use simple, clear language
Outpatient Hand Clinic	Flexor Tendon repair		Physical,social environmental demands	HEP, splint wear, pictures	Clarify and Repeat any precautions

APPENDIX G

IRB Approval Letters



Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
m.jackson3@twu.edu
<http://www.twu.edu/irb.html>

DATE: December 1, 2014

TO: Ms. Florence Kay Brown
Occupational Therapy - Houston

FROM: Institutional Review Board - Houston

Re: *Approval for Integrating Health Literacy into Occupational Therapy (Protocol #: 17809)*

The above referenced study has been reviewed and approved by the Houston Institutional Review Board (IRB) on 11/24/2014 using an expedited review procedure. This approval is valid for one year and expires on 11/24/2015. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc: Dr. Patricia Bowyer, Occupational Therapy - Houston
Gayle Hersch, OT, PhD, Occupational Therapy - Houston
Graduate School



Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
mjackson3@twu.edu
<http://www.twu.edu/irb.html>

DATE: February 5, 2015

TO: Ms. Florence Kay Brown
Occupational Therapy - Houston

FROM: Institutional Review Board - Houston

Re: *Notification of Approval for Modification for Integrating Health Literacy into Occupational Therapy (Protocol #: 17809)*

The following modification(s) have been approved by the IRB:

Modification includes the addition of Harris Health System Injury disclaimer statement to consent forms: Modified Consent Form Study 1, English and Spanish; Modified Consent Form Study 2, English.

cc. Dr. Gayle Hersch, Occupational Therapy - Houston



Institutional Review Board
Office of Research
6700 Fennin, Houston, TX 77030
713-794-2480
irb-houston@twu.edu
<http://www.twu.edu/irb.html>

DATE: October 12, 2015

TO: Ms. Florence Kay Brown
Occupational Therapy - Houston

FROM: Institutional Review Board - Houston

Re: *Extension for Integrating Health Literacy into Occupational Therapy (Protocol #: 17809)*

The request for an extension of your IRB approval for the above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

This extension is valid one year from November 24, 2015. Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Patricia Bowyer, Occupational Therapy - Houston
Dr. Gayle Hersch, Occupational Therapy - Houston
Graduate School