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Reading & Writing Health: Nurses' Experience Of Patients' Health Literacy

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READING & WRITING HEALTH:
NURSES' EXPERIENCE OF PATIENTS' HEALTH LITERACY

by

Susan A Herrgott

A Master's Thesis Presented in Partial Fulfillment

Of the Requirements for the Degree

Master of Science, Health Service Administration

Regis University

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HSA696 MASTER'S THESIS

I have **READ AND ACCEPTED**

the Master's Thesis by:

Susan Herrgott

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requirements for the

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Abstract

The ability to read, understand, and act appropriately on healthcare information directly affects an individual's ability to access services and successfully communicate with healthcare providers. This ability is called health literacy and it includes the skills patients need to communicate with providers, read medical information, adhere to treatments, and decide when and how to seek medical care. Most of the research around health literacy has focused on patients' experiences. In order to fully understand the problem, though, the experience of providers needs to be understood, too. The purpose of this study was to gain insight into nurses' experience of patient health literacy. Nurses tend to have frequent interaction with patients and may be better equipped to assess the health literacy skills and needs of patients than other providers who have limited contact. This was a qualitative study designed to understand nurses' definition, assessment, and influence on patient's health literacy. The ten interviews with clinical care nurses resulted in eight themes related to their perception of health literacy and patient education. Nurses assess levels of health literacy on mental, emotional, and physical levels, mainly through one-on-one assessments, including observation, listening, and the written information provided at intake. The barriers to improving health literacy include patients' shame around not being able to read, their emotional state, lack of motivation or interest in health, limited financial and educational resources, and being overwhelmed by the complexity of integrating knowledge with behavior change. Nurses' perceive family members, cultural, and personal values as stronger influences on patient's health literacy than accurate health education, even when materials are provided at appropriate reading levels, language, and from a reliable medical source. Finally, education is individualized and standardized, depending on the skill, interest and experience of the provider. Ultimately, nurses' believe it the responsibility of the individual to experience greater levels of health literacy, contingent not just on education level, age, literacy and language, but more importantly by each individual's motivation and interest in health.

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Chapter 1 - Introduction

Healthcare costs are rising and the quality of health outcomes is decreasing due to poor health literacy. The ability to read, understand, and act appropriately on healthcare information directly affects an individual's ability to access services and successfully communicate with healthcare providers (Institute of Medicine, 2008). This ability is called health literacy and it includes the skills patients need to communicate with providers, read medical information, adhere to treatments, and decide when and how to seek medical care. Below proficient levels of health literacy has been shown to affect nearly 50% of the population and account for \$106 billion to \$238 billion annually in healthcare expenditures (Low Literacy, 2008). The Institute of Medicine defines health literacy as the degree to which individuals obtain, process, and understand basic health information and services needed to make appropriate health decisions (IOM, 2008). It is a rather broad term for a multidimensional problem that stems from a lack of education, communication breakdowns, educational materials inappropriately written, and medical terminology that is too difficult for patients to understand (Monanchos, 2007). These factors place a disconnect between the approximately 44 million people, or 23% of adults, in the United States who have below basic health literacy and an additional 53.5 million people, or 28% of adults, with only marginally better skills, and the healthcare system (NAAL, 2003).

With nearly 50% of all adults potentially having problems understanding prescriptions, appointment slips, informed consent documents, insurance forms, and health education materials, the consequences of patient health literacy are far reaching. The problem of low health literacy has negative impacts on healthcare outcomes, quality, and costs previously not recognized by providers and administrators. Low health literacy is associated with increased hospitalization rates, less frequent screenings for diseases such as cancer, and disproportionately higher rates of

disease and mortality (NAAL, 2003). It has also been correlated to higher usage of emergency rooms for primary care issues, and more complications due to insufficient adherence to self-care protocols or instructions (NAAL, 2003). The cost of emergency room care is often publically funded and a disproportionate share of patients on public assistance have poor health literacy, meaning that the financial consequences extend beyond the individual and healthcare provider. The results of a 2005 study of Medicare patients in a managed care program revealed that patients with low health literacy used an inefficient mix of services, with more reliance on emergency care and less use of appropriate preventive services (Monachos, 2007). The cycle created by low health literacy leads to rising health care costs for every consumer, negative health outcomes, and an inefficient healthcare system for both patients and providers.

The healthcare profession is responsible for providing patients with the education they need and in ways they can understand to maintain health and manage their health conditions. Healthcare providers have the potential ability to improve patients' comprehension of health information through direct communication and education that is appropriate to the individual health literacy needs of their patients (Mika, Wood, Weiss, & Treviño, 2007). The experts in health literacy research suggest that how providers perceive and address the problem of poor health literacy can influence the ability of patients to maintain and promote their health (IOM, 2008). The purpose of this study is to gain insight into nurses' perceptions and experience with health literacy. The research questions are: 1) how do nurses' define health literacy? And 2) what is their experience with health literacy in their daily work environment? Nurses tend to have more interaction with patients, including giving them instructions about their condition, and may be better equipped to assess the health literacy skills and needs of patients than other providers who have limited contact (Schwartzberg et al., 2007).

Health literacy represents a range of literacy activities that are important in day to day functioning. The spectrum of information ranges from reading an article in a doctor's office about preventive health practices, to filling a prescription and following correct dosage instructions; or electing an alternative treatment, such as an herb or vitamin, based on personal views that may or may not be shared by the provider. It includes the responsibility for parents to manage their children's healthcare, including getting them immunized, taking them for physicals, and having their illnesses treated. Employers and employees are making decisions about health insurance plans and how to determine which are best suited for their healthcare needs, which requires a certain level of knowledge about health. Adult children are often faced with the responsibility of managing their parents' health care, selecting providers, authorizing treatments, and/or choosing a long-term care facility. Older adults must make decisions about Medicare supplementary insurance and prescription drug benefits. Adults without medical insurance may need to determine whether they, their children, or their parents qualify for any public programs. All these activities require, or are facilitated by, the ability to read and understand written and printed information (2003 Health Literacy Assessment).

The inability to read is not something that patients will generally openly admit, and this should be of concern in healthcare where the paperwork can be extensive, jargon confusing, and environment non-conducive to communication. This means the educational materials provided about a medical condition are frequently ineffective. The written consent forms that a patient is required to sign prior to admission or before surgery might not be understood, particularly in a busy healthcare environment where providers and/or staff do not offer a complete explanation. Health concepts that are taught in schools might not be providing children and adolescents with the knowledge they will need to manage their future healthcare needs. Health literacy is an area

of attention for people of all ages and abilities. The minimal research that has been done on communication improvements between healthcare providers and patients has focused on written materials, although patients prefer to receive information verbally from their healthcare provider (Andrulis & Brach, 2007). Additionally, although written materials are a legitimate source of health information for patients, they may be inappropriate for patients with inadequate health literacy, as patients with low health literacy rely primarily on verbal instructions from their healthcare provider (Schwartzberg et al, 2007).

The problem of low health literacy is important for providers and healthcare administrators. Research has clearly shown how low levels of patient health literacy negatively impact patient outcomes, financial systems and the cost of care. In recruiting new staff, the communication skills demonstrated by potential candidates will likely influence how patient's health literacy is perceived and addressed. This impacts employee training, the areas to cover and the cultural importance an organization gives to health literacy and patient education. Administrators determine what resources will be available to staff for assessing and addressing health literacy levels, and in this way directly impact it. The Joint Commission has incorporated health literacy into accreditation standards and Healthy People recommendations. In creating education materials and self-care treatment plans, it is important for an organization to understand the health literacy needs of the patients. The ability of patients to navigate and access the healthcare system is highly relevant to administrators. This includes knowing who to contact regarding health concerns, how to obtain services, and knowing the resources that are available. Improving access through facilitating communication and making room for confusion to be voiced is a responsible goal of healthcare providers, staff, and organizations.

Studies have shown that although low health literacy is more prevalent in disadvantaged populations, people of all ages, races and varying educational and income levels are affected (Quality Matters, 2006). The problems associated with low health literacy are greater for people from non-Western cultures whose cultural beliefs about disease or treatment differ from their physicians' - as well as people with limited English proficiency (Quality Matters, 2006). It is commonly estimated that 90 million Americans are at risk (Black, 2008). Nurses' perceptions are under inquiry in this study because of the frequency of interaction with patients, including giving them instructions about their condition, and may be better equipped to assess the health literacy skills and needs of patients than other providers who have limited contact. Yet little is known about their experience with it in their healthcare environments. It would be valuable for those within the healthcare profession to start considering how patient comprehension of medical care factors into the care plans they create. This includes evaluating how nurses and other medical professionals assess health literacy, and where the organization prioritizes it in determining quality of care.

Chapter 2: Literature Review

Introduction

Healthcare providers have the potential to improve patients' comprehension of health information through direct communication and education that is appropriate to the individual health literacy needs of their patients (Mika, Wood, Weiss, & Treviño, 2007). The experts in

health literacy research suggest that how providers perceive and address health literacy can influence patients' skills and knowledge for maintaining and promoting their own health (IOM, 2008). The purpose of this study is to gain insight into nurses' perceptions of health literacy. The research questions are: 1) how do nurses' define health literacy? And 2) what is their experience with health literacy in their daily work experience?

In 2004, the Institute of Medicine released a report entitled, *A Prescription to End Confusion*, which was the first comprehensive report on health literacy in the United States (IOM, 2004). This ground-breaking report raised awareness of a problem previously not recognized. The report brought attention to the wide-spread prevalence of inadequate health literacy among the adult population in this country and lead to intensive research into the characteristics of individuals and the healthcare system that cause many to have poor health literacy (Paasche-Orlow & Wolf, 2007). The Institute of Medicine reported that nearly 90 million adults do not have adequate health literacy skills (IOM, 2004). The definition of health literacy was described 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"" (IOM, 2004, p 19). This includes basic language and literacy skills, but encompasses skills beyond reading comprehension of health information (IOM, 2004). According to the Institute of Medicine, "Health literacy encompasses the educational, social and cultural factors that influence the expectations and preferences of the individual and the extent to which those providing healthcare services can meet those expectations and preferences"" (IOM, 2004, p 23). All these aspects have been studied in health literacy research since the Institute's report.

The Institute of Medicine estimates that more than 50% of the adult population has poor or inadequate health literacy skills, which is due to factors both within the healthcare system and with individuals' literacy abilities as they interact with it (IOM, 2004). The report evidenced the high prevalence of inadequate health literacy within the adult population, and the increased likelihood that patients who are older have poorer health literacy and experience adverse health (IOM, 2004). It also reported that individuals of all educational attainment, ethnicity, race, gender, income, and health status may not be adequately health literate, and therefore healthcare professionals cannot marginalize the problem to a certain population (IOM, 2004). As individuals interact with various aspects of the healthcare system and as their own health changes, the level of health literacy can vary substantially (Baker, 2006).

A Prescription to End Confusion arose from decades of research, mostly in the fields of health education and health communication (Speros, 2005). It came following the release of the 2003 National Adult Assessment of Adult Literacy (NAAL) reported by the National Center for Education Statistics. Analyses of the report found that functionally illiterate adults have more health problems, fewer years of education, and were more likely to live in poverty (IOM, 2004). The NAAL is conducted by the US Department of Education and it is considered the most accurate portrait of literacy in America (Miller, 2007). The survey includes an in-depth evaluation of literacy skills of a representative sample of 19,000 Americans (NCES, 2005). This was the first time the literacy assessment included a health component.

Analysis of the NAAL survey found that 40- 50% of the adult population had only a basic or below level of literacy, meaning these individuals have difficulty reading and interpreting documents and text, including those encountered in the healthcare setting (NCES,

2005). This was a slight increase in prevalence of low literacy from the 2002 survey, which had reported approximately one fourth of Americans did not have the ability to “Read, write, speak in English and compute and solve problems at levels deemed proficient for functioning on the job and in society” (Kirsch I, et al., 2002; NCES, 2002). The inclusion of more diverse assessment questions, such as those related to health literacy, might have been associated with the decline. Persons with inadequate literacy skills included individuals of all races and socioeconomic classes (IOM, 2004).

The present requirements of the Joint Commission and other national accrediting agencies have made the problem of health literacy an issue for healthcare providers and organizations to be actively addressing. The release of a ‘white paper’ by the Joint Commission in 2007 titled, “What Did the Doctor Say?” illustrates this point. According to the Joint Commission, it is now required that “Education must be provided that is specific to the patient’s assessed needs, abilities and barriers to learning, learning preferences, and readiness to learn (JACHO, 2007, p 5). The paper outlines specific ways for healthcare leaders to make effective communication an organizational priority for patient safety, strategies to address patients’ communication needs across the continuum of care, and policy initiatives that would improve provider-patient communication solutions (JACHO, 2007).

The American Hospital Association has included within the Patient’s Bill of Rights that patients are encouraged to request information about diagnosis, treatment and prognosis from physicians and other providers that is relevant, current and understandable (AHA Patients’ Bill of Rights, 1992). The Academy of Medical Surgical Nurses (AMSN) adopted the Joint Commission’s position. AMSN believes it is imperative that nurses acquire and maintain a

competent knowledge of patient education and be responsible for ensuring patients receive education they can understand (AMSA, 2009). AMSN recognizes that limited patient literacy is a barrier to effective treatment and proposes that nurses have an obligation to their patients to ensure their reading ability has been assessed and that patient education is based on this assessment (AMSA, 2009). The Academy of Medical Surgical Nursing is a professional nursing organization committed to promoting the highest standards of nursing practice, health promotion, and prevention of illness in adults (AMSA, 2009). This organization's core values include commitment, opportunity, responsibility and education, which demonstrate the nursing field's awareness of the scope and responsibility clinical nurses have for educating their patients.

Health Literacy Research Studies

Few references can be found in the literature about the concept of health literacy until 1992. Carolyn Speros conducted a concept analysis of the term 'health literacy' that was published in 2005 and based on a review of the literature of the past decade, including research studies, and citations from the fields of nursing, medicine, public health, and social science (Speros, 2005). The concept of health literacy originated in the last decade of the 20th century, and initially focused on patients' reading ability and the health education materials provided to them (Speros, 2005). Much of the pioneering work around health literacy began in the 1970's and 1980's, arising from the fields of health education and health communication (IOM, 2004). The definition of health literacy was narrow at that point, more closely resembling literacy (Speros, 2005). The assessments were then limited to the skills of reading and writing, as opposed to the various health literacy factors that emerged in the latter part of the 1990's, including numeracy, listening, speaking, and cultural and conceptual knowledge specifically

(IOM, 2004). The defining attributes of health literacy that consistently appear in the literature include reading and numeracy skills, comprehension, the capacity to use information in healthcare decision-making, and successful functioning in the role of healthcare consumer (Speros, 2005). Healthcare providers' understanding of the term 'health literacy' as being different from 'literacy' has not been measured.

A systematic review of the literature published between 1980 and 2003 found low literacy was associated with poorer healthcare outcomes, such as minimal knowledge about health conditions or maintenance, intermediate disease markers, and measures of morbidity, general health status, and use of health resources (DeWalt, Berkman, Sheridan, Lohr & Pignone, 2004). The prevalence of limited health literacy was consistently associated with less education, ethnicity, and older age during an additional systematic review of the literature for the period 1963 through 2004 (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2004). The overall purpose of the volumes of research studies has been to provide healthcare professionals with identifiable characteristics that signify a patient has low health literacy (Paasche-Orlow & Wolf, 2008). The greater prevalence of poor health literacy among patients with these particular qualities is encouraging, although additional research demonstrated the limitations of relying on these factors as a consistent measure of what a patient actually understands and how they ultimately act.

The Prevalence of Low Health Literacy Studies

Patients tend to not admit or acknowledge their difficulties obtaining, understanding and utilizing health information, and some initial surveys of patients with low literacy found that they tend to conceal or hide it, even from friends and spouses (Baker, Williams, Parker & Pitkin,

1996). If they are not open to admitting their confusion or ignorance, health literacy researchers sought to identify patient characteristics or qualities that signify inadequate comprehension to providers, rather than rely on self-report. Differences in health literacy levels due to race and education were widely hypothesized as a contributing factor to health disparities (Speros, 2005). Seeking to support or discredit this assumption, a study was conducted to examine the extent to which low health literacy exacerbates differences between racial and socioeconomic groups in terms of health status and receipt of healthcare (Howard, Sentall & Gazmararian, 2006). This study did not result in significant findings about a relationship between race or income and health literacy (Howard et al., 2006). It was determined that low health literacy was more prevalent among elderly patients, regardless of educational attainment, limited English proficiency, and lower socio-economic status (Howell et al., 2006). As these demographic variables of income, education, race and ethnicity were measured against health literacy the association of age with limited health literacy was a consistent factor.

The recent research identifies health literacy as “functional health literacy”. This term provides a more accurate definition of the scope of skills involved for patients to “communicate with providers, read medical information, adhere to treatments, and decide when and how to seek medical care” according to health literacy experts (IOM, 2008). Studies found that it is consistently markedly lower among older age groups in the literature to date, and a team of researchers investigated the possible causes for this disparity (Baker, Gazmararian, Sudano & Patterson, 2000). One study hypothesized that there could be several specific health and behavioral domains that explain why older cohorts have worse literacy levels than younger populations, despite education, income, and ethnicity (Baker et al., 2000). The sample included

2,774 community-dwelling, Medicare-enrolled elderly persons who were previously studied participants (Baker et al., 2000).

The specific health and behavioral domains that could impair health literacy included one or several of the following: a higher prevalence of dementia or cognitive impairment among older adults, a higher prevalence of chronic conditions that may worsen cognitive functioning, worse health, worse mental health, visual acuity impairment, and/or less reading behaviors (Baker et al., 2000). Through the use of the S-TOFHLA and demographic and lifestyle questioning of the elderly sample, interviews were conducted to gather specific medical information about the patients and health literacy level (Baker et al., 2000). Each assumption was tested and analyzed for explanations for decreased health literacy among elderly adults, but despite a correlation with cognitive impairment, the only characteristic consistently associated with inadequate health literacy was older age (Baker et al., 2000).

This correlation of poor health literacy with older age is important for healthcare providers to realize due to the greater prevalence of medical conditions among the elderly population, which is rapidly growing (Howard et al., 2006; Baker et al., 2000). The American population is living longer and chronic conditions, such as diabetes and cardiovascular disease, affect more and more Americans each day (IOM, 2008). These conditions require a high degree of self-monitoring by patients, including changes in physical condition and comprehension of prescriptions, medical terminology, and adherence to follow up care (Cavanaugh, Huizinga, Wallston, Gebretsadik, Shintani & Davis, 2008). Diabetes self-management requires patients to interpret glucose meter results and nutrition labels, calculate carbohydrate intake, titrate oral medications, adjust and administer insulin, and perform many other numeracy-related activities

(Cavanaugh, 2008). This can be a considerable amount of self-health monitoring for those with adequate and inadequate health literacy, and requires proficiency with understanding the meaning of numbers and computation, or numeracy.

A study was conducted to explore the association between numeracy skills related to diabetes management and perceived self-efficacy, self-management activities, and clinical measures in patients with type I and II diabetes (Cavanaugh et al., 2008). The sample included 398 adults with type I or type II diabetes, and patients with lower diabetes-related numeracy were more likely to be older and non-white, have a lower annual income, have fewer years of education, and have type 2 as opposed to type 1 diabetes (Cavanaugh et al., 2008). This study also demonstrated that low diabetes-related numeracy skills are common in patients with diabetes and are associated with lower diabetes knowledge and perceived self-efficacy (Cavanaugh et al., 2008). The researchers also found that for patients who use insulin, low diabetes-related numeracy was associated with less participation in self-management behaviors (Cavanaugh et al., 2008). They suggested that without recognition and intervention of diabetic patients' numeracy-deficiencies by healthcare providers, successful outcomes are less likely and the risk of non-adherence is high (Cavanaugh et al., 2008)

Cardiovascular disease, HIV, and asthma are also conditions prevalent within the American populations that, like diabetes, require patients' active management for proper control and monitoring. This requires sufficient health literacy and understanding of how and when to respond to the symptoms of their condition, and adherence to treatment follow-ups (Mancuso & Rincon, 2006). Health literacy studies have been conducted with patients who have chronic medical conditions, including adults and children with asthma, cardiovascular disease, and HIV.

