

HEALTH EDUCATION MATERIALS: WHERE ARE THE  
PATIENTS?

by

ELIZABETH WHITNEY POLLIO

DOUGLAS MCKNIGHT, COMMITTEE CHAIR  
STEPHEN TOMLINSON  
MICHELE MONTGOMERY  
SUSAN APPEL  
CATINA O'LEARY

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## ABSTRACT

Inadequate health literacy is a barrier to positive health outcomes and often leads to increased hospital readmissions. Congestive heart failure patients are among the top populations with the tendency to be readmitted to the hospital within 30 days of being discharged. African American females represent a particular population with a significant number being affected by cardiovascular disease. A general qualitative research approach utilizing a semi-structured interview was used to investigate the perceptions that African American adult female patients diagnosed with congestive heart failure have of the healthcare materials that they receive or if there are other factors that influence the discharge process. Results showed that three key factors were identified as influential in the discharge process: 1) consumer-friendly information and materials; 2) humanization; and 3) expertise of the health care team. Consumer-friendly information and materials included readability and comprehensiveness. Humanization included the health care providers showing patience, patient-centered care and personal touch. Expertise of the health care team included exhibiting professionalism and effective communication skills. In conclusion, relationship building and communication skills were factors valued by the patients, other than the materials themselves, which positively influenced the patients' perceptions of the discharge process and fostered knowledge transfer from health care provider to patient.

## DEDICATION

This dissertation is dedicated to the memory of my mother, Peggy Helbig, who always told me that I could do anything that I set my mind to do. Also, to all of the people who encouraged me and guided me through the process of creating this manuscript. Specifically, my father, husband, kids and friends who stood by me and cheered me on throughout the completion of this work.

## LIST OF ABBREVIATIONS AND SYMBOLS

AHRQ Agency for Healthcare Research and Quality

BSN Bachelor of Science in Nursing

CINAHL Cumulative index to nursing and allied health literature

HIV Human immunodeficiency virus

IOM Institute of Medicine

MRI Magnetic resonance imaging

REALM Rapid estimate of adult literacy in medicine

RED Re-engineered discharge

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## CHAPTER 1 INTRODUCTION

### **Introduction**

Hospitals in the United States spent \$41.3 billion between January and November 2011 on readmissions within 30 days of patient discharge (Hines, Barrett, Jiang & Steiner, 2014). The Centers for Medicare and Medicaid Services state that the national hospital readmission rate for 2012 averaged 18.4 percent (Gerhardt, Yemane, Hickman, et al., 2013). This is only a slight decrease from the 19 percent average from 2007-2011. Congestive heart failure was the most common medical condition associated with readmission in 2011 for Medicare patients with 1.35 million readmissions costing \$1.7 billion (Hines, Barrett, Jiang & Steiner, 2014). The costly dilemma of hospital readmissions is being closely scrutinized as a potential factor that influences quality of care, cost of care; transition of care, and interventions are presently ongoing at both state and national levels (Elixhauser and Steiner, 2013). Preventable admissions, those that could have been prevented with the use of primary care visits, are an area where health care costs can be significantly decreased. Changes in hospital readmission rates may signal an improvement or decline in the quality of ambulatory care, in access to timely and effective medical treatment, or in patients taking on healthy lifestyle behaviors (Russo, Jiang & Barrett, 2007). Hospitals are using quality improvement tools in an effort to reduce readmissions and most payers, including Medicare, believe that better organization of post-discharge care, including health education materials, is key to reducing readmissions (Hines, Barrett, Jiang & Steiner, 2014). Health literacy, which includes patients' ability to interpret and follow the health education materials they are given at discharge, is a significant risk factor for hospital

readmissions within 30 days of discharge (Mitchell, Sadikova, Jack & Paasche-Orlow, 2012).

Approximately 36 percent of Americans have basic or below basic health literacy skills, meaning that they are unable to fully understand health care information, the consequences of which include increased hospital admissions (Agarwal, Shah, Stone, Ricks & Friedlander, 2015).

Many researchers consider the beginning of the health literacy movement to be in the 1970s with the marriage of Leonard Doak and Cecelia Conrath. Cecelia Conrath was a commissioned officer in the U.S. Public Health Service, developing and leading continuing education for physicians and allied health professionals, and Leonard Doak was an engineer who volunteered as an adult literacy tutor (Hodorowski, 2012). During a conversation in 1973, Cecelia asked Leonard how individuals with poor health literacy skills usually responded when asked if they understood their health care instructions, and Leonard responded that they fake it and say that they understand so as not to be embarrassed or appear uneducated (Health Information Literacy, 2009). The collaboration of their over 30 years of work, including workshops, articles and books, lead to the conception of the field of health literacy.

During the 1990s, the health literacy movement expanded and social marketing was used as a means to attempt to influence social norms and disseminate health information to the public (Nutbeam, 2008). Nutbeam (2008) suggests that despite this push to influence social norms, interventions relying primarily on communication and education have failed to result in any significant lasting behavioral or lifestyle changes. Therefore, over the years, the definition of health literacy has continued to develop. The Patient Protection and Affordable Care Act, 2010 defines health literacy as “the degree to which individuals have the capacity to obtain, communicate, process and understand the basic health information and services needed to make appropriate health decisions.” Individuals needing health education materials or services must

be able to find the information or services, communicate their needs, process the information, understand their choices and decide what information or services they need (Centers for Disease Control and Prevention, 2015, p. 1). Health Communication and Health Information Technology, according to Healthy People 2020, “make up the context and the ways professionals and the public search for, understand, and use health information, significantly impacting their health decisions and actions.”