These studies have demonstrated that patients with chronic conditions often do not have adequate health literacy specifically defined by knowledge of their condition, how to take medications properly, and self-reports of poorer health status (Mancuso & Rincon, 2006; Black, 2008; Dewalt, 2004; Kalichman, Benotsch, Suarez, Catz, Miller & Rompa, 2000). Based on these findings, it could be suggested that the health literacy skills of those most in need of it - such as patients with chronic diseases - could be substantially lower than what is required to safely and efficiently manage their health.

The Associations of Health Literacy to Health Status, Knowledge & Behavior

Consistent associations have been made between health literacy and health behaviors including individuals' use of preventive health services. The relationship between adult functional health literacy and use of preventive health practices, as specifically defined by pap smear, dental check up, mammogram, vision check up, flu shot or osteoporosis screening, colon cancer screening, prostate cancer screening was performed by a research team (White, Chen & Atchison, 2008). Using the results from the 2003 NAAL, the statistics were broken down and categorized according to preventive practice and healthcare utilization (White et al., 2008). The objective for the study arose from the body of literature recognizing a relationship between health literacy and various health-related outcomes, such as health status, use of healthcare services, and knowledge of chronic diseases (White et al., 2008). The study is one of the first to attempt to find a relationship between inadequate health literacy and decreased health status.

After controlling for age, gender, race/ethnicity, self-reported health status, poverty level, insurance coverage, and oral reading fluency, the study revealed that the relationship between health literacy and self-reported preventive health practices varied substantially by age group

(White et al., 2008). Being the first study to include a sample of younger adults (ages 16-39), the analysis determined that among the entire sample, low literacy was associated with a decreased likelihood of using most preventive health measures only for adults 65 years and older (White et al., 2008). Older adults experience greater illness and multiple medical conditions. Preventive health is likely not the area of healthcare service they would seek, and given the higher prevalence among the elderly of both disease and poor health literacy, this study may have not used the right measure of healthcare utilization as a correlate of outcomes. The assumption that low health literacy among any age groups would be associated with not having access to healthcare provided an interesting outcome of this study, as access was not a factor. Instead, the literature finds that higher demands put on patients by the healthcare system, such as medication management, might be a stronger area to focus efforts on health literacy research and quality outcomes.

The research conducted by Makaryus and Friedman about patients' knowledge of discharge instructions revealed that medications are a particular area of poor comprehension and pose potential risk of medication errors for patients (Makaryus & Friedman, 2005). Functional health literacy and understanding of medications at discharge was studied by researchers through the Mayo Clinic, who sought to understand the relationship between patients' degree of knowledge about recently prescribed medications and factors such as patient age and education level (Makaryus & Friedman, 2005). Based on previous studies about patients' understanding of medications that found it to be inadequate, the objective here was to quantify the level of understanding after discharge and the factors that influence it (Makaryus et al., 2005; Maniaci, 2008). For patients who were newly prescribed a medication and discharged from the community hospital, a telephone survey was administered to 100 eligible participants and found

that among the sample, functional health literacy regarding prescribed medications was “substantially poor” (Maniaci, 2008).

Almost 15% of patients were unaware that they were given a new prescription and only half could identify specific information about medications such as dosage, dosing schedules and purpose, despite having access to the prescription labels during the telephone interview (Maniaci, 2008). This lack of understanding indicates that how patients’ received or comprehended discharge instructions was not sufficient to meet their health literacy needs. The researchers did not include notifying the discharge nurse about the study and follow-up survey that was to be conducted with their patients, nor did it measure the importance patient comprehension of medication was in discharge education.

Poor comprehension of prescribed medications was associated with poor adherence to drug regimes and the potential for adverse medication-related events, as reported by multiple studies in ambulatory care (Gandhi, Weingart & Borus, 2003; Gurwitz, Field & Harrold, 2003). One specific study focused on medication reconciliation with patients who were prescribed anti-hypertensive medications (Persell, Osborn, Richard, Skirpkaukas & Wolf, 2007). Limited-literacy patients were less likely to be able to identify their medications, possessed lower medication-related knowledge, and were more likely to misinterpret prescription warning labels (Persell et al., 2007). The method of reconciliation included a comparison between the patients’ medical record and self-report via interviews, and the researchers’ concluded that limited health literacy was associated with a greater number of un-reconciled medications (Persel et al., 2007). This study is significant for healthcare providers due to the risk of adverse drug effects (Persel et al., 2007).

Health Literacy Measurement Tools

Different assessment tools have been developed and tested over the years to measure patient health literacy. Most of these were designed primarily for aiding research and not for use in clinical settings (Paasche-Orlow et al, 2008). However, the two most commonly used health literacy assessment tools are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in adults (TOFHLA) (Osborn et al., 2007). The REALM is a word-recognition test, comprised of 66 health-related words that are arranged in order of increasing difficulty (Davis, Long & Jackson, 1993). The REALM can be administered quickly, in approximately 2 minutes, with confirmed reliability and validity (Osborn et al., 2007). This makes it a convenient tool, although it only measures reading ability and not comprehension (Osborn et al., 2007). The TOFHLA was developed in 1993 by Davis, Long, and Jackson, and the shorter version, the S-TOFHLA, was developed in 1998, as a health literacy assessment that does measure comprehension skills in addition to reading and verbal ability, with a high degree of reliability and validity (Davis et al., 2006). The shortened version takes approximately 8 minutes to administer and uses actual materials that a patient might encounter in a healthcare setting, including instructions for the preparation of a diagnostic test, interpretation of prescription labels and appointment slips (Osborn, et al., 2007).

The Newest Vital Sign (NVS) is a more recent tool developed to measure adult health literacy and is currently being used in research studies. The test is a “Nutrition Facts” label taken from a pint of ice cream (Osborn et al., 2007). Viewing a full-page copy, patients are asked 6 questions about how the information would be interpreted and acted upon (Weiss et al., 2005). The NVS assesses more complex cognitive functions associated with reading comprehension and

basic problem solving than the REALM (Weiss et al., 2005). This represents the evolution of how patient health literacy is defined and the places it is useful, therefore leading toward a measurement tool that allows researchers to sufficiently gauge health literacy skills (Weiss et al., 2005).

Assessment Tools for the Clinical Setting

The development of simpler assessment tests of functional health literacy has been done with the notion they could be used as clinical screening tools (Paasche-Orlow & Wolf, 2007). The hypothesis that 3 simple questions could be reliable measures of health literacy was researched by Chew, Bradley, and Boyko with the application being utilized by healthcare providers, as opposed to researchers (Chew et al., 2004). The goal was to identify clinically useful questions that physicians and nurses might use to detect inadequate or marginal health literacy among their adult patient populations (Chew et al., 2004). The content of these questions measured five domains that were identified through a previous study as related to health literacy (Chew et al., 2004). These include: navigating the healthcare system, completing medical forms, following medication instructions, interacting with providers, and reading appointment slips (Chew et al., 2004). With previous research suggesting patients' shame could inhibit them from admitting literacy difficulties, this team used methods to screen for stigmatized behavior, such stating the questions as, "How often do you have a problem with" and "How confident are you doing" rather than asking "if" they had a problem with reading or comprehension of health information and instructions (Chew et al., 2004). Based off the results, analysis did find the use of one question – "How confident are you filling out medical forms by yourself?" was predictive of poor, although not marginal, health literacy (Chew et al, 2004).

Usefulness of Assessment in Clinical Practice

There is disagreement among health literacy experts about incorporating health literacy screening into the patient assessment process in clinical settings. The rationale for assessment is based on the premise that individuals with limited literacy have different communication and learning needs, to which providers would uniquely tailor education strategies to meet those individual needs (Paasche-Orlow & Wolf, 2008). This is the approach used in education settings after measuring literacy levels of students, but healthcare settings do not have similar specialized educational strategies established to meet individual health literacy learning needs (Paasche-Orlow & Wolf, 2008). Those that oppose clinical health literacy assessment suggest that it would not be effective because despite the presence of brief literacy screening tools, no program for screening or identifying low literacy patients have shown to be effective (Paasche-Orlow & Wolf, 2007). Because of the shame and embarrassment patients experience, they often use their well-developed coping skills to mask their limited literacy (Cornett, 2009).

The study conducted by Seligman, Wang, and Palacios is the only one that examines the efficacy of health literacy screening and whether or not it improves physicians' care management strategies with patients (Seligman et al, 2005). In this study, the health literacy of a sample of diabetic patients scheduled to see their physician was measured prior to seeing the physician, where one group of clinic physicians were notified if the literacy was inadequate, and one group was not notified (Seligman et al, 2005). The physicians in this study who received notification reported less satisfaction with the visit than non-alerted physicians and no benefit was exhibited for patients, such as use of education-enhancement tools or longer length of appointment (Seligman et al, 2005).

The physicians did not receive specific training or additional educational and disease management tools for individuals with limited literacy (Seligman et al, 2007). The effects of such training cannot be known, as far as how it improves physician-patient encounters. Additionally, this study did not measure patients' shame or potentially feeling stigmatized about health literacy labels, and there is currently no health literacy assessment tool that includes these variables (Paasche-Orlow & Wolf, 2008). The use of clinical screening has been noted to hold potential harm to patients in the form of shame and alienation, as previous research found nearly half of individuals with limited literacy report feelings of shame and hiding the fact from others (Wolf et al, 2007). Without providers' awareness of both the shame related to inadequate health literacy and education in the tools to improve it, health literacy identification alone does not seem beneficial to patients or providers.

Shame as a Barrier to Admitting Inadequate Health Literacy

While patients prefer to receive medical instruction from their physicians, according to the literature there are additional barriers to patients obtaining the information they need in the form they can understand and utilize. Research has shown that patients are not open to admitting to their providers the problems they experience, meaning that shame or embarrassment is a suspected barrier to health literate patients (IOM, 2004). The first study of shame and limited literacy skills was conducted by Wolf, Williams and Parker. In an effort to investigate how shame related to inadequate literacy within the healthcare context, this team measured patients' willingness to have their reading ability documented in their medical records and the degree of shame and embarrassment associated with such disclosure (Wolf et al., 2007). Patients' literacy was measured using the REALM and the degree of shame/embarrassment about literacy skills

was reported through a questionnaire (Wolf et al., 2007). Fifty-one percent (51%) of the patients had low literacy and 48% of which reported shame or embarrassment about their reading ability, and of the 27.9% with marginal literacy levels, 19.2% admitted to experiencing those feelings (Wolf et al., 2007). Despite those feelings more than 90% of these patients reported that it would be helpful for the doctor or nurse to know they had difficulty understanding medical words (Wolf et al., 2007). This suggests that patients may believe healthcare providers are capable of meeting their education needs, or that they suspect their poor health literacy is negatively impacting their healthcare.

Participants in this study who had low literacy skills were more likely to be older, male, African American, and less educated (Wolf et al., 2007). Limited literacy was associated with self-reported problems in taking medications, the need for help with health-related tasks, and difficulty in understanding and following instructions on appointment slips (Wolf et al., 2007). Nearly half of these participants admitted having felt some degree of shame and embarrassment about their abilities (Wolf et al., 2007). The authors support the research by stating that shame is a powerful negative emotion that creates internal conflict and has the potential to inhibit honest interpersonal interactions within the healthcare context (Wolf et al., 2007; Martin, 1993). The researchers suggest that although more than 90% of patients reported it would be helpful for doctors and nurses to know about their reading difficulties, the high degree of shame associated with it means that recording this information may cause potentially negative effects instead of positive (Wolf et al., 2007). Previous studies found that negative feelings such as shame may be externalized to the healthcare provider, prompting counterproductive actions such as noncompliance and malpractice suits (Wolf et al., 2007; Gilbert, Pehl, & Allan, 1994). Shame was associated with submissive behavior, such as avoiding medical care or not filling

prescriptions, which could be due to a lack of understanding of medical issues or not able to read prescription instructions or appointment slips (Gilbert et al., 1994). Within the literature, patients' feelings of shame about limited health literacy are consistent, and this makes inclusion of health literacy assessment as a clinical strategy more of a challenge.

Communicating Health Information

Based on the literacy definition, initial research studies focused on the educational materials provided to patients' with poor reading and English literacy skills (Speros, 2005). Written materials are educational brochures and pamphlets. The documentation is often written at the senior high school level or higher (Paasche-Orlow, Jacob, & Powell, 2006). As research has been published about health literacy and awareness of the difficulty many Americans have in reading at that level, healthcare providers have been encouraged to standardize the educational materials to be readable for individuals with fifth-grade literacy abilities (IOM, 2008). Written materials in the domain of healthcare also include prescription labels, discharge plans, explanation of benefits and services, documents that outline patients' privacy rights and informed consent, and advanced directives. There has been slower progress to lower the reading level required to comprehend these materials.

Although not a direct form of education, the healthcare environment communicates with patients in the form of health insurance applications, benefits summaries, and directions within a medical facility that require skills related to health literacy (Makaryus et al., 2005; Maniaci et al., 2008). These documents and instructions encourage or inhibit the ability of individuals to "Obtain, process, and understand basic health information and services needed to make appropriate health decisions"(IOM, 2004, p 5). Health literacy is unique to literacy and requires

more than simply reading words or speaking, but includes complex cognitive functions and context (Paasche-Orlow et al., 2003). Written materials are commonly available in Spanish versions to meet the literacy needs of the increasingly diverse American population (Andrulis & Brach, 2007). A study of Spanish-speakers comprehension of a Spanish-language drug information sheet found that only 29% of participants were able to fully understand the information (Leyva, Sharif, Ozuah, 2005). The cultural component of health literacy is noted in this study's analysis.

Patients prefer to receive health instruction directly from their physician according to the studies of patients' preferences for health education (Schillinger, Bindman, Wang, Stewart & Piette, 2004; Schillinger et al., 2003). Although understanding physician's language can be a challenge for patients with inadequate health literacy, and several studies found that physicians rarely evaluate patient comprehension of their verbal instructions (Schillinger et al., 2004). The literature offers several studies about physicians' use of medical terms that resulted in insufficient or confusing communication with patients, and greater dissatisfaction with the explanation of their illness or treatment options by patients that they were (Schillinger et al., 2004; Williams M, et al., 2002). The objective of one study was to describe physicians' use of jargon with low-literacy, diabetic patients (Castro et al., 2007). This population was selected based off the previous research identifying diabetics as being more likely to have low health literacy, and the association between the quality of patient-provider communication with diabetic patients' self-care behaviors and clinical outcomes (Castro et al., 2007). They found that of the 74 audio-taped encounters, 81% contained one or more use of complex jargon, 37% of which occurred while giving recommendations and 29% when providing health education (Castro et al., 2007). Telephone questionnaires were utilized to measure patients' comprehension of diabetic

terms, specifically the jargon that was recorded during their visit, and after analysis of the responses, it was concluded that patient comprehension rates did not meet adequate levels (Castro et al., 2007).

Other investigators have reported poor comprehension of clinical jargon among different patient populations and this study has three important methodological strengths that help support the relevance of their findings: (1) use of actual visits as the source for jargon terms, (2) assessment of comprehension of disease-specific jargon terms that were theoretically relevant to patients' experiences and/or consistent with their clinicians' expectations, and (3) analysis of the contextual factors that may influence comprehension (Castro et al., 2007). The data analysis proposes the implications that clinicians could unwittingly be contributing to the difficulties experienced by patients with limited health literacy (Castro et al., 2007). The use of terminology that is too difficult to understand is compounded by the research that finds physicians are not evaluating patient comprehension until critical self-management skills are required by the patient (Schillinger et al., 2003). Physicians tend to overestimate the literacy of their patients, and patients who have difficulty understanding their providers often do not express it, both providing obstacles to effective communication and health education (Wolf et al., 2008, IOM, 2004).

Methods to Improve Patients' Health Literacy

Patients of all literacy levels benefit from health materials that are easy to read and education techniques that involve less traditional approaches of communication by healthcare providers (Paasche-Orlow & Wolf, 2008). While there are reliable tools for assessment of patients' health literacy, the study on shame suggests that there could be risks associated with labeling patients. To solve the problem of health literacy, experts suggest incorporating health

literacy into “universal precautions” and standardized use of techniques to improve patient education and provider-patient communication (Andrulis & Brach, 2007; Mika, 2007; IOM, 2008). Health communication research identifies information sharing, interpersonal sensitivity, and partnership building as core communication skills that predict better patient outcomes (Duggan, 2006). Effective patient-provider interactions are fundamental to achieving successful clinical outcomes. The tenets of clear communication in healthcare are comprised of limiting the number of messages delivered at one time, and using simplified, jargon-free language (Andrulis & Brach, 2007). Effective clinician-patient communication has been linked to improved patient comprehension, recall, satisfaction, and better health outcomes (Heisler, 2002).

Using the teach-back or teach-to-goal method of having patients explain what they have been told and repeating the information until it is clear the patient understands is also a highly regarded method of patient education (Andrulis & Brach, 2007; Paasche-Orlow et al., 2005; Sudore et al., 2006). The ‘teach-back’ model requires the patient to state or exhibit the care plan to the healthcare provider after instruction, and the provider offers additional instruction until comprehension is accurate (Schillinger et al., 2003). Ongoing education until the learner can confirm comprehension is known as ‘teach-to-goal’ educational technique and found to be effective in healthcare settings (Paasche-Orlow et al, 2005; Sudore et al, 2006). For example, a study involving asthma patients’ comprehension of medication regime and inhaler technique revealed that: (1) patients with limited literacy had worse comprehension at baseline; (2) all patients were able to exhibit mastery after the teach-to-goal process; (3) comprehension after two weeks of the process was similar for patients with and without limited literacy (Paasche-Orlow et al., 2005). Available evidence suggests that assuming limited literacy among patients and

confirming all patients' understanding is a worthwhile approach that may decrease self-management deficits and harm.

One method that encourages patients to be more active in improving their own health literacy is the Ask-Me-3 method. Ask-Me-3 is a simple approach developed by a large coalition of healthcare organizations called the Partnership for Clear Health Communication that was developed to improve patient comprehension and their provider interactions (AskMe3, 2009). Ask-Me-3 encourages patients to ask three questions when interacting with healthcare providers: (1) What is my main problem?, (2) what do I need to do (about my problem)?, and (3) why is it important for me to do this? (AskMe3, 2009). The questions were developed to facilitate the aspects of patients' health literacy needs to "obtain, process, and understand" health information (AskMe3.org, 2009). This method encourages the patient to be pro-active in healthcare education, and if providers respond adequately, the health literacy of patients is likely to improve.

To test the effectiveness of this technique a study was conducted in a low-income, predominantly Hispanic pediatric practice within a large, urban area by Mika, Wood, Weiss, and Trevino (2007). Implementation of Ask-Me-3 began with orientation meetings for the clinic physicians, residents, and clinic staff, to review the topic of health literacy and describe the program and encourage them to be responsive to patients' questions (Mika et al, 2007). Brochures in English and Spanish were displayed in both the exam and waiting rooms, in addition to posters of the Ask-Me-3 program (Mika et al, 2007). The measures included a pre-implementation survey of participating parents' satisfaction with their level of care in the clinic, a post-implementation survey about the knowledge and use of the Ask-Me-3 program, and in-

depth interviews with a small sample of the participants regarding their experience with the program (Mika et al., 2007). Analysis of the results showed that 163 (41.5%) of the participants in the post-implementation survey had heard of the Ask-Me-3 program from the clinic, and 50.3% of those parents report they had used the questions during a recent visit (Mika et al., 2007). In-depth interviews revealed participants' experience with physicians were reported as positive, and that parents felt more empowered by the increased communication and knowledge of health after the visit (Mika et al., 2007).

This study demonstrated the effectiveness of the Ask-Me-3 program in a pediatric practice of predominantly low-income, minority patients, which has several limitations. The sample was disadvantaged and of a non-English speaking origin. Despite these limits, it does demonstrate the potential effectiveness of a relatively simple intervention strategy for improving patients' health literacy. The intervention strategy included hanging posters and making bilingual brochures available, and through a follow-up survey six months after initiating the program for this study nearly half of the parents were still utilizing the questions during healthcare encounters, suggesting that simple visuals can be broadly effective (Mika et al., 2007). Limited health literacy is more common among individuals who are non-English speaking, poor, and of a minority group, so the study suggests the potential effectiveness of improving health literacy for a majority of those affected.