The emphasis on the literacy skills needed for individuals to obtain and comprehend health information has evolved into a more comprehensive definition including the ability of individuals to use health information to take control of their own health care decisions. Perhaps more importantly, the definitions continue to expand to incorporate the other side of this ‘double-sided coin’ – the health literacy of systems and providers. As such, the movement has recently come to the foreground as a means of improving access, increasing quality, and reducing the costs associated with health care delivery (Koh et al, 2012). Adequate health literacy skills assist the public and health care personnel to locate, understand, evaluate and use information in health-related contexts. Health literacy, which applies to all individuals and to health systems, includes proficiency in the areas of reading, writing, numeracy, critical analysis, communication and interaction in order to improve peoples’ abilities to act on information in order to make informed decisions to live healthier lives (Coleman, Kurtz-Rossi, McKinney, et al., 2011). For example, The National Institutes of Health (2014) identifies significant areas associated with health literacy which include communication between physician and patient, ability to read medication labels and medical instructions, medical compliance, and informed consent.

The Institute of Medicine (IOM) defined patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring

that patient values guide all clinical decisions” (2001, p. 40). Adequate health literacy, including successful provider-patient communication, is an important factor in assuring quality patient-centered care. With the successful implementation of communication and technology between health care professionals and their patients, society can begin to realize a truly patient-centered health care system (HealthyPeople.gov, 2014). Patients must be able to read and interpret the health education materials with which they are provided in order to become active participants in their health care. A report from The Agency for Healthcare Research and Quality (AHRQ) (2011) states that health literacy includes a collection of skills necessary for people to effectively navigate the health care system and to uncover, properly evaluate and implement health care information. In order to make appropriate health care decisions, individuals need to possess skills including “the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy)” (AHRQ, 2011, p.1). Sorensen, Van den Broucke, Fullam, et al (2012) performed a systematic review of definitions of health literacy using Medline, PubMed and Web of Science and combined their findings to form a more comprehensive definition. The definition that the group developed reads as follows: “Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.” Clearly, health literacy is an important issue in the field of health care and should be considered when caring for patients. Patients need to be able to understand health education materials with which they are provided in order to successfully navigate the health care system and to realize positive health

outcomes; they need to be informed consumers to actively participate in their health care. However, literacy is only one component of health literacy.

Initially, the health literacy movement primarily focused on the deficits that individual patients and the public had that prevented them from complying with the health care recommendations they were given from health care providers and the health care system. The current trend in health literacy is to focus on behavioral change rather than a particular set of skills lacking from patients and the public (Pleasant, 2011). Shortcomings in the health care system as a whole should be scrutinized and corrected. Collaboration among many academic disciplines, government agencies and all individuals holding an interest in improving health literacy must occur in order to realize an improvement (Pleasant, McKinney & Rikard, 2011). This collaboration needs to include input from the individual patients because patient input is necessary to understand the process of communication central to health literacy and to realize the needs of patients.

The focus of the health literacy movement needs to explore other factors, in addition to literacy level, that effect a patient's ability to navigate the health care system and achieve positive health outcomes. In addition to collaboration among disciplines, including the patients themselves, there needs to be an evaluation process. Are the efforts to improve the discharge process being viewed as positive by the patients? Is what's being done helping them to read, understand and use the information being given to them? Are there other factors, besides the written materials themselves that influence the patient's experience of the discharge process? If other factors are present, do these factors influence the patient's ability to accept the health information they are given?

## **Rationale for study**

The main focus of the health literacy movement has been on the written materials given to patients. Despite all of the efforts to assure that patients are provided educational materials at the appropriate literacy level, readmission rates have not significantly improved. Therefore, a comprehensive definition of health literacy should be consulted going forward. Sorensen, Van den Broucke, Fullam, et al (2012) developed the following comprehensive definition: “Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.” According to this definition, other factors that influence a patient’s ability to understand and use the information they are given need to be explored. Meeting the needs of patients is paramount in our attempt to improve health outcomes and decrease readmission rates. Also important is the perception of individual patients. In order for patients and families to become active participants in healthcare, they need to have the perception that their needs and desires are viewed as important to healthcare providers. Determining if patients perceive that health care providers are meeting their needs is an important endeavor and evidence of efforts to do so is lacking in current literature.

The specific population being studied consists of African American females recently hospitalized with congestive heart failure. This particular patient population is being chosen because patients with congestive heart failure are among the top populations with the tendency to be readmitted to the hospital within 30 days of being discharged. More specifically, African American females represent a particular population with a significant number being affected by cardiovascular disease. According to the American Heart Association (2013), among non-

Hispanic blacks age 20 and older, 47.0 percent of women have high blood pressure leading to 6,951 deaths in 2009. In this same population, 48.9 percent have cardiovascular disease resulting in 48,070 deaths in 2009. Also of note, among non-Hispanic black women age 20 and older, 7.1 percent have cardiovascular disease and 4.7 percent have had a stroke resulting in 19,470 and 8,916 deaths in 2009 respectively. These statistics support that African American women represent a population that experiences the effects of cardiovascular disease. In a study of two hundred and two African American women of both low health literacy (less than or equal to 6<sup>th</sup> grade level) and higher health literacy (7<sup>th</sup> grade level or higher), researchers found that ineffective communication with clinicians was a central factor leading to inadequate utilization of care, regardless of literacy level (Bennett, Switzer, Aguirre, Evans, & Barg, 2006). In addition, Weekes (2012) found that although African Americans have a lower health literacy when compared to Caucasians, health literacy studies which focus on African Americans are scarce. Focusing on this particular population, after being recently discharged from the hospital, has the potential of helping us understand their perception of the written health care information they were given as well as any other factors that may influence the discharge process.

Patients are discharged from the hospital with a lot of information, the majority of which is in written form. At this facility, when a patient is discharged, the nurse assigned to the patient provides the discharge education materials and documents the discharge process in the patient's electronic medical record. The nurse is responsible for charting the discharge procedures and printing out the educational documents assigned to the patient by their physician. The nurse reviews the educational material with the patient, address any questions or concerns and document the process in the electronic medical record.

The purpose of this study is to determine the perceptions African American female patients that have been hospitalized due to congestive heart failure have of written health information and the discharge process after they have been discharged. By limiting the study to African American female congestive heart failure patients in the same hospital setting, the healthcare materials received will be similar in content. By controlling for population and the type of healthcare content received, better insight can be gained into the patients' experiences of receiving healthcare information at discharge. Health literacy professionals and health care professionals have made and continue to make a strong effort to provide patients with health care information written at a literacy level commensurate with the education level of a majority of patients. The reasoning behind these efforts is that in order for patients to be prepared to take care of themselves and avoid readmission, they need to have access to the necessary medical information and be able to read, interpret and use such information. Despite the increased efforts to produce and dispense written health information at the appropriate literacy level in order to decrease readmissions, we are continuing to fall short in meeting this desired result. Research is needed to explore if there remains additional goals in meeting the needs of patients when considering written health care information and the discharge process as a whole. Do patients perceive that health care providers are meeting their needs with the health care information they receive? Do patients perceive that health care providers are meeting their needs during the discharge process? Are there factors beyond the written materials that affect the patient's experience of the discharge process? Patient input is needed to gain insight into these questions. There is very little literature written from the patient perspective that addresses these questions.

## **Statement of the problem**

Literacy is an issue that has been addressed for decades. Furthermore, health literacy has been an important topic for discussion among professionals since the 1970s. Healthcare professionals and health literacy professionals have been addressing the problem of inadequate health literacy in an attempt to provide health care information at a literacy level that makes the information accessible, readable and useable for the majority of individuals. Patients need to be able to obtain, read, interpret and use written healthcare materials in order to become active participants in their healthcare. A major focus of the current movement to improve health literacy among patients is to provide information at a literacy level that is readable and useable to a majority of patients. Therefore, a majority of interventions are still focusing on making sure that health education materials are presented at the appropriate literacy level. However, there is scant literature supporting that professionals are inquiring what perceptions patients have of the healthcare materials that they receive or if there are other factors that influence the discharge process. Literature that addresses the patient experience of the discharge process is all but missing.

## **Definition of health literacy**

At its conception, health literacy was focused on the patient's ability to read health education materials. Leonard Doak told Cecelia Conrath that when individuals cannot read, "they fake it and say that they understand so as not to be embarrassed or appear uneducated" (Health Information Literacy, 2009). Therefore, the primary focus of the health literacy movement was on the shortfalls exhibited by individual patients and the public that kept them from following the health care recommendations they were given from their health care providers. Over the years, the definition of health literacy has continued to expand into a more comprehensive

definition. The present-day direction of the health literacy movement is to place emphasis on behavioral change rather than the skills that patients lack (Pleasant, 2011). The previous focus on the literacy skills needed for individuals to obtain and understand health information has progressed into a more comprehensive definition that includes an individual's ability to use health information to take control of their own health care decisions. In addition to the written materials, the patient-provider relationship, including communication and information sharing, is a significant factor in determining patient health outcomes. This more contemporary and comprehensive definition includes the health literacy of systems and providers in addition to the individual patients.

### **Research questions**

This study was designed to answer two particular questions. 1) How do patients experience the written information during discharge? 2) What, if any, other factors influenced the patient's experience of the discharge process?

To date, patients have been underrepresented in the evaluation of health materials and health education during the discharge process. Lack of inclusion violates a core principle of health literacy – audience focus and patient centered design. Data suggest the bulk of health materials are created from medical literature and health educator input without patient or caregiver participation or evaluation. Patient involvement is critical to positive outcomes and linked to hospital readmissions as patients may be discharged without necessary tools and information needed to effectively manage their condition. Patient input into the evaluation of health education materials and how to successfully conduct the discharge process opens the lines of communication and fosters patient-centered care. Asking these research questions has the potential of discovering the patient perspective with regards to health education during the

discharge process and may affect patient health outcomes in a positive way. Also, these questions have to potential to reveal additional factors that potentiate knowledge transfer from health care provider to patient.

## CHAPTER 2 LITERATURE REVIEW

### **Literature review**

A literature review using CINAHL and PubMed was conducted on February 4, 2015 for the years 2005-2015 using the terms health literacy and patient education to attempt to discover important aspects of the field from the perspectives of both health professionals and patients. The search, which included conceptual and opinion pieces, yielded 294 articles. The search was then limited to human adults, United States of America and no mental health or learning disabilities reducing the total number of articles to 165. Among the 165 articles, 43 (26%) included the patient's perspective. The scant literature from the patient's perspective reveals how their perspectives are underrepresented. Seventeen of the 43 articles used qualitative methodology. Thus, only 40 percent of the articles from the patient perspective, 10 percent of all search articles, asked open-ended questions. The search also revealed that there is no overarching theory or model of patient education in general. In order to discuss various contributions to health literacy, the review of literature section will discuss the findings in the literature divided by the perspective it portrays.

### **Health care professional perspective**

The majority of the literature on the topic of health literacy comes from the viewpoint of health care professionals, which includes health care professionals and health literacy professionals. From the literature search, 122 out of the 165 articles (74%), were written from the health care professional perspective. This perspective includes articles with conceptual,

quantitative and qualitative methodologies. The major focuses of articles from this group are health literacy awareness and initiatives for improvement. In addition to initiatives aimed at improving the healthcare materials that are given to patients, these also include initiatives to improve patient involvement, initiatives to improve practitioner involvement, and initiatives to improve health literacy measurement tools. The first focus is to stress that inadequate health literacy is a problem in health care and that the need for awareness and attention to the topic is critical. The second focus of the literature from health care professionals is to promote new initiatives and ideas for improvement. Both of these areas of focus are important to an informed discussion of health literacy. The literature from the health care professional perspective will be divided by methodology used.