Through a review of the literature on providers' perspectives on health literacy, there were discovered to be many scholarly articles encouraging a raised awareness of the problem and interventions, but few on the actual experience of providers in the day-to-day operations of a clinical setting. One study was conducted to explore the self-reported techniques used by

physicians, nurses, and pharmacists to enhance communication with patients with low health literacy of (Schwartzberg, 2007). A survey was administered to a sample of providers attending a continuing education program on patient safety and health care quality that asked participants to rate communication-enhancing strategies by frequency of use and effectiveness with patients with low health literacy (Schwartzberg, 2007). Through analysis of the results it was concluded that strategies currently recommended by health literacy experts were less routinely used, and less than 40% routinely used the teach-back technique currently advocated to improve patient-provider interaction (Schwartzberg, 2007). The most frequently cited were using simple language (94.7%), handing out printed materials (67.3%), and reading instructions aloud (59.1%) although recent research has suggested that there is a clear discrepancy between the skills needed to understand and comply with health-related materials and instructions and the abilities of Americans to comply. Relying on printed materials to educate patients is not effective at addressing low health literacy as it is more complex than simply the ability to read. Although written health materials are legitimate sources of information for many patients, according to Schwartzberg, they may be difficult or inappropriate for patients with low health literacy, and studies note that patients with low health literacy are more likely to rely solely on verbal instruction from their healthcare provider than print materials (Wolf, 2005; Davis, 2000).

Low health literacy is associated with poor self-management of disease and increased hospitalization, and few studies have explored the extent to which providers or providers-in-training consider literacy in patient care (Powell, Kripalani 2005). In an effort to examine the recognition of low literacy as a potential factor in patient adherence and hospital re-admission, internal medicine residents and medical students working in healthcare settings were surveyed to determine the consideration they saw as literacy as a determinant of adherence to treatment plans

and the potential for readmission (Powell, Kripalani, 2005). In this study participants reported the factors they believed contributed to the patients' non-adherence and hospital readmission, including the measures they would take to prevent another hospitalization. This was after reading a hypothetical patient record that included several clues identifying the patient had poor literacy skills. Overall, only 14% of trainees suggested low patient literacy as a factor that could lead to negative outcomes (Powell, Kripalani, 2005). Although 71% mentioned educating the patient as an effective means for preventing readmission, it was primarily through the distribution of written materials. Interpretation of the primary and secondary analysis suggests that physicians-in-training may not be educated in how to assess and address patients with limited health literacy levels. These findings were congruent with other reports that physicians overestimate the reading ability of patients and infrequently use educational strategies that have been recommended by literacy experts, such as the 'teach-back' method, visuals, and improved communication (Castro et al., 2007).

Conclusion

This review of health literacy literature included an evaluation of research studies involving patient demographics and the associations with inadequate health literacy, the measurement tools used to assess health literacy, and the definition of health literacy that has evolved over the recent decade of research. Barriers within healthcare to building a literate healthcare consumer and the interventions for improving patient's ability to understand health

information have been evaluated and studied. Substantial research has been conducted to demonstrate the impacts of health literacy on outcomes such as adherence to instructions, knowledge of chronic conditions, and appropriate utilization of services. The depth of literature demonstrates a strong association between low health literacy and negative outcomes, in the form of higher healthcare costs and lower quality of health status. There have been decades of research into health literacy, providing useful insight into the relationship between patients, or adult healthcare consumers, and the healthcare systems' methods of communicating health information. There has been a lack of academic inquiry into providers' experience with the problem of health literacy, and therefore this study aims to elicit the perceptions of nurses who work directly with patients about their experience with patient health literacy.

Chapter 3: Method

Methodology: Qualitative Research

The purpose of this study was to understand nurses' perceptions and experience of health literacy within their clinical care settings. This is a qualitative study, designed to understand health literacy as it is experienced by clinical nurses whose work includes direct contact with patients and regular interaction with their health literacy. Qualitative research methodology is

used when the lived experience of individuals is sought with the intention of understanding a phenomenon at an in-depth level (Leedy & Ormrod, 2005). According to the authors of Practical Research, Paul Leedy and Jeanne Ormrod, the focus of a qualitative study is to investigate a specific phenomena as it occurs in its' natural setting (2005). By emerging into the real world where the phenomenon occurs, the researcher will discover and reveal all the complexity involved in the topic and how it manifests in participants' lives (Leedy & Ormrod, 2005). A qualitative researcher recognizes that the issue(s) under investigation have many dimensions and layers, and therefore the research is aimed toward portraying it in its multifaceted form (Leedy & Ormrod, 2005). The qualitative approach for a study can lead toward important and worthwhile areas of future study when little information exists on a topic, the variables are not certain, or the utilization of present theories for improving it is not known (Leedy & Ormrod, 2005).

Health literacy is a multifaceted problem. The causes and consequences are gradually being revealed through academic research, but the appearance within clinical care settings is complex and still without clear understanding. This was qualitative in design because it is a study of a complex problem, and the perceptions of nurses' who work in healthcare settings could be multi-dimensional as well. Little research has been done with providers, since the majority has focused on patient variables and experiences. The literature suggests that a simple means of assessment may be a reliable tool for indicating inadequate patients' comprehension and their ability to act appropriately on health information, although the experience of nurses with measurement tools and interventions are minimal. It is unclear how healthcare providers perceive the definition of health literacy, how its' engaged during patient interactions, and what might be going on that prevents them from improving it. One way of differentiating qualitative research from quantitative research is that largely qualitative research is exploratory (i.e.,

hypothesis-generating), while quantitative research is more focused and aims to test hypotheses. A quantitative approach might provide information about utilization of techniques, but a qualitative approach will more likely penetrate the depth of experience with the complexity and multi-dimensionality that it arises (Leedy & Ormrod, 2005).

Research Design

In designing this study, the researcher followed the content analysis approach, as this is a detailed and systematic examination of the contents of a particular body of material for the purpose of identifying patterns and themes (Leedy & Ormrod, 2005). According to Leedy and Ormrod, content analyses are typically performed on forms of communication, including written materials, audio/visual, and human interactions (2005). The methodology involved with content analysis begins with the identification of a problem and the sample to be studied (Leedy & Ormrod, 2005). The data collected is analyzed through coding of material into terms of predetermined and precisely defined characteristics (Leedy & Ormrod, 2005). Coding for themes involves the quantitative use of measuring frequency of similarly stated responses from research participants, and thus is not solely qualitative in approach (Leedy & Ormrod, 2005).

Data analysis followed the Colaizzi's methodological method, which is a seven step approach commonly used in qualitative research. These steps include: (1) reading the transcripts and listening to the subject's descriptions for meaning, making sense of them; (2) extracting significant statements; (3) identifying the meaning of each significant statement; (4) organizing the aggregate formulated meanings into clusters of themes (referring back and forth throughout the data to validate the themes); (5) integrating the findings into an exhaustive description; (6) formulating a statement of the essential structure of the phenomenon; and (7) validating the

findings with each participant (Colaizzi,1978). All these steps were followed or attempted to be, although several participants were unreachable at time of data analysis and step seven was not fully completed.

Methodological trustworthiness in qualitative analysis refers to the attempt to thwart bias and arrive at a meaningful conclusion by maintaining the rigor of the methodology. The four criteria used to judge methodological trustworthiness are credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985, Colaizzi,1978). Prolonged engagement with the topic and member-checking - in which the subjects themselves are asked if the researcher's interpretations - are used to achieve both credibility and dependability. These methods were utilized in data analysis for this study. The researcher is the main "tool" of data collection, and her interpretations form the basis of analysis. Being unbiased is essential, and these approaches are required to minimize bias and confirm the reliability and credibility of the research results. Personal transcription, coding and prolonged review of the data was done by the primary researcher for this study.

The audit trail helps to establish the credibility of qualitative studies and serves to convince the scientific community of their rigor. In qualitative research, the investigators bear the responsibility of convincing the scientific community that the analysis and findings are systematic, objective, and worthy (Wolf, Z., 2003). To accomplish this end, investigators often perform many steps during the processes of data collection, data analysis, and presentation of the results of studies. One of the steps used to establish the credibility and confirmability of a qualitative study is the construction of an audit trail (Wolf, Z., 2003). The audit trail is also called the confirmability audit and it attests to the interpretations of the researcher. This record

provides evidence that recorded raw data have gone through a process of analysis, reduction, and synthesis (Wolf, Z., 2003).

Sampling strategy

Following approval by the Regis Institutional Review Board to conduct the study, active recruitment of nurse participants was done through contact with area hospitals, outpatient facilities, and email listservs for nursing organizations. A flexible sampling framework for collecting qualitative data provides completeness of data and is an acceptable practice within qualitative design (Leedy & Ormrod, 2005). Qualitative researchers aim to gather an in-depth understanding of human behavior and the reasons that govern such behavior (Denzin & Lincoln, 2005). The qualitative method investigates the *why* and *how* of decision making, not just *what*, *where*, *when*, hence, smaller but focused samples are more often needed, rather than large samples (Denzin & Lincoln, 2005). The sample for this study was nurses who had at least one year of experience and have regular, direct contact with patients in clinical settings. Demographics collected include age, years of experience, current employer, gender, race/ethnicity and languages spoken. This information was collected through a participant questionnaire given prior to interviews. The sample includes nurses working within metro Denver, Colorado who are interested in sharing their experience about the topic of health literacy. Those that agreed to participate, read and signed a written consent for participation also approved by the IRB, and the interviews were done in a private, undisturbed setting, including participants' work or leisure setting, like a coffee shop, library, or school.

Measurement/data collection

The pre-determined interview guide was developed in collaboration with the researchers' advisor and approved for use. Data collection included semi-structured interviews based on an interview guide of 10 open-ended questions. These questions were open-ended and intended to elicit nurses' experience with health literacy, if it factors into patient encounters and within their work environments. The interview Guide can be found in Appendix A. Interviews were conducted once and the same questions were asked of each participant. The researcher prepared for these interviews by reviewing guidelines and studies on recommended communication/interview techniques, in addition to practicing interviewing skills. The average interview length for each interview was 30-45 minutes. All were audio-taped with permission from participants and the recordings of the data will be kept in a locked drawer.

To ensure the authenticity of the data, the transcribed interviews were stored in a password protected file, with access given to only the researcher and secondary readers. Password protection prevented distortion of the participants' responses or corruption of the data. Interviews were conducted sequentially until saturation occurred, specifically after the 10th interview. This is when no new themes were emerging, and there was sufficient data for the required qualitative analysis. This research report includes direct quotes from participants, to support that the results are valid and trustworthy. In qualitative research the researcher must reflect on their role in the research process and make this clear in the analysis. As the interviews progress, field notes were kept, incorporated with the audit trail and developed under the guidance of the primary researcher's academic advisor. This was in effort to prevent researcher bias and/or distort credibility of the analysis.

Data Analysis

The data analysis included identification of eight common themes that arose from the nurse participants' experience of what health literacy is and how it factors into their daily interactions with patients. After transcribing the tape recorded interviews, the data was reviewed in-depth, in order to identify statements that are relevant to the topic. Statements were grouped into "meaning units", or categories, that reflected the eight emerging themes. These themes were recorded in a code-book that includes definitions of themes, the key words and inclusion/exclusion criteria. Patterns and themes gave rise to a "typical experience" of nurses' perceptions and experience with health literacy awareness, assessment and intervention. Transcription and analysis occurred simultaneously in order to complete the study timely and be able to make variation to the methodology if a problem became apparent.

A second reader/coder was recruited to review the data and validate, negotiate and/or question the themes proposed. For this study, the coders obtained 88% Cohens' Kappa on the themes presented. Inter-rater reliability was calculated for the reliability of themes using Cohens' Kappa calculation. When necessary, the codebook was revised based on consensus among the two coders. The field notes include support for the rationale of any changes, as to add another aspect of trustworthiness to the research method and conclusions.

Chapter 4: Results & Analysis

Nurse Participant C said, “Health literacy would be anything that one could put their hands on that would give them more information about their own health or the health of others. It might be for research, it might be for further knowledge and I think that there’s different levels of health literacy”. Nurse Participant N said, “I think health literacy would have to be, um, a measure of our proficient knowledge of health and our perceptions of health, whether it be the physical or the mental and everything in-between” Nurse Participant M’s response was, “Reading. That’s the first thing I think of” in response to the first question about defining health literacy. She added, “I think of health literacy is the ability to read health-related information. Whether it’s patient, nurse, you know, physician, medical assistant, anybody, particularly for a nurse it would be nurse information”. Nurse Participant B said, “Health literacy is understanding what a person’s health is; understanding their health and understanding what they learn from their physicians and from other healthcare providers”. It is a broadly defined term and vague in meaning for the nurses that were interviewed. As Nurse Participant N responded to the question, “I guess just being, having accurate information about your health and medicine in general.” Nurse Participant A said, “It can be anything from what you’re teaching the patient about their

condition, or their insurance, or just the hospital policy. I mean that's just so much information, and so varied; it just seems to entail a lot".

Introduction: Nurse Participants

The data gathered for this research study was collected from interviews with 10 nurses that work in clinical and/or hospital settings. All of them have regular interaction with patients, with three who also hold managerial roles and one who currently has a private practice. She is a psychiatric nurse who prescribes and counsels patients who were self-referred or physician-referred for medications related to mood and life-style. The average age of participants was between 30 and 60 years. All of the nurses were female and white, except one who identified herself as "Other" for the category of race and ethnicity, without a further explanation. Of the primary languages spoken, 10 out of 10 spoke English. One selected both Spanish and English on the demographics sheet, and one who wrote a "very small amount" next to the word Spanish in the languages spoken category. The average years of experience varied from 3 to over 20 years, although this was gathered through conversations with the participants and not collected as an official demographic piece.

Eight Themes

Eight themes emerged throughout the course of interviewing the participants in regards to what health literacy means, how nurses educate patients, and how they perceive patients' health literacy. This includes their perception on how well or poorly a patient understands and intends to act on the health information they are provided, which could be in the form of written, verbal, or audio instruction. The preferred method being verbal and individualized, although a strong

reliance on health care standardization of written materials and the policies and protocols that are now much a part of the working nurses' day.

The eight themes include the following:

Theme	Definition:
1.0 Definition of health literacy is vague	Health literacy is an unfamiliar term, often not heard of by nurses. The definition is vague, but relates to knowledge and perception of health (specific to "good health"). It is associated with literacy/reading/writing ability. It is different for professionals and lay-persons, based on education, experience, languages spoken (patient). Complex term/subject
2.0 Written materials	Written material is limited. It's "not good enough" for educating patients ("patients would hate me" if just handed them literature"). It is useful, practical and mandatory. Accurate information and readable, including 6 th grade reading level/standards related to written info. Patients can be overwhelmed by it, and it is often ignored or limited in effectiveness; Internet and television channels abundant but not always legitimate sources. (DVD/TV is good for "when the patient is bored in the hospital")
3.0 Verbal Teaching, Patient Assessments (non-verbal)	Patient teaching is predominately verbal, individualized, and direct. Nurses conduct assessments with patients, teaching to their perceived level of health literacy. Face-to-face, instruction includes nurses' assessing non-verbal's clues about comprehension and body language. This includes "tuning" into patient, and elicit return-demonstrations/patient feedback and assessing need for other professionals.
4.0 Nurses as health educators (Connecting with patients w/health)	RN's are patient educators, developing relationship with patients that are committed to improving patients' awareness of health. Providing education through demonstration, expression, simplifying information and requests, finding other resources for patients or helpful providers. Opening patients to health concerns and issues. Their role as very important even if "late in the game".

<p>5.0 Emotional/Psychological State</p>	<p>Emotional/psychological state of patients. Nurses relate to the emotions/mental and psychological states, including fear, anxiety, shock, overwhelmed (emotions and trauma) in addition to distraction, denial, and external demands on patients which prevent them from learning/listening. Then they are “not in a place to learn.” (<i>Immediate influences involved with health literacy assessment/ability</i>)</p>
<p>6.0 Language, Literacy and Family influences</p>	<p>Patient/nurse can't speak the same language. In the immediate situation, family and translators facilitate communication with non-English speaking patients, but long-term impacts are questionable, perhaps not helpful. Translation services are available, but costs money, are late/must be scheduled and create a disconnect with patient. Useful but create a barrier; Translated materials are not helpful if the patient cannot read. Intimidated by language barriers.</p> <p>Family is relied upon to communicate for the patient but against policy. Don't know what they're actually saying. Family and culture are a bigger influence on health literacy than nurses/medical professionals.</p>
<p>7.0 Healthcare standardization and protocols</p>	<p>Healthcare organizations provide rules to follow and protocols around patient education. These are mandatory and readily available – both an asset and perceived hindrance. (Useful resources: intake forms, standards on patients' literacy and language preferences, educational classes, translated written materials and medication sheets.) Nurses receive conflicting messages from healthcare organizations about health literacy, as the day-to-day experience of RN's/unspoken messages emphasis turning over beds, time, money, and limits to staffing. (education classes are perceived as boring and tedious and do not specifically address health literacy).</p>
<p>8.0 Individual Responsibility</p>	<p>Self-Responsibility is very important. It is ultimately up to the individual. Each person is responsible for their own health and has their own priorities/agenda. Each nurse determines how to present the information to patients; Includes motivation and willingness, taking responsibility and limits to nurses' impact on patients' health literacy. Relates to general theme of cynicism nurses have about changing patients and doubt they will follow through.</p>

Theme One: Defining Health Literacy

When asked to provide their definition of health literacy, the response often came as a question. The nurses did not seem confident that they knew exactly what it meant. Nurse Participant T said, “Um, I guess it would be your perception of health...Is that right?” Nurse Participant A said, “I was going to ask if that meant. Is that your understanding and knowledge of research behind your field, I mean, is that being “health literate”? Or is it about health in general, I don’t know”. Nurse Participant E said, “I know what literacy means, but not health literacy”. Nurse Participant B said, “You said health literacy, but is that from the patient point of view, is that from health care, like the nurses and the doctors’? You know, it’s kind of a broad term”. Health literacy as a term is unfamiliar to these nurses, as Nurse Participant T said about her healthcare organization, “Nobody really used the term health literacy”. Nurse Participant L said, “I’ve not specifically heard the term before, but what I would, or how I would define it would be patient’s ability to understand health, what helps them be healthy, what’s not healthy, what kind of behaviors, the behaviors that are healthy”. Nurse Participant L thought it related to “good health “what kind of state in their body and minds is a healthy state versus not a healthy state.” At the end of the interview with Nurse Participant L, she said, “So you were saying “health literacy” and I was thinking just overall health”. Health literacy was associated with “good” health for several nurses. Nurse Participant B responded with, “What is “good” health, what’s “bad” health, and what contributes to that? What do they know? That’s health literacy”.

Health literacy is different for healthcare professionals than for the average “lay person”. As Nurse Participant T elaborated on her definition, “I would imagine the perceptions from the patient’s perspective and the doctors’ perspective and the nurses’ perspective and the public perspective would all be very, very different”. Nurse Participant T continued, “I think if you asked all those different people what their perceptions of health were, I think they would all give you very different perspectives and definition”. Nurse Participant C also said, “I think that there’s the professional health literacy for professionals like you and I, nurses, physicians, physical therapists who are prepared for their career in healthcare. And the two are completely different”. Based on how a person is trained or works professionally in the field of healthcare, their health literacy “May lead the person down the wrong road in terms of their information search”, she added.

Health literacy is a complex term and a complex subject. As the interview with Nurse Participant L progressed, more possibilities for what health literacy means began to arise. Nurse Participant L said, “I wasn’t aware that health literacy could include information about access like health insurance or whatever but I certainly see what you mean. And we deal with that issue all the time, too. Like, “What insurance plan do you have, if you have any insurance?” Their means of paying, whether they know about their insurance, in terms of what it covers - Do they have a deductible? I mean, if they don’t know, or maybe most people know those terms pretty well. They know co-pay, for sure. Um, most people know “deductible”. But some people don’t...It depends how much they’ve been dealing with their insurance, it’s the biggest thing. So we deal with it all the time and I’m always explaining things to them because if their insurance doesn’t pay much, or if it does pay much”.

Nurse Participant M said, “So I find the education level to understanding basic health and compliance is the biggest barrier”. Each individual interprets information differently and people have different ways of gathering health information that makes sense to them. As Nurse Participant C said, “I think that we are raising a generation of people who now know different ways to get the information that they want and need through the internet, through the library, through networking. I think that there’s a lot of that out there.” She adds, “It depends on their level of education” and “I think it’s a higher skill”.