### **Conceptual articles from health care professional perspective**

The conceptual articles from the perspective of health care professionals address the prevalence and impact of inadequate health literacy, emphasizing that individuals should be able to read, understand and use the written health information they are given. This perspective emphasizes that older adults are particularly vulnerable to the impact of inadequate health literacy. These articles include how health literacy is evaluated as well as initiatives to improve health literacy. Health literacy professionals report that inadequate health literacy is a major influence on health disparities which leads to poor patient outcomes.

Inadequate health literacy and insufficient patient-provider communication are associated with poor patient outcomes. These factors also impair patients' abilities to understand and recall information and actively share in the decision-making aspect of their healthcare (Amalraj, Starkweather, Nguyen & Naeim, 2009). Health literacy professionals argue that improved health literacy will lead to greater patient involvement, which, in turn, should lead to better patient

outcomes (Johnson, 2014). Because health literacy and health outcomes are linked, Saver (2014) believes that we should take a “universal precautions” approach to health literacy. Additionally, health care professionals believe that there is a stigma attached to inadequate health literacy. This stigma may contribute to poor health outcomes (Mackert et al, 2014). Eadie (2014), in her conceptual review of health literacy theories, expresses that health literacy’s focus is to enhance individuals’ health literacy abilities through education and community collaboration. The goal is to combine education of individuals with community involvement to promote healthy lifestyle choices. Importantly, nurses, in their roles as patient advocates, are on the front line of patient care and have the obligation to identify and assist individuals with inadequate health literacy in order to decrease health disparities (Eadie, 2014). The Agency for Healthcare Research and Quality (2015), stating that only 12 percent of adults in the United States have sufficient health literacy skills to navigate our health care system, has developed a Health Literacy Universal Precautions Toolkit containing 21 tools which focus on simplifying communication, assuring comprehension, making sure the health care system is maneuverable, and encouraging patients in their efforts to improve their health.

Older adults, a population experiencing considerable growth in the United States of American, are disproportionately affected by illiteracy which is compounded with sensory changes associated with aging. Health care professionals need to be aware of health literacy and strategies to address this issue with older adults (Billek-Sawney and Reicherter, 2005). As a result, nurses must be knowledgeable about health literacy and be able to assist patients to become active participants in their healthcare (Cutilli, 2005). Older adults, effected by sensory changes, require unique strategies to address their health literacy needs such as additional time, mid-morning appointments, speaking slowly and written health education materials (Speros,

2009). A systematic literature review reinforced that positive health outcomes are associated with supporting health literacy skills in the older adult population (Manafu and Wong, 2012). Another systematic literature review showed that motivational interviewing was more promising in improving self-efficacy in older adults with heart failure than self-management or symptom monitoring (Falk, Ekman, Anderson, Fu & Granger, 2013).

Health care professionals have suggested a number of initiatives to attempt to lessen the effects of inadequate health literacy on health outcomes. Scudder (2005) tells us that people with poor health literacy skills have difficulty reading prescriptions, filling out medical forms and may not use health services for which they qualify. She states that nurses need to be at the forefront to increase the probability of at-risk populations comprehending the medical information with which they are provided by making sure the information uses plain language, follows a logical order and incorporating appropriate graphics. To help ensure comprehension, the nurse should use such strategies as teach-back, where the patient is asked to teach the health care professional, and Ask Me 3, where the patient is allowed to ask three important questions to the health care provider (Scudder, 2005). Knowing a patient's health literacy level, which enables health care professionals to provide the appropriate health education materials, leads to better patient-centered care. Monachos (2007) advocates for screening all patients for level of health literacy. The implementation of specific practice behaviors such as using simple sentences, encouraging questions, using drawings or diagrams and using the teach-back method to ensure patient understanding can increase effective communication and produce better outcomes (Monachos, 2007). In a review of literature, various approaches to health education were examined, revealing that identification of individuals with marginal or inadequate health literacy is important in order to provide education in an effective manner (Cutilli, 2007).

Pleasant, McKinney and Rikard (2011) summarized findings from two discussions concerning health literacy measurement held by the Literacy Information and Communication Systems (recognized as the largest and most comprehensive group of health literacy professionals). The group stressed that a comprehensive approach to measurement of health literacy is needed and that engaging the public and policy makers will help to ensure validity, relevance and utility (Pleasant et al, 2011).

Patient education, which is an important aspect in providing nursing care, is essential for good patient outcomes and a part of accreditation standards and should be culturally diverse to meet the needs of all patients (Chang and Kelly, 2007). Lorenzen, Melby and Earles (2008) described how one health care system is incorporating health literacy into its informed consent documentation and process. The various goals of this initiative to incorporate health literacy include education of staff on the concepts of health literacy, developing an understanding that informed consent is a process, developing a reader-friendly consent form, increasing the number of patients reading the consent form prior to signing and using the teach-back method to ensure patient understanding (Lorenzen et al, 2008). Roberts (2008) argues that nurses are at the forefront of patient education and should be open to using a variety of strategies, in addition to or instead of printed materials, to meet patients' health education needs. Gruman, Rovner, French, Jeffress, Sofaer, Shaller and Prager (2010), after performing a literature review and interviewing 57 individuals who have researched patient engagement, developed an "engagement behavior framework" which supports researchers and clinicians developing ways to encourage patients to actively participate in their care to the fullest extent possible in order to improve outcomes. Making the move from the health care provider deciding what the patient needs to know toward shared decision making will lead to increasing and optimizing patient provider communication

(Hoving et al, 2010). The challenges to implementing this change include health care provider training, patient training and including patients' social environment (Hoving et al, 2010). Three current health literacy initiatives promoting the push from health professionals deciding what information patients need to shared decision making which are showing significant health outcome improvements are: 1) simplifying written materials and making it easier to understand; 2) improving providers' communication skills; and 3) improving patients' self-management skills (Koh, 2012). Health care professionals believe that educational materials may need to be tailored and supplemental material may be needed to meet the needs of diverse populations and their families, especially those with inadequate health literacy (Martin, Pisu, Kvale & Johns, 2012). In a review of articles to determine the effectiveness of primary healthcare providers to supply the information needed to convince individuals to make healthy lifestyle changes, results showed that the capacity of healthcare providers to supply interventions at the proper literacy level and with adequate intensity is necessary to support lifestyle change (Dennis, Williams, Taggart, Newall, Denney-Wilson, Zwar, Shortus & Harris, 2012). In order to improve patient-provider communication, healthcare providers need to recognize low health literacy and utilize interventions tailored to the patient's literacy level (Mullen, 2013). Use of The Teach-Back Method, where the healthcare professional has the patient teach the skill or information, is helpful in achieving positive patient outcomes and increasing patient satisfaction (Tamura-Lis and Winifred, 2013).

### **Quantitative articles from health care professional perspective**

Quantitative articles from the health care professional perspective reveal the prevalence and impact of inadequate health literacy, discover inadequacies in the health care system and evaluate interventions aimed at decreasing the impact of inadequate health literacy and

improving health outcomes. A study of 69 individuals was performed to see if there was an association between education, literacy and asthma management. After controlling for income, gender and race, results showed a statistically significant association between participants with lower aural literacy skills and less successful asthma management (Rosenfeld, Rudd, Emmons, Acevedo-Garcia, Martin & Buka, 2011). In a study of 399 patients, perceived disease knowledge was associated with greater objective knowledge and greater satisfaction with physician communication (Wright Nunes, Wallston, Eden, Shintani, Ikizler & Cavanaugh, 2011). In a study of 330 patients with hypertension, significant pathways from health literacy to knowledge, knowledge to self-efficacy, self-efficacy to physical activity and physical activity to health status were revealed (Osborn, Paasche-Orlow, Bailey & Wolf, 2011). In order to examine the association between health literacy and 30 day hospital readmission or emergency room visit, Mitchell, Sadikova, Jack and Paasche-Orlow (2012) followed 703 individuals from the Project RED trials for 30-day reutilization of hospital or emergency room, planned readmissions were eliminated, and then evaluated for health literacy level using Rapid Estimate of Adult Literacy in Medicine (REALM). Study results showed the individuals with low health literacy were significantly more likely to be readmitted to the emergency room or the hospital within 30 days (Mitchell et al, 2012). In a study involving 54 participants who had their health literacy evaluated using the Newest Vital Sign, it revealed significant correlations between health literacy and education and between health literacy and race/ethnicity (Heinrich, 2012). One hundred eighty seven participants utilizing free clinics were surveyed to assess physical and mental health, health literacy and social support. The survey results revealed that a higher level of health literacy was associated with better physical health, whereas a higher level of social support was associated with better mental health and fewer cases of severe depression (Kamimura,

Christensen, Tabler, Ashby & Olson, 2013). Mixon, Myer, Leak, Jacobsen, Cawthon, Goggins, Nwosu, Schildcrout, Schnelle, Speroff and Kripilani (2014) conducted a study of 471 patients hospitalized with an acute cardiac problem. Discharge medication lists were compared to patient-reported medication lists and medication errors were present in approximately half of the individuals. Medication errors were more common in patients with lower health literacy (Mixon et al, 2014).

The patient-provider relationship, including communication and information sharing, is a significant factor in determining patient health outcomes. Of notable importance, a survey of 498 patients, 265 from a county clinic and 233 from a private clinic, found that regardless of health literacy level, most patients get their health information from their health care providers. These findings stress the importance of health care providers being able to provide appropriate information to their patients (Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014). The assessment of the transcripts of 86 conversations between residents and patients revealed a large number of jargon words and a low number of explanations which suggests that many patients may not understand information provided (Deuster, Christopher, Donovan & Farrell, 2008). The health literacy knowledge of 361 senior baccalaureate level nurses was assessed and revealed that although they were able to identify low socioeconomic groups at risk for low health literacy, there was a lack of ability to identify older adults as a high-risk group (Cormier and Kotrlik, 2009). In another study, the actual health literacy level of 143 patients was compared to the physicians' perceptions of their health literacy level and revealed that screening questions were better measures of health literacy level than provider perceptions (Ohl, Harris, Nurudtinova, Cai, Drohobyczer & Overton, 2010). In a study involving a group of 103 sophomore level Bachelor of Science in Nursing (BSN) students, the students were exposed to a brief education session

about health literacy. When comparing a pre-test and a post-test, the educational intervention proved to increase knowledge of health literacy; however, in the clinical setting, students were unable to identify behaviors that patients use to compensate for low health literacy (Sand-Jecklin, Murray, Summers & Watson, 2010). ). Jucks, Paus and Bromme (2012) performed a study involving 150 first-year medical students in which the medical students received an email from a fictitious patient. Some medical students received an email containing low technical jargon and some received an email containing high technical jargon. In both types of these emails, the patient self-reported a low level of medical knowledge. Because medical students gave more technical responses to the emails containing high technical jargon, the study results supported that technical jargon, not self-reported knowledge, was a better predictor of medical student responses to patients (Jucks et al, 2012). These studies emphasize the need to improve health care provider awareness of the impact of inadequate health literacy and to improve their perception of such in patients.