Nurse Participant O said, “I do think people understand what I say, and with the written stuff, maybe not. I try to not, but I say words like NGO, which really means “Nothing to eat or drink” which people don’t understand at the time”. She adds, “It’s NGO, it’s Latin, and I don’t even know what it is. But it means for us, “Nothing to eat or drink”, and so we’ll say, “You’re NGO” and then they’re like, “What is that? I don’t get it.” So I have to catch myself and try not to do that. I have to be more aware of what I say so patients can understand. But usually they’ll ask if they don’t know what it is”.

Nurses make a variety of assumptions about a patients’ health literacy, including what they understand and how they are able to incorporate health information into their lives. This includes education about a medical condition, how to navigate the healthcare environment, respond to safety protocols, or means for adopting a healthy lifestyle. Nurse Participant C said near the end of our interview, “It depends on what the learner, how they accept that information”. Her statement bridges theme one – differing levels of health literacy, to themes three and four, which are about how nurses are educators and health navigators in constant relationship to it. They are in a position to assess patient’s ability to “understand process and act

on health information”, and be influencing it, either positively or negatively. In summary, theme one includes the health literacy definition as being an unfamiliar term and broad for nurses, relating to knowledge, and perceptions of health, education and literacy levels. This is primarily assessed through verbal exchanges and written documentation provided during intake procedures.

Theme 2: Written Information

According to health literacy research, printed text is the least effective means of communicating effectively with patients, but it is the primary, and often only, tool used by many providers (Schwartzberg et al. 2007). Theme two is defined as written materials being limited and “not good enough” for patient education. Nurse responses included, “Patients would hate me if I just handed them literature” that they would potentially not read, not be able to read, or understand. Patients seem overwhelmed by the amount and complexity of written forms, and not interested in reading the discharge or follow-up material provided.

The environment of healthcare is known to be full of documentation, paperwork, signatures and consents. Evidence suggests that it may not be understood, even if written at a 5th grade level or in the patients’ language of choice. There is abundant information available through the internet and media, which can be a barrier to nurse education with patients or a positive adjunct. Nurses see written materials know written materials have important information for patients but see that it is often ineffective due to being ignored or not understood. According to the IOM’s report, patients overwhelmingly prefer to receive medical information directly from healthcare providers, not on paper, and makes many recommendations to improve the communication skills of physicians and nurses (Bryan, 2008, Andrulis and Brach 2007). Yet

it is a primary method for promoting adherence and follow up. Videos, television channels, and educational classes were also discussed as a form of patient education, but not mandatory or always seen as helpful for nurses or patients.

It's a back up

Nurse Participant T said, "After talking to them and explaining to them, I print them out materials and send them home with it. Then they feel a little bit more in control, like they don't have to remember so much, because it's a lot to remember, so at least they have something written down". Written materials are used as a discharge and follow up tool. Nurse Participant C said, "We have a folder that we give to patients on their admission and then send home their instructions and their prescriptions and then information about each one of the medications that they are going to be taking at home, especially if it's a new medicine".

Nurse Participant O said, "I give them written stuff about what I've just gone over, but that's really the preferred method for teaching, because it's easy, and it's the most practical. When that's just how you're interacting in a hospital setting when half our patients are drugged, and they're not reading a lot of stuff (chuckles), so... You just talk to them, tell them several times, (laugh) what is going on". Nurse Participant L tries to encourage patients to pay attention to the written information. She said, "So I'll refer to things that they're going to have written, as opposed to them just throwing it away. They're going to tune into it more, or I just, kind of, prevented them from over-reacting or getting scared". Written materials are relied on for follow up, although may not be used or understood. Nurse Participant G sometimes uses literature to relieve anxiety, and to do so she asks, "Is there anything that I can do to make you feel more safe?" when giving it to them.

Nurse Participant T said, “We have a lot of printed material”. Nurse Participant A said, “I know that all of our literature, and I think it’s hospital-wide, but I know for sure on our floor that everything’s written to like an 8th grade reading level. Because we have such a huge range of patients everything’s made so at an 8th grade level so it can kind of cover most people anyway”. This reassured her that written materials are readable for patients, based off their documented language preferences and reading abilities. It is a supplement to verbal instructions. Nurse Participant B said, “We sit down with the patient and make sure they understand, and we have written things that we give them, like “Ok, here’s your prescription for physical therapy, make sure you look at it, take it with you”. Nurse Participant L said, “I use a little bit of websites, um, a little bit of written materials not a whole lot. I certainly write instructions a lot, like um, I for sure write instructions about their medications. You know, what to do, when to call me, if there’s any problems with it”. These nurses expressed the need to explain in addition to giving out written materials.

Starting place

Nurse Participant C gave her response to what types of educational techniques her organization uses with, “Yes we do use written, absolutely, but it just seems so very impersonal to always do that”. This begins to express the limitations nurses’ experience as far as relying solely on written exchanges, and preferring more direct and personal types of communication. Patient encounters often begin with written forms, according to nurses like Nurse Participant L who said, “One of the ways I get information, the first way, is during intake they fill out a history form,” and, “One of the questions is stressors in their life. One of the questions has to do with medical conditions and medications they’re taking. Their goals for therapy, what brings them in,

alcohol and drug usage, things like that”. Written materials include the use of questionnaires, forms and consents that patients were obligated to complete. “It is a starting point”, Nurse Participant L said. Nurse Participant N said, “We used a digital/analog scale for pain and another health questionnaire, a functional questionnaire” to gather information.

Word meaning & definitions

Nurse Participant L said, “So they fill that out and then I have that form in front of me, it’s kind of a reference point, a beginning level of information. And then I add to that”. From what she said, the theme emerged about confusing terms and word definitions in healthcare. The definitions of terms can be different for patients than nurses or doctors. Nurse Participant L talked about using written information as a starting point, because often times her patients did not realize the full impacts of the questions it asked. She said, “Like on the section of asking, “Describe your use of drug or alcohol” – Do they use them and to what extent? Often people will put something brief like “social drinker”, well that’s not very specific” and therefore not complete. Nurses need specific information so she said, “I ask very specifically how much and how often, on alcohol or any drug usage, I get very specific, and I add that in, after they put down whatever they think their definition is of you know drug and alcohol”.

Interestingly, Nurse Participant L also said, “People tend to under-report on alcohol and drug usage” on the intake forms. She said verbal dialogue helps her to get more specific and more accurate information about patients’ health behavior and knowledge. “I get much more accurate information and it makes all the difference in the world... including on whether medications can work or not. So it’s very, very important to have”. In her experience, “People

tend to under-report or keep it very general, and they don't know what I need. It's just kind of a beginning question on the form".

Documentation and paperwork

Nurse Participant B spoke about the extensive paperwork and documentation she must go over with patient. "I have a packet that is our spine surgery manual that I use with patients". In one experience, she said, "I went over the consent form with him, and I go over each of the sections, which is what are you having, and the patient needs to write down what they think they're having". She continues, "You know it says more than, "This is the surgery procedure" but "Why are you having that?" And then, "Read through here and initial that you'll accept a blood transfusion here". She said she knows it can be daunting, so in response, she tries to keep it simple. Nurse Participant B said about literacy demands on patients, "They have to write down what they're having, and say, like "I broke my arm." Keep it real simple. "Broke my arm" "Back pain" They have to write that down".

Theme two includes written information as a reference point for patient education, communication and involvement with health literacy. This includes intake forms, medical documentation, and pre-printed instructions. Most materials are now available in Spanish, put in "layman's terms" and written for a 5th grade reading level. The intake and admissions forms were a starting point for patient assessment, and influence perception of health literacy. These forms are a part of healthcare protocols and standard procedures. The discharge documentation and in particular, the medication and follow up information, were regarded as essential to patient education. Words can have unclear meanings, though and definitions are vague or

misunderstood. Based on an individuals' perceived health literacy, the prospects for written information improving their condition were reportedly slim.

Abundant information, self-education

According to estimates by the Pew Internet and American Life Project (2007), almost 70 percent of the U.S. adult population access the Internet, and 80 percent of these users look for health-related information (Bryan, 2008). Nurse Participant B said, "There's just so much information out there". Later adding, "I will direct them online because there's lots of stuff out there. And there's people that are not medical people that are giving you this information. So I'll say "Go to the Academy of Orthopedic Surgeons.org. Or to e-d-u. Go to this place because you're going to get real clean information"..." because they can even get information from other countries". She helps patients to navigate the abundant informational resources available and find trustworthy sources.

Nurse Participant N said, "So most of them had done a lot of online kind of stuff and research before coming in" about patients that were inquiring about having elective surgery. There are more patients doing their own searching of health information, yet not necessarily coming from valid sources. This brings to light the challenge of deciphering so much easily assessable health-impacting information, in particular the internet sources. Nurse Participant B identified the internet as a barrier to her ability to improve patients' health literacy. "Internet! It's one of the barriers! (laughs) Yeah, it can be a good tool, but it can be a barrier that can cause patients not to understand exactly what's going on". Nurse Participant B continued with, "And there's so much out on the internet that patients read, and then they call you and they're like "What is...?" And you're like, "Man there's too much information out there. Because they

don't understand a lot of it and not all of it is in layman's terms. They don't even know what it means for like, swelling". Health-related and health-influencing information is abundant, and it can easily be confusing for people. Nurses rely on trustworthy resources to share with patients.

Providing trustworthy information

Nurse Participant E said, "It's all evidence-based, we'll pull it off whatever the latest research is". Nurse Participant M said, "All the materials are approved or made by the University or purchased by the University, so I don't just hand them things from Wikipedia or something like that" meaning that hospital approved literature can be trusted as reliable and legitimate. Nurse Participant O said, "We do have some resources at our disposal like for educating the patients. They provide a program called, CareNotes on our intranet at the hospital that is full of stuff like post-op instructions and every type of thing. Like if a patient goes home with a catheter, or - you can look up procedure information, or you can look up medical and medicine information, drug interactions and stuff like that. It's for patients. It's for patient education. It's written in lay-terms".

The written materials and hospital-approved materials are regarded as valid sources of health information these nurses could provide to patients. As Nurse Participant E said about what she shares with her patients, "What's the newest evidence-based that the latest studies are showing" and this she deems as beneficial. In offering "reliable" and trustworthy sources of health materials, Nurse Participant E said, "I find my information from a couple of different journals. For research studies on the web, there is a brief access through the hospital that offers the {Med Info?} system, so you can pull things up, and you can do literature searches". The sources are important.

“One factor that contributes greatly to perpetuating low health literacy is the overwhelming lack of standardization in the area of health information and communication. Inconsistency in printed materials, variation in prescription messages and warnings, complex processes for accessing and navigating the system, and convoluted health insurance requirements test even the most literate healthcare consumer” (Paasche-Orlow et al. 2006; Wood 2007). Nurse Participant L said, “So, a lot of times the level of information is very low. I’m kind of amazed by it sometimes, because I feel like [the information] is all over the place, but it’s all over the place to me, because that’s the kind of thing that I tune into. And there’s gobs of information out there”. Nurse Participant B said, “I really feel that sometimes we are way above their head” when she described the various levels of health literacy and how it differs for healthcare professionals and the average patient.

Nurse Participant B identified terms used by professionals as, “fancy terms” which are used in health settings. She said in relation to this, “Because of the internet there is more that we can comprehend and you always have to assist our patients in understanding. I mean if you have someone whose obsessive-compulsive, the internet puts them over the edge. They have too much information”. The information can be overwhelming, which links to theme five about relating to patient’s emotional and mental state and health literacy. For Nurse Participant G, she realizes that whether in written, verbal, or digital form, as she said, “Whereas another woman will say, “No, I don’t want to hear any more detail, I just want to get to surgery and get it out.” So I do like to ask those, ‘cause I could on and on, give details, and it’s too much information. It’s overwhelming”.

Materials for education: websites, videos, dvd’s

“We do have the DVD that we make at least all first time parents watch”. Nurse Participant A said about educational materials for new moms. Perhaps to meet health literacy needs, or to make health education more interesting, understandable, or accessible to different learners, there are videos, internet and television channels. The impression given by Nurse Participant N was that health channels and media are good for entertainment, or occupying a bored patient in the hospital. She said, “I know that as far as somebody laying in bed post-operatively, there are television shows, and that we have a health channel that’s geared towards that”. Nurse Participant T added, “Print materials are a good thing for a lot of people to go home with. They get bored in the hospital room so printed materials is good for when they’re bored in the hospital ...When they’re bored in the hospital it gives them something to read and look at”. There was a tone of tediousness around the standardization of patient education.

Language and literacy

If the patient is illiterate, the printed materials are not effective. Nurse Participant M described an experience she had with a patient she perceived to be have low health literacy. She said, “So I have Spanish forms, and that was a Spanish form (that I used), but he couldn’t read it. He couldn’t write.” There are limits to standardized, self-reported measures of literacy. As she continued to say, “We do print it out in the language of their choice” which does not mean the patient is literate. Another nurse gave a similar example of a patient who was health illiterate, and she said, “It actually had more to do with the fact that he wasn’t literate, or he couldn’t read” that made the translated text ineffective. Nurse Participant E said, “Some people might speak English quite well but may not be able to read it as well”.

Nurse Participant O said about language, diversity and literacy barriers, “A lot of our written instructions will come in – say like that CareNotes, you can print it off in Spanish and some stuff in Russian,”.. “So we can communicate that way, by giving them the written stuff in their own language; as long as they can read. I sometimes wonder about that, though....” She stressed the importance by adding, “Because we can’t communicate it verbally, (then the written) becomes really important” and she said this was a concern when interacting with health illiterate patients and those that she suspected could not read. “Sometimes I do wonder, because I don’t really know” if they can read it or understand and this comes from non-verbal clues. Nurse Participant O said that she assessed this “By the expressions on their face, they don’t really read it, they just kind of set it aside” told her a patient was not interested or receptive to the written materials. She continued, “And it’s like, “Read this!” Especially when there is that communication barrier, it’s important that they read it. I know that is the best way for them to find out the information that they need”.

Written is back up

Nurse Participant E said, “Every patient gets a set up discharge instructions when they go home, which is a list of all their medications, we have print outs of what their medications, when you should take it, when you shouldn’t take it, all the guidelines. They have just a wealth of pamphlets, there’s a lot of written information. There’s phone numbers to call if you have questions, for follow up. And it is a written-based thing, so there is a lot of information, written information”. Yet she continued, “And it should be something that you should be able to read”. The written materials are a back-up resource or educational tool, and regarded as very necessary when patients are not in a mental, physical or emotional state to receive and comprehend health

information. As Nurse Participant C said, “Certainly the people who are very angry, or busy picking up the stuff in their room while you’re trying to do the discharge instructions, and they aren’t going to necessarily listen to everything, but what you’ve done is provided the written word to go home with” and then adding, “Maybe at some point they would open that up” she hopes, but it is not a guarantee.

Patients are not expected to really use the written materials, as Nurse Participant E said about written materials, “I don’t require them to read it. We don’t assign homework. And my people do best on their own, you know. If you’re sitting there alone and if you feel like learning about it, you will. You know everyone will learn at their own pace. So if we have at least put together a packet of stuff for reference that they can go home to, because we can talk ‘til we’re blue in the face, but if you’re not in a receptive mood you won’t remember it”. Nurse Participant G said, “I try to assess the anxiety level and so I don’t necessarily hand this book with mastectomy pictures to a person who this might really make them feel uncomfortable” and this relates to the theme of written materials being limited, in that from this nurses’ experience, it can create more anxiety. She adds, “The last thing they want me to do is be just like here, hand them books and tell them to read all these books and take all this information home, and then they hate me”. There was a theme that nurses are consciously or unconsciously assessing how useful printed versus verbal instructions are for each patient.

The written materials are relied upon as a “back up” for follow up instructions, but there was a theme that they were often disregarded. As Nurse Participant O said, “Well one of the nurses I work with has been doing this for 15 years and she was telling me that we’ll send a patient home after we teach them all this stuff, and then, it’s just from talking to nurses that do

home care, and then we also give them a card so that they can call us back once they're discharged for on-going education or if they have problems. And the calls that we get are like, "I don't know how to empty this bag." Well, we went over it several times in the hospital. Or like, "I don't know what my diet is", "Well we talked about that and it's all written out in the folder", but... They're just so overwhelmed by it all that makes it difficult".

There are clearly limits to these resources as the only means of impacting patients' health understanding and ability to act. Nurse Participant N said, "I can give 'em ten thousand pamphlets and 45 DVDs and I can connect them with everything in the world and impart as much knowledge as I can about their issue with them, but if they don't give a damn, it doesn't matter". Nurse Participant N expressed the contradiction by adding that, "The flip side of it is then you've got another portion of the population that comes in and wants me to explain to them in one breath what it means that their platelet count is eleven platelets below normal". Nurse Participant E said, "We can give them health information but then you go home and you know, on television, advertising, and like, there is dinner of "Hot pockets" and as far as eating, everything they advertise on t.v., it's like, oh god, (she laughs) no wonder...".

In summary, the documentation requirements and healthcare organization protocols was said to be useful, practical, relied upon for follow-up. There are many mandatory classes and trainings that are good to exist, but attendance and participation is tedious at times. The DVD/TV is good for "when the patient is bored in the hospital". The Internet and media sources offer abundant health messages and sometimes useful information, but it might not be accurate or from a legitimate source. Nurses referred to using trusted sources that they deemed valid and

legitimate. They sought to help patients decipher what is reliable, good information, and what may not be.

Theme 3: Verbal Teaching & Patient Assessments

Patient teaching begins with assessment. Nurse Participant N said, “Part of anybody’s teaching is sort of assessing somebody’s baseline knowledge of something”. Assessment means, “My understanding [of health literacy] would be communication, that’s how I interpret it. Just because literacy can be reading, writing, how you communicate. And so health literacy is how I am assessing this patient’s ability to communicate and understand my teaching” according to Nurse Participant G. She continued, “I do an assessment and as a nurse you’re trained to. I could assess you for 10 minutes in your ability to communicate with me, taking in your anxiety level, your stress level” and this forms her perception of a patients’ health literacy.

Nurse Participant C said, “I think you have to assess if they are ready for learning before you can even begin to assess their willingness and their ability to learn.” Nurse Participant N said, “We have to assess patients’ readiness to learn and their best capacity, you know how they learn best, and if they give a return demonstration”. The “assessments” are reciprocal, as nurses take in information about patients by their words and behaviors, perceiving non-verbal clues as well as messages related to patients’ external circumstances. This shapes their impression of a patients’ ability to learn. Nurse Participant T shares her approach to teaching with, “You have to assess them, and you have to have a good perception of your patient and where they’re coming from. If you’re talking to a farmer from, I don’t know the middle of Nebraska or the middle of nowhere, I’m probably going to use some different lingo than I would if I was treating a physician who was in my hospital bed being sick”. Nurse Participant G said, “For a 21 year old

daughter of a mother who's sitting here just diagnosed with breast cancer, she's crying and can barely communicate, then I would simplify, you know, I would change my approach of communication. If she was Hispanic, or non-English speaking, or just spoke a little English, or you know, you just change as you go along. It's an automatic, trained sort of thing". It changes with their assessment of a patient. Nurse Participant C also spoke about the circumstances influencing patients' ability to communicate and act on health, "Some might be financial, it might be social, it might be a physician conflict, I mean there's a lot of other situations that I'll get pulled into that I really may not hear about than just saying "Hello, how are you doing? ""

Non-verbal cues and body language

The nurses mentioned body language and non-verbal signs of patients' readiness to learn and how well the education is understood. Nurse Participant G said, "They'll either look completely flat-affect and lost when they leave and don't say much, or they'll say, "Thank you so much this was really helpful". Nurse Participant L said, "Part of it is how they respond non-verbally and verbally. Like if I say something and I can tell if they are taking it in, at least be able to tell to some extent. Like does it seem that it makes sense to them? Do they look glazed over or are they engaged? You know, are they attentive or are they distracted? So I pay attention to body language". This implies that nurses are measuring patient's health literacy in a non-formal or standardized way, but through indirect means like visual and verbal characteristics.