The way that health literacy is evaluated and the written health information that is given to patients is another focus of health care professionals revealed in the literature search. Jordan, Osborne and Buchbinder (2011) evaluated 19 screening tools for purpose, validity, reliability, responsiveness, feasibility and generalizability. None of the tools evaluated measured a person's ability to seek, understand and use health information. Most tools focused on reading comprehension and numeracy (Jordan et al, 2011). Three hundred thirty two consent forms acquired from 75 transplant centers were reviewed for reading levels using the Lexile Measure, Flesch-Kincaid Grade Level, and the Gunning Fog Index. The consent forms were found, on average, to be written at the college level which is much higher than the 5<sup>th</sup>-6<sup>th</sup> grade level recommended by policy makers (Gordon, Bergeron, McNatt, Friedewald, Abecassis & Wolf,

2012). The readability of the basic facts and information sections of the Health-in-Aging website revealed that the average reading level of the text was 10<sup>th</sup> grade. This is significant due to the fact that more than half of adults aged 65 and older have limited health literacy skills (Weiss, Mollon & Lee, 2013).

Health care professionals also studied the effectiveness of interventions used to try to lessen the effects of inadequate health literacy. In a study of 834 primary care patients, the effect of AskMe3, an intervention which has the patient ask the provider three questions, was compared to no intervention. The results revealed no difference due to the fact that the patients were already part of a population in which asking questions occurs at a high rate (Gallagher, Post, Weiss, Dickinson, Manning, Staton, Brown, Hickner, Bonham, Ryan & Pace, 2010). A study in which 30 mothers were given written information about childhood immunizations and the teach-back method was used to assess their ability to comprehend and communicate information about the vaccines revealed that mothers with higher literacy levels provided more correct responses; however, most mothers gave incorrect answers for safety suggesting the need for further assessment on how to best educate parents about vaccines (Wilson, Baker, Nordstrom & Legwand, 2008). In another study, 270 patients were randomized into two groups: 1) receiving colorectal cancer screening information or 2) receiving information and barriers counseling. Results revealed that when counseled to ask for screening tests, patients were more likely to receive colorectal screening tests (Katz, Fisher, Fleming & Paskett, 2012). Health literacy, along with diabetes education, was found to be a significant influence on self-efficacy in 150 patients with type 2 diabetes (Bohannon, Wu, Liu, Yeh, Tsay & Wang, 2013). In a study to assess if health literacy screening affected patient satisfaction, Komenaka, Nodora, Machado, Hsu, Klemens, Martinez, Bouton, Wilhelmson, & Weiss, (2014) evaluated 2025 individuals at a

Breast Surgery Clinic for health literacy using the Newest Vital Sign as part of their routine history and then later asked to rate their satisfaction with their clinic visit on a five point scale. The results showed that routine health literacy assessment does not decrease patient satisfaction and may help identify barriers to patient-physician communication (Komenaka et al, 2014).

### **Qualitative articles from health care professional perspective**

The literature search yielded five qualitative articles from the health care professional perspective. These articles emphasize that health care professionals should take health literacy level into account when speaking with and providing patients with health information. In a study of observations of 44 patient-physician encounters of primary care physicians and adult male patients, only 36 percent of the cases where the patient met the criteria did the physician discuss prostate cancer screening. Among the barriers to discussion were comorbidity, limited education/health literacy, physician forgetfulness, and lack of time (Guerra, Jacobs, Holmes & Shea, 2007). Using the case study of a 63 year old man with pneumonia, the authors demonstrate that nurses should consider inadequate health literacy when labeling a patient as non-compliant or non-adherent to a medication or treatment plan (Reyes, 2010). The geriatric population has the highest rate of low health literacy when compared to other age groups; research and clinical experience has showed that interventions such as teach-back, visual aids, clear and simple language and support persons are effective strategies in helping these older individuals better understand how to care for themselves (Cutilli and Schaefer, 2011). Guglielmi, Stratton, Healy, Shapiro, Duffy, Dean and Groah (2014) brought together a panel for a “Table Talk” which included a nurse, a surgeon, an anesthesiologist, a chief nursing officer and a patient, to discuss how patient engagement influences patient outcomes. All of the contributors’ stories supported the belief that patient and family engagement are linked to

positive outcomes. Raimondo, Harris, Nance and Brown (2014) performed a case study to examine two provider-centered initiatives to addressing the issue of health literacy. One initiative was a health literacy class for health care providers taught by librarians and the second was an Institutional Review Board consent form review service (Raimondo et al, 2014). The initiatives have fostered a new relationship between staff and administration and, although not yet evaluated, they hope that research subjects have benefited (Raimondo et al, 2014).

### **Benefits and limitations of health care professional perspective**

Health care professionals have provided a lot of literature to inform readers of the importance of addressing the issue of inadequate health literacy in our patient populations. Health care professionals point out that because people with inadequate health literacy do not necessarily look any different from those with adequate health literacy, we should assume that everyone needs assistance in understanding health information. The information gleaned from health care professionals states that a majority of adults do not have adequate health literacy to read, interpret and use the health information they are given. Contributions from health care professionals are worthy of attention when trying to understand the impact and significance of inadequate health literacy. Health care professionals deal with patients on a day-to-day basis and their input should be taken seriously. Expert opinion from the perspective of health care professionals is valuable because these individuals are on the front lines of patient care. Part of patient care is patient education. Therefore, health care professional input on written health materials is vital in addressing health literacy issues. They have first-hand experience in dealing with patients with inadequate health literacy and have valuable knowledge on how to address inadequate health literacy in their patient population.