Nurse Participant T said, "I look at a lot of non-verbal cues. When you're speaking with somebody and they're watching the television or they are looking away. I mean, there's obvious disinterest in what you're saying. Also, you'll maybe see that they're agitated". Nurse

Participant L said if they repeat back what she says or ask questions, “If they’re saying something along that line, then that tells me they are taking it in...asking questions, or saying something...acknowledging that they’re taking it in and it’s making sense. And that they’re receptive to it”. Verbal exchange and observation shape nurse’s perception of patients’ comprehension and receipt of knowledge about their health. Nurse Participant E said nursing is, “A lot of coaxing, teaching, saying, “This is what I’m looking at and this is what I’m seeing” about how she changes her approaches to a patient based on observation of their behavior. Nurse Participant E said about observation and patient encounters, “So you have to balance what you’re doing to somebody’s health vs. what they ask for, and it doesn’t make sense. See what I mean? You just have to use your judgment, and you have to use clinical judgment as to what is acceptable range” and be attentive when “the behaviors don’t match”.

Body language communicates to nurses what might not be coming through on paper, as Nurse Participant E said, “People gesture when they talk”. She adds, “If you ask a question about their tummy, they’ll point to the area as they’re talking back, that kind of thing. So then you know the question got passed through” about non-verbal giving the impression that the patient understands or does not understand. Although patients want to look like they understand, and nurses intuitively know that they, “Just aren’t getting it”. For example, Nurse Participant B M. said that sometimes there is a verbal response of comprehension, “But the patient is clearly not understanding, and they clearly don’t want to make it look like they don’t understand it”. The paradox is that, “Sometimes they tell you what you want to hear, and a lot of times they just want to get out of the hospital so desperately, so you pick up on a disinterest and you’ll pick up on a desperation to be out of the hospital”, according to Nurse Participant T.

Additional signs of adherence come through body language. As Nurse Participant C said, “Direct eye contact has a lot to do with it, if they’re able to ask questions about the information that you’ve shared, either for clarifications or “I’m not really sure I can get this, what would you recommend?” or “what would you do in this particular circumstances?” Or those questions that reflect back to the care provider to say “I need more. I need more””. Body language clues were a theme in regards to how nurses assess the likelihood that a patient understands their instructions and will comply. It also gives them feedback about what needs to be repeated. Repeat-back and return-demonstration were mentioned as educational techniques. Nurse Participant E added, “If they don’t give eye contact, you know that just doesn’t make sense, or somebody changes the subject, or asks questions that don’t quite match what you were saying, and it’s just like, hmm, I don’t think they got what I was saying, so maybe I’ll review it, but... Repetition. Repetition, helps, too”.

Specific information

Nurse Participant N said, “From them I need real specific data like when they last had something to eat, whether they’ve got any medicine, or whether they’ve got any metal in their body anywhere, and what surgery they’re having done. That’s what I mean, stuff that’s current”. Nurse Participant L emphasized the specific data need, “I get pretty specific because I know it’s not just, “Oh I have a good appetite” versus not (having one), because that’s just very general. That doesn’t tell you anything about health or not nearly enough”. She adds, “So I get pretty specific”. The need for specific data from patients and their possible insufficient health literacy, or health literacy needs that are not accurately assessed by health professionals, holds great

potential for poor health outcomes. Miscommunication and insufficient health literacy are root causes of many errors in health care and negative consequences to patients' health (IOM, 2004).

Nurse Participant E also said, "You need to get really specific" as far as knowing what a patient needs. She adds, "It's a lot of having experience with what there is out there, and what people are looking for" when addressing their health concerns and literacy needs. Nurse Participant G said, "People in Boulder are highly educated, and for the most part, and they do their homework. And one question I do ask people is, "Are you an information-gatherer or would you rather not get a lot information today?"" which describes how she targeted patient's specific health literacy needs in her patient teaching. Additionally, this ties to how demographics and characteristics about a patients' life factor into how a nurse perceives their health literacy. These are gathered through observation. Nurse Participant T said, "A lot of observation". She continued, "If you do enough listening and open-ended questions, and a lot of time patients can't afford to be there. They're missing work, or they have a husband at home that has Alzheimer's and they can't take care of themselves and they don't have family around". She continues to describe her role in nursing, "There's a lot of listening that you need to do to your patient. I don't think people listen to them enough".

Nurse Participant G said, "So it's kind of a lot of hand-holding and planning and interpretation, I mean, it's so much, it's a lot" as far as she tries to teach patients in ways they will understand. Nurse Participant T said, "I don't think that anyone is really going to absorb any information, whether it be written, whether it be verbal, unless you've established some sort of repore with them, and you've done a good amount of listening to understand where they're coming from and what their concerns are". She continued, "I think, before you can teach

somebody you have to really, you really have to establish a relationship to assess patients' health literacy needs. This was mainly done through listening, observation, and individualizing through assessment. Nurse Participant G also said, "You listen. You basically listen and take mental notes. By listening you're not being pretentious and you're not being, boarding over somebody. I come down to their level". Getting down to the patients' level, establishing a rapport and meeting them where they're at is best described by Nurse Participant G when she said, "It's more like let's get down and sit on the same chair level and let's sit closer and there might be a hand touch, and there might be a (she pats my arm). Nurse Participant G adds, "But a lot of listening goes on then". Based off listening and observing patient behavior, nurses' individualize their approach to patient education and comprehension.

Individualizing plans of care

According to Nurse Participant G, as a nurse, "You're taking all that in as you introduce yourself to somebody, "Hi, my name's Nurse Participant G" and you're just watching their behavior. So that takes you to the next step of- "Ok, I'm dealing with an educated person who knows how to read and write", and so you just tuck all that away and move your conversation along with a language level and education level that matches that person". She continues, "I would change that with every single person who I introduce myself to based on my assessment that I'm doing automatically as a nurse". There was a theme about individualized approaches to patient teaching.

Nurse Participant O said, "It's an individualized thing". The starting point may be written forms and intake information, but as Nurse Participant L said, "I don't expect them to go into a lot of detail there on the form. They don't have to go into a lot of detail. I individualize it

according to what they say”. This also relates to the theme about written materials as a starting point and preference for verbal exchange. Nurse Participant E said her approach to pain control would change based on individual assessments. “If this is somebody who has a long lifespan ahead of them or not then obviously your philosophy for pain control would be different - depending on the diagnosis”. She added, “Each person is different”.

Talking about health

Nurse Participant B said that she asks patients, ““Tell me what you understand that we just told you.” You know, ‘cause I have patients that walk out of here after talking to a physician sometimes and they’re like, “You know, after he said I needed surgery, I didn’t understand him.” And that happens probably more than you know”. Verbal exchange is how nurses’ assess comprehension and likelihood of adherence. Nurse Participant G will ask her patient ““Tell me what you’re thinking. Tell me what the doctor said yesterday. What’s your understanding of this new diagnosis? Can you explain what you understand about it?” And that way you know, you can catch up with their knowledge base”. Dropping an “agenda” helps to reach patients about health, and everyone has an agenda.

Nurse Participant G said that after she listens to patients, “Then they start asking questions, once they get that all out, then they’re like, so now, “What does this pathology report mean?” Or, “Now what do I do?” She adds, “I’m not interrupting them, and trying to get my agenda done, then - coming in without an agenda is kind of like doing that automatic assessment, realizing this is an individual, maybe different than the one I spoke to yesterday. Just getting a

sense of where they're coming from and letting them get it all out there, if they have anything to say". This is how she engages her patients with their health. Nurse Participant G said, "They don't know what questions to ask" adding, "So I'll help them formulate some questions".

Teaching is a part of nursing and this can be to help a patient know what to ask, similar to the Ask-me-3 approach or teach-back methods for improving health literacy.

Demonstration, Pictures, Teaching Techniques

Nurse Participant A said, "A lot of it is both demonstration and just verbal teaching" when asked about the types of educational techniques that she uses. Nurse Participant M said, "I like to sit down with someone and explain and show". Nurse Participant O said, "A lot of it is verbal, just talking back and forth with the patient, just them asking questions to me, and I would say about 80% of my instruction is verbal". Nurse Participant N said about her techniques, "It's all verbal... the amount of time that I have with them is in the 3 to 5 minute range. So the education that we do is 100% verbal". Nurse Participant E said, "There's a lot of verbal teaching and facial teaching. There are some video tapes we give away, there's a grant that provides a video on diabetes, there's a video on breast cancer, big things that we see a lot of that we can give to them something to take home and watch if they wish". Again, written materials are a back-up. Nurse Participant C says, "I use, of course, the verbal word. I use a lot of expression. I'm a person whose always talked with their hands and so for me to demonstrate". She continues, "There's lots of ways to teach a patient."

Nurse Participant G said, “We draw pictures. I draw a lot of pictures of the breast anatomy and what might be going on in the breast and that helps people to visualize and helps them to understand that there really is something going on here”. Nurse Participant A said, “So we do a ton of demonstration”. Nurse Participant N said she used “We had, pictures and models of the discs and models of the spines” to explain the benefits/costs around elective spinal surgery to patients and research study participants. “Because people want to see what the stuff that’s going into their back looks like”. Nurse Participant E said, “It’s usually verbal or demonstrative or drawing. Usually I’ll draw pictures when I describe. Or I’ll get printed information if it’s regarding medication, depending on if they’re English-language speaking or Spanish speaking. I’ll ask which is more comfortable for them to have”. Nurse Participant G said, “Active listening, drawing pictures, I show them pictures in books. I hand them literature” is how she relates to patients health education and literacy.

Return Demonstration

For a younger nurse, Nurse Participant O, she uses repetition and repeat demonstration with patients, as she said, “It’s just repetition. Repetition is how I do it”. She adds that when it seems a patient is not understanding, she repeats the instructions and requests return-demonstration for confirmation of comprehension. Nurse Participant O said, “We do a lot of demonstration” with materials used as a supplement, and “tons of written information” which is “pretty much our teaching”. Nurse Participant E said, “I was trained to do return demonstration, and it is a real good way of learning, to confirm” that patients understand, which emphasizes the importance of her nurse education and how it impacted her inadvertent involvement with health literacy. She uses this to gauge comprehension and the likelihood of adherence and she added,

“You go and see if they took your recommendation - Are they getting up, are they taking walks, are they looking out the window, into any type of distraction, you know that kind thing”. The non-verbal clues are a sign about how well a patient understands and the behaviors they take with the information.

Simplifying

Nurse Participant M said, “And I made like an X on this sheet of paper I wanted him to sign. I kind of went like this (she demonstrates her hand on table top making X) and he didn’t know how to write. And later on, you know, we moved on and I said “Ok”, and then one of the family members came back and said, ‘Oh he can’t read or write’ So when I handed him the piece of paper he had no, no clue what I was asking him to do. And she said, even when you do ask him to sign something he just makes a check mark, some mark on it, he doesn’t know how to sign his name”. Simplifying demands on patients to “get the job done” may or may not be beneficial for improving the actual health literacy of a patient, though, and yet it is routinely done in the real-life healthcare environment.

Being Creative, Trying to Gain Their Attention

Nurse Participant L said, “I mean, you know, try to be real creative in how to say it, describe it, to get their attention, whatever will have meaning to them. So if they feel irritated by me talking about eating fruits and vegetables or something, or exercising, then I back off. And I can tell by their expression, you know. Like someone might be like, “Uh, like give me a break” or “Get off my case” or something, and then I back off. Because if I keep pushing, they’ll blow me off completely and I don’t want to do that”. Nurse Participant G said, “Pictures and

motions and hand signals and everything you can you do to communicate with somebody to solicit their safety and wellbeing, like “That’s a purple pill, and I don’t take a purple pill. Why are you giving me this purple pill?” Someone who might be illiterate, they’re like, “This must be ok, my nurse is giving it to me”.

Nurse Participant T said, “I do a lot of verbal teaching. I do more verbal teaching than written, and I think that’s how I assess a patient. Depending on how that goes and their response to it, then I’ll provide them with printed materials”. Here again, the written materials are mentioned as a secondary means for education. This also suggests that she reaches limits in her ability to improve a patient’s perceived level of health literacy and supports theme eight about individual responsibility. Nurse Participant L said, “You can refer them to a website, I go over it kind of verbally, too. Just verbally with them and then I’ll write some things down that, things that I want to make sure that they remember. I also will refer them to others, like when they pick it up from the pharmacy because the pharmacy-print-out has a lot of different things about medication. I’ll say when you pick it up from the pharmacy you’ll see a lot of different things in terms of side effects”.

Referring to others

About referring to others, Nurse Participant T said, “And thankfully for us in the hospital setting we have social workers and case managers and palliative care and chaplains and a lot of support services that you can start bringing in to make people feel that they’re not alone, that there’s other people out there that can help work with them. I wish I could see more of the outcome of that, you know how productive it is, but at least it’s something to offer them”.

Nurse Participant O said, “But we have a case manager on our floor that I refer them to, who can

answer those questions. And we happen to have an awesome case manager on our floor, so I feel pretty lucky”. Nurse Participant A said one of her new patients had just given birth and, “She was just depressed right from the get-go, and it’s sad, but thankfully we do have a social worker on our floor and we can get those resources”. She adds, “And the social worker will set them up with a lot other like support groups and stuff like that, and the pediatrician needs to be aware”.

During an encounter with a mentally distraught patient, Nurse Participant G said she, “Immediately referred her to the mental health, behavioral health counselor. It’s beyond my scope” expressing the theme of reliance on other healthcare professionals to meet patient’s health literacy needs. Nurse Participant G said, “We refer those people out”. Nurses mentioned frequently using other healthcare professionals for follow up and while under their care, like Nurse Participant C who said, “We have a several different ways that we talk to our patients here. We have a woman who does screen for substance abuse that she asks very point-blank questions about their tolerances and usage, and gets very clear answers back from them”.

Nurse Participant N said, as nurses, “We’re interviewing them”. Interviewing was another way nurses described their assessments of a patient, how they teach them and perceive adherence to instructions. This may begin with the written information gathered from a patients’ medical record, added to by the words they share and the body language they present. Nurse Participant E said about her role as a nurse in a hospital, “I interview them to find out where they’re living, do they need help with finding different living situations, or if they want the chaplain to come see them. I do a lot of teaching as far as where in the hospital, what to expect, how to prevent getting pneumonia, how to prevent getting leg clots. I also am kinda a resource”.

Theme 4: Nurses as Health Educators, Connecting with Patients

Nurses seemed dedicated to helping patients obtain better health in their lives. For example, Nurse Participant N said, “The doc’s that I work with and I, we all heavily encourage people to quit smoking and to be as close to their right weight as possible”. They try to reach patients’ where they’re at physically, mentally, emotionally, and report, “I mean, I brought it down to whatever level, I thought they needed” to adopt healthier habits (Nurse Participant N). Communicating with patients in ways that work was described by Nurse Participant T, who said “My favorite part of training to be a nurse” was training in communication. She said, it was a “A big thing in nursing 101”, where she was taught that in patient encounters, “The sender and the sender sends out a message and it’s received by the person, they have to interpret it and then send it back”. She blends theme two and four, “Cause anyone can read a book on biology and learn about human systems, and learn about pills and what they do, learn about ventilators and what they do, and learn lab work, but, the principal of nursing is pretty simple - it has to do with relating to people”. Theme four is about nurses as a bridge for patients to access the world of health.

The definition of theme four includes nurses are patient educators and health navigators. Through developing relationship with patients that go beyond standardized forms and protocols, they express a commitment to improving patients’ awareness and knowledge of health. They sympathize with patients and help them navigate the complex world of health. They see their role as very important even if “late in the game” and ultimately limited in effectiveness. Theme four came from hearing key words: “It’s what I do”, connecting, navigator, sympathize, “Click”

(with patients), “Tune into” patient, open awareness, prepare for discharge, develop a plan, Share information, and be a role model.

Teaching is nursing

Teaching is what nurses do. Nurse Participant A said, “That’s probably about 95% of our job, especially in post-partum, because, especially if they’re first time parents”. For Nurse Participant O, “There’s a lot of teaching” done with patients about many aspects of their health, “in general a lot of my job is teaching. We’re teaching the patient, you know, they just had surgery and so you have to figure out what they can and can’t do, and stuff like that. So we do a lot of teaching, it’s almost all verbal, demonstrated, or written. Those are the three teaching techniques that I use”. Nurse Participant M said, “I’m teaching surgery instructions, chemotherapy instructions... directions, where to park, where to be, different departments of the hospital, I have to use maps, I have to explain and I have to provide written information. So I have to do all three. And I use all three, because there’s no way if I just mailed the instructions or the information, there’s no way I feel that that would be good enough”. The impression here is that she views her role as being a patient health navigator, and using a variety of tools or methods to accomplish that.

Sympathize

Nurse Participant O said, “I can sympathize. I can’t necessarily completely understand it, since I haven’t gone through it, but it’s very overwhelming. And it is a lot to learn. I mean you get thrown a lot of information all at once”. Nurse Participant G sympathizes through actively listening, “Cause they could go on for 20 minutes about how their doctor never listened to them, or their mother never listened to them, or their sister or husband, and they’re going through this

whole new crisis, and all I did was sit there and listen, and they'll go, "Gosh, I feel better." They say, "Thank you for helping me" and really you're just listening. Actively". Nurse Participant T said, "I think people are less likely to lie to you if they don't feel threatened by you or judged by you. So maybe just try to get on their level". She later added again, "Listening is a huge thing". This is a part of what Nurse Participant T called, "repoire", as she said reaching patients effectively through education requires, "Trying to get the patient to open up to you and establishing a repoire".

Nurse Participant O said that she sympathizes with patients going through medical experiences, "That is a very overwhelming experience for patients" and shows how she "reads" patients' experience of health care and how this factors into her perception of their health literacy. Nurse Participant T said, "Or maybe they're the mother, like myself, of a couple small kids and God forbid I get sick, what will happen to my kids? Who will take them to school?" Nurse Participant O said, "I still think just me being a patient or going to the doctor can sometimes be complicated, especially, it's like I have a deeper knowledge base and I still that it can be tough. I think being on the outside can be tough, but you know being inside it, like in a hospital, I think it's pretty easy. You know, once you get into the hospital I think it's ok, but just getting appointments and seeing the doctor and getting to the right doctor, and you know, I think that can be kind of complicated and intimidating".

Nurses as navigators

Nurse Participant G describes her role as it relates to health literacy with, "So I prepare them for their doctor visit". Nurse Participant B said, "I really believe as a healthcare provider it is our responsibility to make sure patients understand what's going on with them". Theme four

is nurses as health educators, care coordinators, and “translators” of health information. Nurse Participant E said about being a patient navigator, “People usually just throw their hands up and say, “Forget it”. Now our job is to say, “Well, you kind of navigate it” and you will get through it”. Nurse Participant G talked about the history of nursing and she said, “The nurses become navigators... they saw it was *such* a benefit to patients – it decreased anxiety, it helped them to know where to go and what to do next”, adding, “So if you have a navigation system on your ship, you know you can get from point A to point B safely ”.

Nurse Participant L said about increasing a patients’ receptivity, “Especially in the first appointment, it’s - I’m totally new to them, they don’t have a trusting relationship with me, so I have to be really careful in the first appointment to not, uh, to not give them too much information or make too many recommendations”. Relationships tie into receptivity. Nurse Participant G said, “I can be an intermediary”. She adds, “I play the role of an advocate and I help them make appointments. I help them make a plan. So by the time they leave my office, we have a plan”.

Nurse Participant O said, “The doctor’s will come in and write discharge orders and we’ll be the ones who share them to discharge the patient”. She continued to say about follow-up calls from patients who need more understanding, “And we just expect the calls, and I guess I can understand it because that’s what I’m there for. That’s my job”. Nurse Participant E said, there are things like back-ups, like “These are the phone numbers of people you can reach” about reliance on the patients’ following up. Nurse Participant L said, “Yes, yes, to tuning into patients more and all over the place. Like physicians will often say, “The nurse practitioners do great in helping my diabetic patients on managing their diabetes”. Because they’re very good at, you

know on evaluating their needs and the education part of it, and all that kind of stuff. All that education kind of focus. It's just something". Nurses play an invaluable role, as Nurse Participant N said, "I was doing everything *but* their surgery".

Nurses see their role as important for improving patient health literacy, as Nurse Participant G said at the end of the interview that nurses are, "Very important, highly important. There'll be gaps if I don't make sure they're understanding". Nurse Participant L said, "Nurses are seen as, or as nurses we see ourselves as patient teachers. You know, about health, about uh, their medication, about their health conditions, about whatever. That's a major, major role in our work with patients". Nurse Participant L said about empowering patients, "You know, I have to address some of that stuff or else, you know medications alone can't do it all. Plus it's part of giving them some things to do to empower them, I think, things to empower themselves".