Studies from the health care professional perspective have their limitations due to the fact that most of the literature from this group is written in the form of professional opinion. These expert opinions are generally coming from a single viewpoint. Although their expert opinions are valid and many argue for patient involvement, they fail to include the patients' perspectives in their writings. With the focus on health literacy being empowerment of patients so as to allow shared decision making, the patients' perspectives should be included. These ideas need both patient input and trials with patients' responses. The focus of health literacy is empowerment of patients through accessible and usable health information so as to allow shared decision making. Therefore, the patients' perspectives should be included.

Research studies which include findings by health care professionals are beneficial in that they are coming from individuals on the front line of patient care. The studies do have their limitations. Mixon et al (2014) performed their study on a specific patient population which decreases generalizability. They performed their follow ups by phone interview which decreases reliability. The limitations of the study performed by Jucks, Paus and Bromme, (2012) are that medical students may have viewed self-reported knowledge as subjective whereas the use of technical jargon could be viewed as more definitive. Although Guglielmi, Stratton, Healy, Shapiro, Duffy, Dean and Groah (2014) did include the patient perspective in their "Table Talk" discussion, the findings are limited due to only including five participants. Lorenzen, Melby and Earles (2008) described how one health care system incorporated health literacy into their consent document and process. This is valuable information but may not be generalizable to other health care systems. Although the initiatives proposed by health care professionals tend to be evidence-based, they lack input from patients. Patients' wants and needs should be addressed in the health information they receive. The majority of literature from health care professionals

does not include the patient's perspective at all. In fact, one study included input from patients regarding level of medical knowledge and their input was ignored by the medical students. If we truly want to provide patient-centered care, patient input must be solicited and taken seriously as a part of promoting health literacy.

### **Patient perspective**

Inadequate health literacy is a barrier to patient involvement in health care decisions and is a contributor to poor patient outcomes. Because patients are the best to decide what information they can read, understand and use, their input into creating health information materials is valuable. Also, patients have ideas of what kinds of information they would like included in the health information materials they are given. They also may have some information that they feel is needed in order to take care of themselves that health care professionals are unaware of. Patients should have input into how materials are presented and what information is included.

Researchers which focus on the patients' perspective on health literacy have given us a wealth of new knowledge. The literature can be divided into four categories. The first category from this perspective addresses how patients are affected by inadequate health literacy. The second category focuses on communication between patients and health care providers and the patient-provider relationships, which are important factors influencing the discharge process. The third category addresses patient preferences of the presentation of the health information they receive. The fourth category discusses the use of technology in delivering health information to patients. When creating health information materials, efforts to discover the consumer's needs, the patient's needs, should be undertaken to attempt to increase the effectiveness of the materials.

## **Quantitative articles from patient perspective**

Inadequate health literacy, which has been shown to be a contributor of health disparities, can have damaging consequences to patients. It is important for us to know, from a patient's perspective, how they are effected by inadequate health literacy. Aikens and Piette (2009) assessed 573 diabetic patients to understand how beliefs about medications relate to medication underuse and health status. Concern about medication side effects and harmfulness leading to underuse was found to be associated with low health literacy (Aikens & Piette, 2009). Morris, Grant, Repp, Maclean & Littenberg (2011) studied the prevalence of compensatory strategies of limited health literacy in 103 hospitalized patients and found that over half rely on health care professionals and one fourth look to family member when making decision concerning their health care. In a study of 254 patients aged 70 and over that had been admitted to acute medicine services for greater than 24 hours, Lindquist, Friesema, Baker, Jain and Fleisher (2012) administered face-to-face surveys at hospital discharge and obtained medication lists from written discharge instructions. Phone interviews revealed that 56 percent had medication discrepancies 48 hours after discharge. The phone interviews also revealed that individuals with inadequate health literacy were more likely to have unintentional non-adherence, whereas individuals with adequate health literacy were more likely to have intentional non-adherence. In an effort to determine the effect of health literacy on shared decision making and trust in physicians, 502 veterans in a primary care setting were surveyed revealing that African Americans had lower health literacy and a greater dissatisfaction with their role in decision making (Rodríguez, Andrade, García-Retamero, Anam, Rodríguez, Lisigurski, Sharit & Ruiz, 2013). Serper, Patzer, Curtis, Smith, O'Connor, Baker and Wolf (2014) organized a study of 784 patients aged 55-74 which included assessing for health literacy and administering structured, in-

person interviews. Findings from the interviews showed that inadequate health literacy is associated with poor physical health and depression (Serper et al, 2014). To examine the educational information desires of patients and their families in the emergency department waiting room, 544 individuals were surveyed and found to reveal a high demand for emergency department function and medical emergencies (Seibert, Veazey, Leccese & Druck, 2014). This is evidence that patients are feeling the effects of inadequate health literacy.

The patient-provider relationship is an important factor in how successful patients are able to utilize and navigate the healthcare system. In a study of 202 African American women with low and high literacy levels, it was discovered that all women had poor utilization of prenatal care and cited communication with clinicians as an influence (Bennett, Switzer, Aguirre, Evans & Barg, 2006). When comparing the self-identified cardiac health needs of 81 female patients to those identified by their practitioners, the findings suggest that health care providers do not accurately identify patients' most important self-reported educational needs (Parks, Turner, Perry, Lyons, Chaney, Hooper & Burns, 2011). When analyzing the questionnaires of 571 women with urinary incontinence, it was found that, regardless of race, improved patient-doctor relationship and public education may foster healthcare seeking behavior (Berger, Patel, Miller, Delancey & Fenner, 2011). In a survey of 399 patients with chronic kidney disease, it was found that higher perceived and objective knowledge of disease was associated with greater satisfaction with physician communication (Wright Nunes, Wallston, Eden, Shintani, Ikizler & Cavanaugh, 2011). Chu and Alex Tseng (2013) conducted surveys followed by face-to-face questions with 144 patients. Information from the patients, 56 percent of who had an education of primary level or less, revealed that perceived low empathy from physicians may negatively affect patients' understanding of information. In an effort to discover the opinions of patients and

providers about team-based approach to controlling blood pressure, patients were found to appreciate quality communication and not losing their relationship with their primary provider (Donahue, Vu, Halladay, Miller, Garcia, Cummings, Cene, Hinderliter, Little, Rachide & DeWalt, 2014).