Opening the door to health

Like Nurse Participant L said, "And right after I talked to him about that like the next day he heard a report on the news about it, so he noticed it and he said "Yeah, I found out all these different things" about it and so it connects, it clicks. So me giving them some information, then they start to tune into it more, and so they're just more open to it in other places, too. Because there's lots of health information out there, and it makes them more aware of it and just more sensitive to what's out there and they start adding to it". Nurse Participant E said, "So it's really more teaching them how to read the labels, steering them towards healthy" about her role in improving patient's health literacy.

Nurse Participant L added, “The most important thing is to develop a trusting relationship, a working alliance, a working together. Where they are receptive to what I say, and I hear what they say, and use their information, what they have to say to me, and then they become open to what I say to them. So that’s the first thing, is how they’re responding, and if they say something verbally back”. To tune into where patients are at, “You need to slow down for that patient”, Nurse Participant C VI said, and this was a theme among the more experienced nurses that were interviewed.

Like as Nurse Participant C, says, “We have a responsibility to get them resources.” She later adds, “It’s a big puzzle to try to do all of that and sometimes you are very successful and sometimes you’re not.” Nurse Participant E said, “I think if you’re aware of what’s going on with yourself, you can take better care of yourself. The more information you have, the better decisions you can live with. So yeah, I think it’s very important that they understand what’s going on with health issues”. Yet it’s a challenge to “read people”, as Nurse Participant B said about assessing patients’ ability and interest health information, especially how they interpret and act on it. “That’s a tough one, on adherence, you can’t always read people,” she said. Comments like this lead to the development of theme eight. Theme eight includes nurses’ cynicism and skepticism in regards to the impact they have on patients’ health literacy, and that ultimately it is up to the individual how they perceive, interpret and act on health.

Expectation of Nursing

Nurses are patient educators and impact patient’s health literacy through providing a multi-faceted role in patient care. Even if not specifically “trained” in it, as Nurse Participant L said, “There wasn’t like a whole lot of emphasis on your role as to teach them, that kind of thing

because it's just so engrained, you do that already, and we do it well generally. So, uh, there wasn't focus specifically on like how to teach patients or the need for it, because it comes very naturally by this point. Uh, and, nurses tend to be good at relating to patients, listening, taking the time to get information, uh, it's rare for a nurse to do a 10-minute check-in".

Nurse Participant N said, "It's just part of the expectation of your job, is that patient teaching is part of it. I don't know how to state it any differently. I don't know how they specifically can mandate it; it's just an expectation and a role within their job" about training nurses about patient education and health literacy. Nurse Participant T said, "I feel that it's every nurse's intention to educate". Nurse Participant E said, "That's basic nursing education". "What are your goals while this person is here? What do you need to teach them? That kind of thing".

Nurse Participant O also said, "A huge part of nursing is educating. So I feel like you learn that in school a lot, and you're writing up all these care plans and such". Nurse Participant E said, "Every nurse is required to do teaching. You know whatever you have, that is one of your basic tenets of nursing. You teach people about where they are, what's going on". Nurse Participant B said, "I think there are good role models" in nursing and this impacts health literacy awareness training. Nurse Participant O said, "I feel like the way I educate patients is with my knowledge. So I am just sharing my knowledge with patients, just because there's a lot of people that don't know anything about healthcare. So it's just really just telling them what's going on and what to expect and what is going to be done and explaining procedures and stuff, so... you know I guess I feel like I am educating by the knowledge I have gained". Nurse Participant A said, "And I feel like that's the majority of our job and that's what we're there for, for the most part, especially in our field. But, then a lot of times you go home feeling like, gosh,

all I did was pass out juice and make sure that they got crackers (laughs) and change bed sheets, you know, which is important to feel comfortable and it's the easiest part of your job, but it's also the part of the job that you think, "This isn't nursing. This isn't what I do".

Theme 5: Emotional and Psychological Factors on Health Literacy

Emotional, mental, and physical factors influence nurses' experiences with patients, and theme five is about how they influence the perception of health literacy. During the interviews, there were many reports of how nurses relate to patients' psychological state, including strong emotions like fear, depression, shame or anxiety. They also perceive their mental state such as how distracted, overwhelmed, in shock or averse they are to the health situation. This includes reactions like trauma, denial and depression, all of which were cited as barriers to effective patient education. Nurses in this study identified the many demands that are placed on people in a medical situation, and how they may not be in a situation to handle them, mental, emotionally or physically. A theme emerged about nurses' relating to the emotional and psychological condition of patients, possibly more or equal to their immediate, medical situation.

"He was nervous, and I could tell that he understood me verbally, but, you can look in their face, and see that this might not be true" Nurse Participant B said. "When she came in, you could see she was visibly upset. I mean, visibly upset, rigid, visibly having a hard time to even communicate" Nurse Participant G shared. The nurses in this study talked about adjusting their approach to patient education in response to emotions. There was a theme about patients' receptivity to processing health information and it being a barrier. Nurse Participant L responded about barriers, "Their emotional state, yes, their emotional state, if they're real depressed, or how overwhelmed they are with other things in their life. You know their mood

state, like depression, anxiety, obsessive thoughts about something else, you know, just worried...what kind of state are they in, (makes me ask) - Are they able to take in?”. Nurse Participant T said, “When I come across learning barriers and I see withdrawing, and I see anxiety, and I see stress, then teaching can’t take place within that circumstance until you start addressing some of those issue”. Nurse Participant A said, “There’s a lot of other barriers, just exhaustion, I mean, mothers that even if on a full night’s sleep would be really patient with you and work with you and listen to what you’re saying and take in all the information - that would be ideal - but I mean, after midnight, after being awake for 24 hours, they just don’t have it in them”. Nurse Participant L said, “My patients deal with fatigue, low energy, low motivation, depression, and the blood sugar’s very connected”.

In response to the question about barriers to patient education Nurse Participant G said, “I would say emotional barriers. Denial. If they’re so emotional they’re not going to hear anything I have to say. They aren’t going to hear it. Or they’re going to come away with maybe two words. And it could bad, negative, or positive words that I said. But emotions are a big barrier”. Nurse Participant N said, “Disinterest, apathy, confusion” as some examples, which are psychological states and emotions, not medical problems. When asked about the barriers she’s encountered to patient education and impacting their health literacy, Nurse Participant G said, “I’d say emotional” barriers are huge, and “Denial is a huge one, a lot of women will come in, straight into denial, “Well that path(ology) must be wrong”. Or, “Maybe they made a mistake, or maybe I’ll wake up tomorrow and this is all a dream”. And it’s normal. Denial is a normal process”.

Nurse Participant N said about patients that needed to lose weight or change diet for health reasons, “But the problem is that they were in so much pain, and so incapacitated by their pain or their narcotic use, or usually both, that it’s not like they could go out and exercise to the point where they can lose weight”. She adds there are, “A lot of those people who are really in a catch 22”. Nurse Participant B said, “If they’re in a lot of pain, it’s difficult for them to comprehend a lot of things we may be telling them,” causing what she identified as “a pain barrier”.

Nurse Participant A said, “Yeah, yeah, for sure, and if they’re in pain, had a c-section, and you can’t get their pain under control, I mean they’re not gonna sit down and talk about baby care and diapering”. She said exhaustion is a barrier that she relates to during her experiences with patient education. She added, “So in that way we can help them get sleep and say (to them) “In the morning we can go through this other baby care. After you get some sleep””. Nurse Participant E said, “You need distraction when you’re in great pain. There’s only so much pain a person can endure, after surgery”. Nurse Participant N described her experience with patient education as mediated by their level of anxiety. She told me, “What I say is not going to impact them at all because they’ve got a baseline anxiety level, they’re about to walk in the door of an operating room. And they’re about to get Versa, which is going to give them retro-active amnesia, so they’re going to forget the lions’ share of what I say. I mean their family won’t but the patient certainly will”. And this expresses how nurses’ are relating to both the patients’ psycho-mental state and often turning to the family as a back-up resource, or influence, on the patients’ health literacy.

Nurse Participant L went on to say that for her patients, “If their energy and motivation is still way low, or their too depressed, or they’re stress is too high, or they just run out of time between kids and family and work and whatever. It’s a wide range of things. But determining it for each individual person”, the impact stress and mood has on health. Stress was also a common theme. Nurse Participant L said that, “A huge area of health - is stress; stress levels”. Nurse Participant E also said stress was a barrier. “It could just be stress”. Nurse Participant C says, “They’re in such a state of stress that even going to have chance to hear anything that you say.” As a nurse, she responds by telling patients, “I always encourage patients when they go to see a physician that they take a second person with them who will take notes just in case they are hearing bad news and they may not hear all of the information”. These are some of the emotions that influence a persons’ receptivity to health information and learning.

Nurse Participant M said about emotional barriers to her communication with patients is, “Frustration on their part that don’t understand, anger about their diagnosis - that’s a big barrier because I can’t, they won’t listen, or I can’t get the information across”. According to Nurse Participant T health situations are, “Usually just a very overwhelming process”. It is easy for a patient to “be really overwhelmed” she added. As a nurse, her role is “Definitely helpful in reducing their fears and that’s the first step in that path of learning. And feel more control”.

Increasing receptiveness

These nurses could sympathize with the stress patients’ experienced in relation to health concerns and problems. A theme emerged about increasing receptiveness to health information by addressing the perceived levels of stress and anxiety that a patient is experiencing. Nurse Participant L said about reaching patients on emotional and mental levels, “He was receptive to

it. He was receptive. Now, this was our 4th appointment. Part of it depends on what kind of state they're in emotionally. He's in a fairly stable place. Uh, he got a lot better from the last session a month ago to today because of a medication change I made. So he was less distressed and more receptive to and able to take in and understand information better”.

Nurse Participant L continued, “So once you take care of the most kind of crisis level, or the heavy-duty kind of symptoms, people have more energy and cognitive, physical energy, and emotional energy, to be able to tune into other areas of health”. For example with her patient, once he was no longer plagued by paranoid thoughts, “He was no longer paranoid. He had been paranoid and super anxious and just really worried and worked up. You know paranoid people, as we're talking about it, you can't tune into other health things very easily when you're distracted by paranoid thoughts”.

Nurse Participant G said about her experience in oncology, “The foreboding word, “Oncology”. I think when people hear the diagnosis, or even see the word “cancer”, they assume they're going to die. And so it's a foreboding diagnosis.” Which shows how terminology elicits emotions in patients and physical health can directly tie to mental/emotional states of mind. Nurse Participant G adds, that for her patients they react with fear, “All of sudden it's like, “Am I gonna die?” that's the first, almost always the first, question out of their mouth. And so part of that communication and so forth is to reassure them”.

Nurse Participant T said, “You can address their fear and then you can link it to preventive measures” as one way she educates patients and works with emotional and mental states. Nurse Participant T adds, “I think that if you can in any realm provide education and explanation, it gives them some tools to feel more in control of their situation or their body, I

think that that's reassuring to them and kinda reduces anxiety". Nurse Participant B said, "And it's like, patients get nervous when they come in here, they're scared", which reinforces the theme of patient's emotional state and preparedness for a traumatic health situation. This impacts their ability to read, comprehend and act on health information, and nurses' sensitivity to it.

Providing reassurance

Nurse Participant O said, "I try and re-iterate everything, tell them multiple times and just reassure them that things will get better. Luckily, especially with the ostomy, it's temporary most of the time, so they can get them reversed. I just try and tell them they'll only have to deal with this for a certain amount of time and it will get easier. Tell them that people lead normal lives with it; and you know, people are just really self-conscious, so I'll reassure them". Nurse Participant N said, "Any teaching that I do with people pre-operatively is mostly geared toward reducing their anxiety".

Interest and willingness to receive health information was a theme that emerged as nurses identified barriers they perceive to patient education. Nurse Participant T described that in her experience with patients, "You'll find that they can't afford to be there, like when you see somebody that's pulling away from you, or withdrawing or disinterested, and often times you see it as urgency and stress and wanting to get out and that's the priority. So until you address that concern everything else is null and void. So it becomes, "You seem anxious". We do a lot of reflecting. "You seem anxious to leave." This shows how she is perceiving patient's state of life and mind, and relates this to the factors influencing health literacy.

Nurse Participant L said, “Sometimes people are not open to it and kind of feel kind of irritated. And you know, sometimes they feel like I’m acting like their mother, like nagging them” about relating to patient’s emotional state and having a sensitivity to how people respond emotionally to health information. According to Nurse Participant O, in her experience with patients’ who had undergone osteotomy, acceptance and emotional reactions like repulsion, were shared. She said, “People are repulsed and disgusted by it and they don’t want to deal with it. So just getting them to accept it is a big part of it”. These nurses’ used emotional states to determine their patient’s ability to receive information.

The mental & emotional toll on health

According to recent research, both intrinsic and extrinsic factors are at play, which are often difficult to identify but can significantly influence an individual's health literacy. For example, the complexity and emotional toll of illness or disease can leave even the most highly educated patient or family member confused, frustrated, and mentally exhausted (Bryan, 2008).

Nurses may not be trained to handle this aspect of patient-provider encounters. As Nurse Participant B said some nurses, “They’re totally not either trained for or they’re frightened about it”. She continued, “I’ve had employees come to me and say, “I’m a little nervous to go talk to this patient because she just screamed at me the last time I talked to her on the phone.”” Along these lines Nurse Participant E also talked about anger directed toward her by an emotional patient, “But when I did that, she screamed at me and said, “I came in here for my vacation! You guys promised me a vacation. I want that medicine!” And I said, “If you want,” – she was swearing – I said, “Let me just step back and wait and why don’t we let things cool down.” And I came back in 5 minutes and she goes, “You’re right, I’m sorry, I lost it. I normally see the pain

clinic up at Mapleton, and you're right, I did totally lose it. It was inappropriate, let's just go slow." And I said, "I'm sorry, I just don't know you that well". Whoa".

"There's nothing worse than not being understood. That's where you get really aggressive, unhappy people", Nurse Participant G said. Here she links the verbal and non-verbal assessment nurse do with patients to changing her communication approach based on what she picks up from them. Avoiding patient's anger, fear or shame was a theme around patients' health literacy and nurses' experience. Nurse Participant O said, "I guess I don't want to embarrass them" about how she responded to a patient she believed to have insufficient health literacy. Nurses are aware of emotions like fear and shame, which as Nurse Participant C points are is compounded by factors like family members influence. She said during our interview, "But I think there was a component of fear, as well as a component of whether or not we were going to turn him in, and probably embarrassment being in front of his family and not being able articulate his needs".

Readiness to learn

"It's overwhelming" Nurse Participant L said about health encounters. "Plus they're coming in with a lot of symptoms or they wouldn't be here, you know. So there's only so much they can handle". The state of mind is also physically linked, as with medication-induced sedation and this was identified as an immediate and long-term influence on health literacy. As Nurse Participant N said, when she sees patients in the pre/post op setting, "We sedate them right before we are walking out the door of where I am. So a lot of it is sort of addressed to the patients and their families" because the patient is not ready to learn or process new information.

Another example, Nurse Participant T said, “There’s a huge issue with, you know, being ready to accept learning” about how nurses’ perceive psychological influences and readiness. Especially when the health encounter and instructions are so far reaching, like when Nurse Participant T said, “If you just told someone they were, they have heart disease and that they have major exclusions and they’re going to have to change their whole diet and their lifestyle and they just had a heart attack, they’re probably not going to be in the mood to learn a lot about cardiac health. They’re probably just freaked out by the fact that they almost died”.

The luxury of being prepared mentally and emotionally for health situations was also clear in Nurse Participant C’s responses about patients’ being health literacy. She identified it as, “the luxury of being prepared versus unprepared”. She said, “In our setting patients don’t always get the luxury of preparing to have surgery, or preparing to have, uh, a life-altering event”. Nurse Participant O, who also works in a hospital setting, said, “A lot of it depends on what the circumstances are surrounding their ostomy is. Some people come in knowing that they’re going to walk out with it, some people come in and have emergent surgery, and they’re never expecting or planning to have it. So the people that know that they’re going to have it, and they come out of surgery more prepared....Well their preparation and pre-op preparation has a huge impact on it”. The circumstances around a patient as well as the internally experienced factors were noted by these nurses.

Safety is a concern for hospitals and part of the incentive to promote patient-provider communication education. Nurse Participant T said, “Upon admission they ask them what their greatest fear is and what their greatest need is, and I’ve never heard or seen of that in another hospital. When I go to my patient summary, it says “Greatest need” “Greatest fear”. And I think

that's a really pertinent question because you can't really teach somebody unless you know what the biggest issues are in their head". Nurse Participant G said, "If you're nervous about your care, it's going to be harder to get well and get discharged. So the nurses responsibility with taking care of the patient is also assessing whether they feel safe or not". Nurses' dealing with patients' sensitive emotional state and providing reassurance links to the hospitals' concern for health literacy and safety. Nurse Participant E also said, "But when you shift into a new environment, you sometimes, you just need to just give it time and it's safer. It's for nurse safety and safety is a big concern. The idea is 'Do no harm'".

Nurses talked about patients being overwhelmed and more information could be harmful, not helpful. Nurse Participant E said, "There comes a time when some people have heard too much. They're at a cap and you just have to stop. But I also know that when people come into the hospital they'll say, "Nobody ever told me that before." When truly it has been said, it's just that when you're under stress, you only hear a little bit each time. So that's why you give them written information to go back over later; it helps". As the immediate situation may be filled with emotional barriers, nurses' rely on written materials to provide a "safety net" for patients to get the information they need to understand and act on health.

Leading into theme two, Nurse Participant O said, "The barriers include feelings of overwhelmed, they're repulsed by it. Again, also, medication and the recovery from the surgery, you know we are dealing with people who have just undergone major surgery, so they're tired, they're weak, they're getting medicated with pain medications - it's not an optimal teaching "environment" or situation for them. So that makes it difficult. We have learned that 80% of everything we tell them is just forgotten. And so that's why we do it all in writing as well".

Theme 6: Language & literacy, culture, & family influences

Nurses use patient's family members to communicate with patients even though it is against hospital policy. According to the nurses that were interviewed, family is an important factor in patient education and health literacy. Nurses are relating to them often, as a means to translate for a patient who has a language or literacy barrier, and indirectly as a part of their perception of how a patient will ultimately act on health information. Family is respected as an essential source of support for people going through a medical crisis or coping with a health condition, but also recognized as a force more dominant in a patient's life than the professional medical advice of nurses or doctors. Observing exchanges with family, and influencing the perception nurses' have of a patients' health literacy was best noted by Nurse Participant T who said, "I hear them talking to their family or friends or loved ones, you might hear a very different side of them".

Interpreters that are medically-trained and contracted with a hospital are readily available although not always convenient to arrange, and cost money. When available, they are regarded by nurses as useful to communicate messages to and from patients, although there was a theme about a "disconnect" created by the use of a 3rd person, whether professional or family. This was a barrier identified by nurses in this study, along with translated written materials that are not helpful if a patient cannot read. The issues around language, literacy and culture make it more difficult for nurses' to know if the patient is "really getting it" and able to understand, know and act on health education.

Language barriers

“Language is a barrier” to education identified from Nurse Participant E. Nurse Participant B said, “The other biggest thing I need to share with you is that the language barriers that we have with the Spanish-speaking”. Nurse Participant N said in her experience, “There’s tons of language barriers issues that come up, because we have a big Spanish-speaking population, there’s a pretty big Latania(?) community in that neighborhood as well and those experiences are hard to deal with”. Nurse Participant O said about her patients, “At Rose we have a large Russian population, because we’re Jewish, so there’s a large Russian Jewish population here. And I don’t speak a word of. I know one word in Russian. So that can definitely be difficult. We do have Spanish speakers as well, and I do actually speak some Spanish so that helps. But no Russian”.

Relying on minimal skills

Nurse Participant A said, “I did take a medical Spanish class, and we have such a huge Spanish speaking population, I get to practice a lot. I’d say every time I’m at work, I have at least one if not all of my patients that are Spanish speaking”. Nurse Participant N said, “I speak it (Spanish) well enough to help them wake up from surgery and to have them take deep breaths and move to a bed. And explain their pain meds, but that limits it. But if we need to really get a solid health history from somebody or get their informed consent and that kind of stuff we have to use a translator phone”. Nurse Participant M said, “He spoke Spanish only and either the interpreter was late or wasn’t coming, you know not speaking the same language, sometimes there’s a disconnect with whether a patient actually needs a translator”. She followed up by saying, “And in this instance, he had no translator, no family nearby, and I was trying to communicate with him the best that I could”.

Nurse Participant B also talked about the impacts of cultural diversity and language. She experienced the “Language barrier, and it’s not just Spanish, we have had Vietnamese. A little bit of Russian, too. Language is a big barrier to effectively communicating with patients”. On the topic of cultural diversity and ethnicity, Nurse Participant A said, “Oh, we see a ton. We keep seeing more. We see a lot of French, like from African nations, and then a lot of like Arabic and Farsea (sp?), there’s a lot. We just recently had a big influx of Burmese, which is kind of odd. And then, just kind of a lot of like people that are Ethiopian and Somalian, but I don’t know exactly what they speak, but it’s a language I don’t know”.

Nurse Participant E said, “There’s interpreters, for the language barrier”. Nurse Participant N uses a telephone service. She said, “It’s a 3-way phone, and we have a contract with a translator service, so we call them with our account number and what language interpreter we need and they magically appear on the phone”. Nurse Participant E said, “When there’s a language barrier, there’s an awesome resource, there’s Inter-Nurse System and the hospital has a system of, well first, we do have Spanish interpreters in house, so they can just come with you. But if they only speak Lithuanian, or Korean, or whatever, there’s 1-800 number you call, and you ask the questions, you ask like 3 or 4 questions and hand them the phone, they ask the questions and then you ask, they say, do you have any questions back. It’s kind of a back and forth thing”.

In order to meet some of these language challenges, nurses mentioned things like, “We have translator phones” (Nurse Participant A). Nurse Participant M continued, “So we actually have to use a service, state the time we need them to translate and sometimes they’re late, or still at another appointment and you can’t talk to the patient until they get there, so, you kind of get

by with gestures”. Nurse Participant C “I think that we communicate through our translator phone when we have people who don’t speak English is not their primarily language. We have this phone service that we can call.”

She said, “So we had to find the right translator to even be able to tell her what was going on with her person. It’s very specific. And in healthcare you cannot rely on family members to translate to give them, you’ve got to make sure that you’re giving them the right information at the right time to the right person and you can’t always rely on family members to be able to do that”. The contradiction is again clear through the words of Nurse Participant C when she replied, “We used the Sericom phone as well as his family to try and discern what the patient really did need. And through the 2 sources I think that we were able to achieve what the intent was, although I’m still not clear that he knew exactly what he was supposed to be doing”.

Translation services

Translation services are a gift, yet a hindrance and barrier to relating to patients’ health literacy. For example, Nurse Participant G said, “I’ve had several Latino women and language is a (barrier). I wish, I wish, I wish I spoke Spanish, at a medical level. Because even going through an interpreter, you lose so much of that intimate, uh, cause you have a tendency to stare at the interpreter rather at the person, and the interpreter says, “You’re trying teach him, now don’t look at me.” You look at who you’re talking to like you’re having a normal conversation. But there’s still a wall, I feel like I can’t just get in there and do my realm”.

Nurse Participant A said, “I’ve never run into having a language that they don’t have a translator for, which is amazing.” Nurse Participant A added later, though, “So they get on the

phone and you talk to the translator and the translator talks to the patient so you have this middle person. Which I mean it's nice, that there can be some communication, but it definitely takes away the um, I mean you can't really bond with a patient, I think that well, through a phone". This supports the theme of there being a "disconnect" created by telephone/translation services and interpreters.

Per Nurse Participant B, "That's the biggest thing (language), because we don't want the family to interpret for them. Because they're not medical, so that's where we get, you know, the lights are on and they're shaking their head and they don't understand". Yet dealing with this can cause additional problems, as she add, "- we have to pay for an interpreter to come to the appointment with that patient"..." the State made mandatory that you have to have an interpreter there and we have to pay for it". It costs money, and as a management level nurse, she is acutely aware of this factor when relating to (and attempting to address) patients' health literacy.

Family to translate

Nurse Participant M said about a translator being too late, "But in this instance I couldn't communicate with him. So I just waited 'til the family came back". She added, "I just used the family, just to get the signature required". Nurse Participant O said, "I don't think I've ever run into a situation where I've had a non-English speaker that didn't have family there. We use a lot of family to help communicate. And usually I can communicate the needs to a family member who is there to help". Yet she was not 100% trusting family, as she adds, "I don't know if they're getting the information they need. That's the only way I have to communicate with them, and then they can't read, and I can do all my everything, but who knows if they're getting

it”. Nurse Participant O said, “I sometimes wonder what some of our Spanish speakers... sometimes I feel like I hand them stuff and they kinda like, I’m not sure they’re really getting it”.

Communicating with family

Family is a tool, for example Nurse Participant M said, “Usually it’s the people that they bring to the appointment that are the ones they want to know their health information, so we’re ok there but, when I get phone calls I have to verify that sort of thing.” As Nurse Participant N said, she sees patients “and seeing their families”. Nurse Participant E said, “And if your patient just isn’t getting it, you work on getting a family member. Say to them, this is kind of what I’m trying to say, so at least they’ll have somebody at home they can ask”. In line with the family theme, Nurse Participant L routinely asks patients, “What support systems do they have, like family. What support systems they have because those are all very inter-connected to health status, emotional health, physical health, you know, that kind of thing”.

Family is considered a positive factor in patient communication and education as Nurse Participant C said, “I think we try to do as much teaching as we can with family, but a lot of times there is no family around”. Nurse Participant E said, “We work to make sure that they have homecare visits, another person actually in the home that can check on them on a routine basis, if it’s something that’s beyond what they can do themselves. Or if there’s a family member that we can get to help like that”. Family is a tool, and one that is heavily used. Nurse Participant C said, “Yes, as a tool, but not as the primary way to get information to the patient. Certainly there’s a component that you want to make sure that family understands what’s going on with the patient. And maybe a separate conversation as opposed to a concurrent conversation, with family and friends”.

Nurse Participant B shared this story, “His wife asked if they could have a moment, and I said, “That’s fine”. So I left them alone and the she came out and she said, “Um, he’s very embarrassed because first of all you talk in bigger terms than he understands, and the doctor, too, ‘cause the doctor goes over the procedure”. Her perceptions of patient health literacy are inclusive of the family that is or is not present, and here was evidence of how greatly it can impact the nurse-patient experience.

According to Nurse Participant B, there is a flip-side to family, though. It creates a complex layer between a nurse and patient, and one that may be a barrier in the immediate situation. She identified, “Over-bearing spouse” as a barrier to what she thought to be effective patient education and communication. When I inquired as to how, she said, “They interrupt and they will be the person answering the questions”. In responding to them, she says that she said, “And it’s like, wait a minute, we’re talking to him, you know. So sometimes that’s a big barrier because you don’t know if you should be telling her everything or let’s do it together, let’s talk to the husband and wife together”.

Nurse Participant G talked about a patient of hers that was newly diagnosed with breast cancer and, “Her husband wants to have another baby and that’s his focus, **not** her breast cancer right now”, and that was influences her perception of the situation and ability to act on health information. Nurse Participant A spoke about the new mothers that she works with and said sometimes, “Dads are really supportive and they’ll watch the baby and do all the diaper changing and wake up and be fully helpful with the care. So a lot of times you can do the teaching to the dad, because he’ll be more responsive or he’ll just be at a better place to learn, and then hope that he can communicate to the mom later on”.

She adds, “You have to see where he’s at. You know, some dads are like “This is her deal, don’t talk to me about it” you know, so you just kind of have to get an idea of them”.

Nurses relied on family members to communicate essential messages to patients, despite it being against company policy or an accrediting body’s guidelines for patient communication. Nurses realized this because using family means that they do not know exactly what is being communicated. Yet theme six includes family and culture because these are important and strong influences on health literacy. Family, language and cultural diversity were some of the founding catalysts for health literacy research and the basis of much of the increased awareness in the health care world. Nurse Participant M said, “And technically we’re not supposed to use family to translate, we’re supposed to get somebody, but in this instance, when you have high turnover, I’m like “Ok, can you please tell him this, tell him this, tell him this, so we can get moving, you know. But one of the family members had to sign the paperwork for him, but they read it out loud to him”. She added, “No, you’re not supposed to. You’re supposed to have a, uh, because you don’t know what they’re actually telling them, the family”.

Diversity in healthcare and health literacy

Nurse Participant O said “I also think previous experiences influence them, like when they know people who have had them and had bad experiences, so they just think they’re going to have a bad experience” and this shows how family influences patients’ health literacy. “Additionally, low health literacy is often compounded by shame, a social network with equally poor health literacy skills, and personal and cultural perceptions toward health and disease” (Andrulis and Brach 2007; Paasche-Orlow and Wolf 2007).

Nurse Participant A spoke about the influence of culture and family on patient's health literacy when she said, "A lot of it is cultural and you almost kind of know right off the bat, especially a lot of our Spanish speaking moms, especially our Mexican moms, there's a culture". She adds, "You kind of do teaching about, "This is significant. This is colostrum, it's great for your baby, blah, blah, blah." But they'll say I want to do both and I need a bottle. So they'll bottle feed regardless of what I tell them". Nurse Participant A said, "But these other moms are like, "No, no" especially if there's a grandma in the room, whose like the matriarch of the family, and maybe if that person wasn't there, the mom would not feel as likely to not". She adds, "You know, that person has obviously more stock in what their mom says a lot of the time than what the nurse says. And so that can be a barrier".

Theme 7: Policies, Procedures & Standardization of Care

"I am very passionate about patient care, and wish there was more time, more hours in a day to do what we want to do for patients", said Nurse Participant C. According to the nurses' interviewed, in the "real world" of nursing, there is pressure to "keep things moving". The shortages of time, staff, and financial resources impinged their intentions for proper patient education and communication. Theme seven is about how hospitals have policies, protocols, and standardization of care because they are more concerned with "image" of safety, than nurses' ability to actually improve it.

"Everything is mandated"

Nurse Participant E expressed, "The hospital is very clear that you should be teaching. You should be teaching, you should be teaching. There's care plans for every patient, they need

to be updated every day”. And it is mandated, as Nurse Participant N said, “Everyone’s mandated to do a ton of teaching. Everybody’s mandated to do teaching on whatever, and patient teaching is a part of mandatory documentation. Patient teaching is mandated, and if we don’t have any documentation that we’ve done any teaching with somebody that is going to be a big red flag with regulatory agencies”. She adds, “I mean it’s dictated as part of our care and that we need to do it. It needs to be documented and addressed”. Nurse Participant L added, “It’s required, it’s a necessary part of treatment. Prescribing medications requires that you give patients adequate information about what they’re taking and making sure it’s very clear”.

Literacy needs are required to be assessed upon intake and is mandated, according to Nurse Participant T, “When patients come into the hospital there’s always a screening so for me as a nurse it’s sort of a no-brainer as far as literacy issue. That’s addressed in most hospital systems to my knowledge pretty upfront and it’s part of the screening process upon admission into hospital systems”. Nurse Participant A said literacy screening is a part of admissions process and, “They have to ask questions about language” which she trusts to be accurate. Policies and protocols may be excessive or intrusive to patient education, although it seems that that healthcare organizations impose them to create a safe environment and help providers pick up on those hard to read patients. Clear guidelines are in place to protect patient, nurse, and provider from unclear situations leading to safety hazards. Nurse Participant G added, “So communicating patient safety to your patients that they are safe, you, if you don’t feel safe, you’re not going to well”.

Image of safety

Nurse Participant G said health literacy policies and procedures are, “Vital for safety. Safety is the hospital’s primary concern”. The hospital policies and procedures around patient health literacy are a part of creating a safer health care environment. She adds, “I’m assuming literacy means the way I defined it, unless you have a different definition of literacy. I mean the word ‘literacy’ means “Can you read?’ Are you literate?” Then if you have an illiterate person come into the hospital system who can’t read the nurse call light, or doesn’t know the sign on the door says “Exit”, or they fall out of bed because they didn’t realize they weren’t supposed to because the nurse couldn’t communicate with them, well that’s a safety is huge”.

Nurse Participant N said her hospital is, “Supportive of it”. Nurse Participant T said about her new hire training, “They go over policies and procedures, and the groups tend to get smaller and more specialized, so it gets a little bit more specific. It’s basically just their policies and procedures, and there’s a lot of computer training in their computer systems” and not about health literacy assessment or impact. Nurse Participant O said at her hospital trainings on patient safety and education is required. “They’re mandatory twice a year...and we have ongoing education on the computer”. She adds, “Those are mandatory”. Nurse Participant T said during her new-hire orientation as Good Samaritan hospital, “Well, they give you the whole corporate spiel about what Good Samaritan stands for, like when they were established, or how they were established, and what their core beliefs are... the image that they want to portray”.

Image versus reality

But the instruction actually provided to newly hired nurses may not be adequate. At Nurse Participant C’s hospital, she said patient education is on the agenda, but “Patient education is actually only given about ½ a day in priority”. There’s the ideal world and the realistic, and

according to Nurse Participant C the training scenario can fulfill that image because, “That’s in an ideal setting. Because, again they don’t have a full patient load, and it’s kind of like taking it of the context of the everyday work week until it gets toward the very end”. Nurse Participant T said, “Good Sam the corporation or Good Sam in actuality?” about her health care organization’s priority for patient education and nurse communication, again bringing up the theme of perceiving conflicting messages.

According to Nurse Participant E, the limits on time and staffing “It’s the nature of the business”. Nurse Participant N said, “It’s not the reality of what those nurses’ day is like, that they can sit down and do ½ an hour of teaching with somebody about their new diagnosis of diabetes. And that’s why we have various educators who hopefully are picking up some of that slack. It’s just not realistic to”. Nurse Participant C said, “My nurses have a very high nurse-to-patient ratio of 5:1 on days and 6:1 on nights. So the luxury of being able to teach a new diabetic is slim to none. Or the opportunity to teach them about their newly diagnosed heart condition or their blood pressure or something like that is kind of like “Here read this” you know”.

Nurse Participant C said, “We need to keep patient flow going so that we don’t back up all the intensive care patients in the ER and in the OR and that through put thing is a big deal. There’s a lot of pressure there, a lot of time pressure... They give a lot of lip service to it. Again, because of the whole through-put thing”. Nurses felt limited by time, and despite intentions and hopes of fully educating and engaging with patients, they reported, “The window that I have on that is tiny”. Nurse Participant T said, “We’re supposed to be explaining what we’re doing, but the sad thing is that a lot of your time is pretty limited”. She adds that in the real world, “There’s

a lot of “Yup, yup, sure, yup.” (from patients). But are they really understanding? Probably not, and how much time do I have to hang out to evaluate how much they’re learning? Not much”.

Nurse Participant O said about time constraints in her hospital, “Hospital stays, they’re getting shorter and shorter, so there’s people that come in with these major surgeries and go home with ostomy’s and their only in the hospital for 2 days, so you know, the time frame for teaching is really short”. Nurse Participant C adds, “But we had a patient not too long ago that was a brand new diabetic who, thankfully, somebody had the time to talk to them about community resources and who to hook up with and get some teaching because that wasn’t built into our day”. Nurse Participant A spoke about her experience as an OBGYN nurse. She said about hospital protocols and procedures that “And it’s kind of hard for us, and hard for the patient, because that’s not what we do and we’re kind of lost and they don’t get probably the care that they could get if they were on the medical floor” about the staff shortages and financial pressures.

“Physicians frequently overestimate the health literacy of their patients and often, in the rush of the day, lapse into using medical jargon--a practice that exacerbates patients' reluctance to ask clarifying questions” (Bryan, 2008, Castro et al. 2007; Kripalani and Weiss 2006). For Nurse Participant T, she said, “Basically the education comes down to, “Hi my name is Nurse Participant T, I’m going to be your nurse today. I have a couple pills for you. This one’s for your heart, and the one’s for your cholesterol, and do you have any problems swallowing pills, are you hungry, do you need to go to the bathroom?” And then I leave. That’s the education”. And as Nurse Participant M said, “That’s hard, because there’s what I have to tell them and what I want to tell them, and then, yeah, protocols are a barrier at times”. Nurse Participant T said,

“We’re not supposed to document, “Patient is angry”...” “Patient was anxious.” Patient was...., but you’re not supposed to. And it’s hard because you want to say, “They’re screaming obscenities at me!””.

Nurse Participant C said, “What they do is that there are policies and procedures in place that state what we do with patient education and literacy” and she added, “The expectation is that you do follow those written policies and procedures that you will provide this and you will provide that, but the operationalization of that left up to the individual. And again, it depends on your level of expertise”. This ties into the theme about individual responsibility and despite policies and procedures being in place, there is always an individual involved who has a choice. For Nurse Participant E, she said at her hospital, “The culture is very patient-central. You know, it’s very patient-centered. You are to ask them what their goals are when they first come in. You know, “What are your goals for being here?” Most people look at you kind of blankly, and go, “To go home.” But other people, you know, out of the blue, every once in awhile you hear a goal, and then you’re like, “Oh, ok, yeah, we can work on that while you’re here.”

The conflicting messages from healthcare organizations about health literacy put a discrepancy between the day-to-day experience of nurses and the hopes of fulfilling that mission. The pressures to save money, the limits on time and staffing, in addition to mandatory documentation requirements overshadow the messages they are given about the importance of creating a patient-centered, health literate environment. Also, the training is mandatory, tedious, and perceived as boring. This theme is about both the benefits and drawbacks to standardization of health literacy screening, assessment, and patient education.

Theme 8: Individual Responsibility

Each person is responsible for their own health. Everyone has their own agenda and priorities that affect their health literacy. This was the impression given by the nurses in this study and lead to the creation of theme eight: self-responsibility. There are limits to the scope of influence these nurses have in improving patients' health literacy. During the interviews nurses proclaimed that it is ultimately up to each person how health literate they are or can be and that their job "ends when they walk out of the door" and they cannot "change the world". Skepticism about people's motivation to change and their dedication to better health and health literacy was a theme. Self responsibility is required and this also applies to nurses and how they each ultimately decide how serious to take patient education responsibilities. Each nurse chooses their methods of teaching patients, whether simply "following the book", i.e. protocols and policies for the minimum, or completely individualizing the needs of each patient and addressing those.

Self-responsibility

Nurse Participant N said, "It is totally up to them and how motivated they are". Nurse Participant G said, "It's really up to the individual person, how far they take it and how serious they take it". Nurses' assess patients' motivation and willingness to engage in health, including the likeliness of follow-through and adherence. Nurse Participant C added, "But it's a choice if they want to come back or not". The theme here being that nurses do the best they can to educate their patients, but they do not take responsibility for the outcomes. There are limits to what a nurse can do for a patient, and there are patient responsibilities.

"I feel in a lot of ways my job ends at the time they walk out the door" according to Nurse Participant O, and she said, "I have done what I could while they were here. But when

they're done, it's really then they are in the doctor's hands. If they have a problem, call the doctor – they don't call me. I mean, I reiterate with them, if they have any questions or concerns, they need to call the doctor because I don't go with them, basically". Nurse Participant T said, "When it comes to when they leave, it's out of your hands and you don't know whether they're going to do it". She added, "I think you just do the best you've got and send them on their way and hopefully, hopefully you had a chance to care about them, and you had a chance to care about them enough to encourage them to care for themselves". Nurse Participant O said, "Unless they have a complication I don't see 'em again. Again, my job ends when they walk out of the hospital, so follow up is really not my concern, it's theirs. I just do the best I can while they're there and teach them what they'll need for home. Hopefully I've given them all the information they need for home".

Nurse Participant E said, "But if somebody is motivated to change, like if they show up with a heart attack, and if motivation is really high to change, but then if they come back in 6 months and their weight's the same, they're still eating all this salt, it's like, what can I say? You know, "I gave you all the information. It's up to you to act on it". She added, "It's still their responsibility" even if she is involved in their medical care. She adds, "There is a lot of self-responsibility, you know, we (nurses) can't take it over. You know, I can try to change **you** to do everything I think is right for you, but all it's going to do is piss you off (laughs). You know, the idea is to do this together, "Here's the information" you can act on it. You can do what you want with it".

The question of how well a patient might have understood the information they were given, as to be able to act on it, was not specifically mentioned though. The absence of this is

noteworthy in light of the health literacy definition. Nurse Participant C's response here: "If they're prepared, if they've done the reading that they need to do, gotten the knowledge that they've needed to, I think their outcome is going to be better than what it was without that information. But I don't know for sure". Preparation is part of planning for health, yet Nurse Participant C said, "What you've got to worry about is that group of people who have the unexpected, or the unplanned, and how you reach that group to be that same savvy, as your group of elective people." Nurse Participant T said, "So I think often times unfortunately those things become issues the patients cause them to ignore a lot of their health cues, a lot of their sickness, so they don't take care of themselves because they're so preoccupied with taking care of other people, or a job, or trying to make money, and they don't have a choice". The ability to prepare, and the decision to be prepared amongst all the other priorities of life are perceived influences on patients health literacy.

Individual Nurse Responsibility

Nurse Participant G also tied it to nurses' individual responsibility by saying, "I think it's up the individual nurse how serious they take it". Nurse Participant A said, "I think a lot of the nurses are complacent and do a lot less teaching". Nurse Participant C said in her interview, "I really didn't do the research that I needed to when I had my knee surgery done" and therefore she was irresponsible. Many nurses brought it back to themselves, linking the responsibility they feel for patients to their own limits. Health literacy is partially a choice. We all make decisions about our own health literate we are and the choices about how to act and what to believe.

Patient Responsibilities

Nurse Participant O speaks about the limits to what she can provide to patients as far as impacting their health literacy, when she said, “Some of that stuff (about healthcare) the patient has to know. There are many different insurance companies and they all have, you know, different policies and whatever, so sometimes patients *do* have to do their own leg work and find out what their financial responsibility is”. Nurse Participant E said about her encounters with patients requesting pain medications, “There’s times when they/you need to take responsibility and understand that someone’s passing through your gut with a scalpel, and it’s going to hurt. So you need to get up and you need to move and you need to look around, you can’t just lay curled up in the fetal position, and say, “I hurt. Give me more meds”. Nurse Participant T said, “They’ll say, “My sugar’s have been good.” Once again they tell you what you want to hear” which expressed the skepticism she felt about patient’s desire and willingness to change their behavior toward health. Or as Nurse Participant B identified it, “I mean they always have 100 excuses... They make up a lot of excuses as to why they cannot comply, or all they want is a quick fix, “Give me a pill.” You know, “Give me a pill for this”, and I’m like “No.”” These responses indicate some skepticism about patient’s motivation or their engagement with appropriate health decision and responsible health action.

Cynicism

Nurse Participant N said, “I mean if you tell a smoker to quit smoking because of their health, it’s not news to them. There’s not one person on the planet who smokes, or there’s not one person on the planet that’s overweight and doesn’t know that they need to eat right and exercise. So a lot of it is – there is a lot of people who know what to do, I mean me included;

You know I've got 30 lbs. to lose and I had potato chips with dinner last night (laughs). So there's tons of people who know what they should do and either are unwilling or unable to do so". Nurse Participant E said, "You know I have my agenda, but obviously when they're in the hospital they have their goals as to what they want to learn, too. Whereas I may feel I think it's really important that you learn about hypoglycemia, diabetes, because your blood sugar is beyond, and you're going to pass out and so I feel it's real important to teach you that. But if you're like, "No, no, no,... So you keep focusing on that, and it's like (sigh)". Nurse Participant B said, "I do a lot of the triage calls with patients who are calling and saying, "You know, I had surgery and I don't have any of my information." And I know darn well that they had surgery downstairs, they go through the sheet with the person that takes them home. So I'll say, "You know, who took you home?" "Well, my wife...." "Where's your wife?" She went out to get the pain meds. (laughs) Ok, "There is a sheet of paper, now ask your wife when she gets home..." - Because she has the information".

Some of the cynicism comes from experiences like this one told by Nurse Participant T, who worked in a hospital that had "frequent flyers". She shared with me, "That's what nurses would call them, 'frequent flyers', patients that just keep coming back, same problems, they keep coming back because they're smokers and they don't want to quit smoking. We had one guy back home that the ambulance would routinely pick up and he'd have a six pack on his porch, and smoking cigarettes with his oxygen on. His liver was shot, he didn't want to quit drinking, his lungs – he was oxygen-dependent, didn't want to quit smoking either, but yet he would continually come back into the hospital, and what do you do? "

"You can't change the world"

Part of this theme has to do with nurses' feeling as if they reach limits, yet they "do the best they can". Nurse Participant E said, "There's just sometimes when you just don't click with somebody. You have to understand you can't change the world. So you have to go on to the next nurse, and say, "I tried this, see what you can do." And sometimes a different approach - because everybody has different learning styles, and there's a limited amount of time, I mean, I could do my best". Nurse Participant A shared her concern for improving health literacy, but hitting barriers with teaching new mothers about breast-feeding. She said her concerns are, "Not about the baby in general but, you know, breast-feeding is great and it has so many benefits, but they're thinking, "But the bottle's easier and why..." why would I be worried about my baby getting diabetes 20 years from now!? I feel, this is important, I say to them. But you have to stop yourself and think this is really what's important to them and if you can give them just a little bit of knowledge maybe it's good".

Nurse Participant N said, "I know that if I'm taking care of a homeless alcoholic, I'm not going to impact that guy's health literacy. And neither are you, nor is any campaign on the planet, going to do nothing about that unless that guy decides to stop drinking. In which case, he will connect himself with the resources that he needs to improve his literacy". Later Nurse Participant N said, "So, the short answer is that I think health literacy is very important, the long answer is that I can't make anybody take responsibility for their own health".

Nurse Participant E said about patients who are admitted to the hospital who smoke, "If you get admitted and you're a smoker, we'll give you the information, and it's up to you to act on it. We gave you the information, and you just can't smoke in here"... "I'll get you a nicotine patch. For me, it's just like, it's your choice on how you decide to live your life. If you wish to

do that, you know, I can teach you that you're going to get pneumonia when you have surgery and you're going to recovery slower, because of the junk in your lungs, and that's just the way it is. But, to act on it, if you're not at the point in your life where you're gonna quit, you won't but you still have an option".

Nurse Participant M said about the barriers to patients adhering to health information, whether written or verbal, that there are, "People that do fully get it and you know have their own agenda and they're going to do what they want either way". Motivation and self-responsibility are essential, according to these nurses, who also present some cynicism around people's true intentions and abilities to act appropriately on health information. Near the end of my interview with Nurse Participant B, she said, "You can't force someone to comply. You really can't". And in the first interview, Nurse Participant C said, "So you've done the best that you can with what you have on that day that you're doing it". She adds, "There's a responsibility that the individual needs to accept about their health. And that they need to come prepared and ready to do the work of getting well".

Empowering patients & self-responsibility

Nurse Participant L said, "It's important for them to think in terms of their own responsibility for their health". She adds, "Plus it's part of giving them some things to do to empower them, I think, things to empower themselves" about how important it is for her to improve health literacy. Nurse Participant O said, "It's your body you got to find someone you trust" about the how important it is to be health literate. Nurse Participant C" There's a responsibility that the individual needs to accept about their health, and if they come prepared and ready to do the work of getting well, they can". She added, "It's truly participative. If

they're prepared, if they've done the reading that they need to do, gotten the knowledge that they've needed to, I think their outcome is going to be better than what it was without that information".

Nurse Participant G said, "The nurse's job is to communicate (to patients) that it's ok to speak up, without getting in trouble or feeling bad". Nurse Participant E said, "Yet you have to teach them, 'You will get through this.' 'You can do this. Believe it or not, you can do this.'" Nurse Participant L said, "It's very empowering to them. They're the ones who will be determining their health, more than anyone else in the world. More than me. You know, there are things I prescribe, or things I say, but they're the main person who's going to make the main difference. So helping them get information and helping them be able to use it, you know, it's not *just* giving them information".

"I mean it's truly participative" Nurse Participant C said again and again. Nurse Participant L described her role as opening awareness for patients to health, "When I give them some beginning information, or add to whatever level they have, I add to it. And then they tend to be more aware or open to new information in other places. Because it's on the news all the time, all kinds of things. Like eating at least 5 fruits and vegetables a day. Exercising, we hear that all over the place, but whether you tune into it or not, partly depends on just what your priorities are, what's important to you". Nurse Participant E said, "Like if it's a new diabetic, I start laying the ground work with what diabetes is and how you're going to treat it, but each nurse that goes in adds a little bit more, teaches a little different way".

Chapter 4: Summary

There was a theme from these interviews of nurses wishing they had more time for patient education. Nurse Participant A said, "I think it's huge and I also think that it's the piece that I wish we had more time to work on. I mean if we only had more one-on-one with patients it would be great because you could just, I mean, I think you feel like you could thoroughly answer all the questions, and make sure that I would feel more confident going home, and feel like they got good care and they know what's going on and that they were thoroughly helped". The nurses in this study expressed a need for more time to address their patients' health literacy needs. In general, they do formal and informal types of assessments. This is primarily through face-to-face contact and the written intake forms secondary, so they are evaluating patient's body language, emotional state, and their "readiness to learn" in addition to their physical condition. Nurses are forming an opinion about patient's motivation, their "agendas", and their patients' willingness to integrate health information with new behaviors that demonstrate their comprehension and commitment to health. They see this ability being influenced by how and when they share information, as well as the presence of other responsibilities in patients' lives, like family, work, cultural attitudes, and financial pressures. The barriers to improving patient's health literacy include patients' emotional state and preparedness for the medical situation. There are also family/language/literacy factors, and patients are more swayed by cultural and personal values about health than nurse education.

Within the healthcare environment, there are barriers related to translation services. They are costly and inconvenient during busy times and in a fast-paced environment. Additionally, the presence of a translator, whether professional or not, can be a hindrance to patient-nurse communication. It makes it harder for a nurse to determine how well or poorly a patient understands what they are teaching when not able to communicate directly. The use of translator

may facilitate immediate communication that meets the documentation requirements for nursing staff, although may be ineffective for addressing patients' health literacy needs. The use of a third person can create an obstacle to "connecting" or "tuning into" patients and accurately assessing their understanding. The third person is essential, though, to meet documentation requirements and to "get moving" along with patients in busy environments.

Because nurses really do care about whether or not patients follow through on health education, and their long term health, even if it's ultimately "up to them" and their own responsibility. Each person is responsible for their own health literacy, but nurses view their role as very important and invaluable toward meeting their health literacy needs and improve patient care. Self-responsibility was a reoccurring theme in the nurses' responses. Nurses do their best within the limits of healthcare circumstances, resources, and the patient's abilities to learn and be open. If they want to learn, they will, according to these nurse participants, and providing written materials and resources gives them a sense of reassurance that they did their job. The written information is perceived as possibly intimidating to patients, when they are in a state of being overwhelmed, disinterested, or distracted.

The written materials are ineffective if the patient cannot read, disregards them or does not know what the words on the page mean. Patients can read "too much" and get confused or overwhelmed. This intensifies emotional barriers and nurses respond by offering "accredited", approved, and reliable sources of information (websites, pamphlets, educational classes). Nurses make assumptions about patient's comprehension of health information, yet realizing so also use healthcare standardization and protocols to facilitate their relationship to patient education. Nurse Participant A said, "The whole thing about health literacy, it encompasses so much. Say one person can be literate about the system and one person can know about their bodies, and it's

just two different things. It's huge". The complexity and far-reaching scope of what health literacy means was captured by Nurse Participant O, when she said, "As far as the insurance questions, yeah, because even I don't know really a lot about insurance. I mean, there's so many policies and everything, and I don't really know how they all work". As Nurse Participant B added about needing information from patients and confirmation that they understand they have a broken bone, it's confusing "Cause we say, "You have a fracture." and patient doesn't know what a fracture is. "You have a broken bone." "You broke your bone." We try to keep it as simple as possible" so they understand.

As far as the nurse impact on health literacy, Nurse Participant M said, "And you're trying to educate them about a huge amount of information. And what I find is the biggest barrier is competency or understanding the information, or putting it at a level that they could understand". Nurses are mediating patients' health literacy and what is needed by them to act within the healthcare system. As Nurse Participant C said about an experience she had with a patient that she perceived to have low health literacy, "He did not understand a lot of the questions. It was at a higher level of knowledge than what he was used to being even able to communicate". Nurse Participant M said those with low health literacy are "low socioeconomic status people, people with not a lot of knowledge, not a broad based knowledge in general. Not just about healthcare, but just about everything, so, how do you put it...they are uneducated people". This is how 10 nurses that work in healthcare and have direct patient contact experience and perceive health literacy in this study. The eight themes were analyzed by the primary researcher through in-depth analysis and prolonged engagement with the material. The Cohen's kappa for this study was 88%. Consensus was reached and validated by the faculty research advisor.

Chapter 5: Discussion, Conclusion, and Recommendations

The majority of the nurses interviewed for this study were not familiar with the term “health literacy”. Although unaware of the term itself, they were very attuned to the influence they have on patients’ ability to read, understand, and utilize health information. The lack of knowledge of the term ‘health literacy’ and the impact it has on healthcare is evidence that nurses need more education about the topic and, in particular how it relates to the clinical care setting. This means nurse/provider education about cultural diversity and language barriers, in addition to training them how to address the specific health literacy needs of their patient population. This should encompass the scope of diversity among our population and how to appropriately handle the complex factors involved with education, like patients’ values and the concerns, questions, and potential shame they experience in regards to their health skills and abilities and ways they conceal it.

The many barriers mentioned by the nurse participants in this study include family members and cultural influences, translation services, and the psychological or emotional states of patients. This offers insight for administrators about the topics that nurses and healthcare providers need to be educated about in order to improve patients’ health literacy. This could take the form of training in effective communication with emotionally distraught patients, how to use an interpreter, and methods for appropriately involving family members instead of banning their use. Nurses need more resources for patient education than handing out written materials, and ones that can be used in the fast-paced, culturally diverse, and economically sensitive healthcare environment. The Ask-Me 3 and teach-back methods are good examples. For example, teaching nurses to ask questions, such as “Are you an information-gatherer?” or does the written material

cause feelings of overwhelm and further distress them, as an experienced nurse in this study suggested.

Some questions to consider for further research are, “If the patients cannot receive information due to emotional overwhelm, what can be done to ensure that they know when and how to seek needed medical care?” What can be done to help prevent nurses’ from becoming cynical, or skeptical of patient’s motivation and interest in health to the point where they stop trying? Or nurses becoming burned out because their patients do not seem to care, or the messages they receive by organizations about the importance of safety and patient education appears to be only lip service given? Health literacy is defined by the Institute of Medicine as, “The degree to which individuals obtain, process, and understand the basic health information and services they need to make appropriate health decisions”. From this research study, it seems as if the ability to understand information and the degree to which individuals act appropriately is incongruent; there is a disconnect between knowledge and action. This suggests that there is something about the ability to act that needs to be investigated as the definition of health literacy continues to evolve. These are questions worthy of additional research and ones to be considered as health literacy initiatives are explored.

Overall, low health literacy creates a fundamental disconnect between the patient and the health care system, too, and this inevitably leads to a lack of trust and honesty, poorer outcomes, and higher costs. Competency on the part of the healthcare provider for effectively communicating health information and instructions is essential for creating a system that is accessible to all and could mitigate these factors. Low health literacy is often an underlying constant factor in many of these crises--is not a new phenomenon, yet it garners little attention. Two of the contributors to the Institute of Medicine’s report, Parker and Kindig, recently shared

an assessment of the healthcare industry's progress to date (2006) toward the recommendations put forth in the report. They conclude that, although federal and private agencies have substantially increased funding and support for health literacy research, there remains marked stagnation of organizational support for the development of appropriate policies and initiatives, an absence of literacy-related quality standards, and a lack of effective tools using educational modalities beyond simple written and oral communication (Parker & Kindig 2006). Recognizing the issue is an important first step toward establishing an environment in which health literacy becomes the rule, not the exception. With recognition of the issue comes a responsibility to give healthcare providers the time, skills, and support necessary to transform the typical provider--patient encounter into one that supports health literacy.

Recommendations

The ability to communicate effectively with patients who have low health literacy depends on staff at all levels 'ability to recognize the problem and create a patient-centered and shame-free healthcare environment. Because patients with low literacy are often ashamed or embarrassed, and have devised well-developed coping skills that mask their limited literacy, it is even more important that healthcare professionals be trained to recognize it and address it. It is important to remember that even people with good literacy skills find that understanding healthcare information is a challenge (Cornett, 2009). They often do not understand medical vocabulary and the basic concepts in health and medicine, such as how the body works or how to navigate the healthcare system (Wolf et al., 2007). Stress and anxiety limit their ability to listen, learn, and remember the education they receive.

Creating an environment that promotes health literacy requires helping patients navigate the system, prepare for engagement with their health and productive interactions with healthcare

providers (Cornett, 2009). Simplifying forms, offering all patients help in completing them, and providing a confidential avenue for questions to be asked or information exchanged, are several solutions. Often the patient is told to read a referral form and call to make an appointment. The patient in this situation had to find out where to go, follow instructions about how to prepare for the referral, determine if insurance will pay for the services, and complete new registration forms or paperwork, which can be an overwhelming task for anyone. Those with low health literacy skills are even more challenged by this, and making the referral process easier can be accomplished by healthcare administrators.

Preparation for appointments and medical interactions is essential for patients to become active partners in their care (Cornett, 2009). As the nurses in this study said, preparedness was a major factor in patients' ability to receive, integrate and process healthcare information. Encouraging patients to write down questions, bring lists of medications, or have a family member accompany them to appointments are some of the ways. Even patients with good literacy skills may feel intimidated and avoid asking questions, and this behavior may be misinterpreted to mean that they understand the instructions (Baker et al., 1996). Health literacy may be a difficult problem to recognize, yet by observing closely and asking the right questions will provide "red flags" that a patient is not comprehending or reading the information correctly, and prevent the adverse health outcomes and errors that arise from the epidemic of low health literacy.

Limitations & Strengths

The limitations to this study include the number of participants, gender and location. All the participants were female, primarily Caucasian and native English speakers. All the nurses

work in an urban setting, and workers in rural populations were not included which could have provided insight into nurse experience of patient health literacy with a different demographic group. However the study was strengthened by the varying levels of experience the participants had and their current job placements. There was a range of years working as a nurse, from less than 3 to over 30. This gave insight into how nurses' perception of addressing patients' health literacy can change over time and with experience, providing strength to the reliability of all the themes listed. The themes are an additional strength, in that the scope and depth offers many areas for future research, such as patients' motivation and health literacy, the relationship between health knowledge and health action, and nurses' accuracy with assessing patients' health literacy levels.

The study could have been more profound if there was data on the health literacy levels of the patients' who were treated by these nurse participants. This type of quantitative data would have been interesting, as well as observing nurse interactions with patients in real-time and setting. As far as obtaining more in-depth qualitative data, to have observed the nurses in their natural settings with patients would have added validity to their responses and gave the researcher more insight into the reality of how health literacy is assessed and addressed. In retrospect, additional follow up interviews with the nurse participants, more participants, and a narrower list of questions on the interview guide could have produced a deeper layer of responses.

Despite expressing limitations to their perceived effectiveness, these nurses clearly care deeply about their patients and see themselves as having a very important role in improving as far as improving their connection to improved health. Knowing about their care and sympathy for sufficient health literacy, provides a fertile ground for empowering them and making changes

that benefit the current health care environment. Patients with low health literacy often have problems understanding information given verbally during the patient-provider encounter, and research has shown that patients only understand about 50% of what they are told (Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Without the comfort or confidence to ask for clarification, it is recommended that providers know to be specific, concrete, and vivid, rather than general, with instructions (Doak, Doak, & Root, 1996). In an era with increased attention on accountability, medical-error reduction, quality improvement, and chronic disease prevention and management, healthcare providers and executives must focus on issues surrounding health literacy.

Appendix A:

Interview Guide

1. How would you define health literacy?
2. Do you use educational techniques with your patients?
3. If so, what types of techniques?

4. Can you think of an experience when it was clear that the patient was not health literate and how you responded?
5. What barriers have you encountered in educating patients about their health?
6. How do you assess the likelihood of adherence to health care instructions?
7. How do think your health care organization perceives health literacy?
8. What kind of training is or could be provided by your organization to improve educational techniques that nurses use with patients?
9. How important is it to you as a health care provider to improve patients' health literacy?

Demographic information to be collected through a self-reported written form:

Age group, years of experience, race/ethnicity, languages spoken, and gender.

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