The way in which healthcare information is presented to an individual or population can influence how well the information is understood and whether or not individuals or population take action based on the information. A cultural-based breast cancer educational intervention among Hmong women compared 354 in the intervention group to 80 in the control group. Results showed that use of the cultural-based intervention led to increased use of services, knowledge and attitudes (Kagawa-Singer, Tanjasiri, Valdez, Yu & Foo, 2009). Pictogram preference of 2719 participants was assessed using pictograms showing medication side effects. Results showed that individuals prefer cultural-specific and education level-specific pictograms (Richler, Vaillancourt, Celetti, Besançon, Arun & Sebastien, 2012). When comparing the preference of patients viewing information about risks and benefits of medical treatment, although there were no differences in the understanding of information, patients preferred pictographs and bar graphs over text and pie charts (Tait, Voepel-Lewis, Brennan-Martinez, McGonegal & Levine, 2012). Screening by patients of a family and patient centered informational and evidence-based decision aid for patients with end stage renal disease written at a 4<sup>th</sup> to 6<sup>th</sup> grade reading level revealed that careful attention to the design process of a decision aid may help patients and families make informed decisions about their treatment options (Ameling, Auguste, Ephraim, Lewis-Boyer, DePasquale, Greer, Crews, Powe, Rabb & Boulware, 2012). In a study of 100 patients, it was discovered that Magnetic Resonance Imaging (MRI) reports reworded using an eighth-grade reading level and using neutral descriptive words

led to better patient emotional response, satisfaction and understanding (Bossen, Hageman, King & Ring, 2013). In a study of 272 patients receiving after-visit summaries after their primary care office visits, it was found that although patients were satisfied with the summaries, the amount of information provided and health literacy level had no effect on patient recall and satisfaction at 2 days and 2-3 week post visit (Pavlik, Brown, Nash & Gossey, 2014).

The use of technology in healthcare has been shown to have the capability to improve understanding and reduce barriers for individuals with inadequate health literacy. In a comparison study of consent form delivery systems, a computer agent offering no time constraints, ability to re-ask questions and lack of bias, was preferred over human delivery, especially among individuals with limited health literacy (Bickmore, Pfeifer & Paasche-Orlow, 2009). A website to meet the needs of low health literacy in Neonatal Intensive Care Unit parents was developed and then evaluated to reveal that visuals with text improved understanding and concrete and realistic pictures with clear captions maximized the benefit (Choi and Bakken, 2010). A computer-based questionnaire was developed to assess asthma symptoms in children of low health literacy parents and was compared to the traditional paper questionnaire. 48 parents were divided into 2 groups for comparison which revealed that technology that is interactive can help reduce barriers to access due to inadequate health literacy (Vargas, Robles, Harris & Radford, 2010). A random sample of 227 rheumatology patients completed questionnaires assessing their use and intent to use online support services for rheumatic diseases and found that all patients were interested and intended to use the online support regardless of level of literacy (van der Vaart, Drossaert, Taal & van de Laar, 2011). Self-management guidebooks using cartoons to depict patient experiences, daily dilemmas and decision making in patients with such chronic conditions as inflammatory bowel disease,

diabetes, chronic obstructive pulmonary disease and chronic kidney disease were evaluated by 27 participants and found to invoke pleasure, understanding and contemplation (Kennedy, Rogers, Blickem, Daker-White & Bowen, 2014).

Patients are a good source of information as to how living with inadequate health literacy affects them. Chu and Alex Tseng (2013) had limitations to their study in that they collected all their data from a unique patient population so the findings may not be replicable in another setting. The study conducted by Serper, et al (2014) was mostly comprised of older, white females and may not be generalizable, especially to younger populations. Linquist et al (2012) coordinated a study of seniors, so their findings are not generalizable to other populations. Although patient input is important, studies need to be performed to assess the effects of inadequate health literacy in other populations.

### **Qualitative articles from patient perspective**

Qualitative research studies concerning health literacy allow the researcher to gather information from the patient perspective. They are able to discern what patients' understanding of health literacy is, what factors they feel are important concerning the topic, and how inadequate health literacy effects their ability to actively participate in the healthcare system. The studies can uncover what health education materials patients desire and how they prefer these materials be presented to them. Patients are able to tell researchers how they are effected by inadequate health literacy.

Qualitative studies which focus on the patient perspective allow the researcher to discover how the patient feels about and understands a topic and what factors surrounding that topic are important to the patient. Jordan, Buchbinder, and Osborne (2010) examined the issue of health literacy using the patients' perspective. After interviewing patients, they were able to

identify seven key abilities related to health literacy which were of importance to the patients: knowing when to seek health information; knowing where to seek health information; verbal communication skills; assertiveness; literacy skills; capacity to process and retain information; application skills. The patients felt that these abilities would assist them to participate in their health care. Buckley, McCarthy, Forth, Tanabe, Schmidt, Adams and Engel (2013) conducted 5 focus groups using 14 patients, aged 18 and over, as part of a quality improvement initiative. Patients desired input into content and layout and flow of documents. Patients suggested such changes as alternate word usage for complex terms to ensure clarity and including the addition of pictures. In the past, patients have not enjoyed much inclusion in the process of developing health materials. Usually, these materials are created using information from medical literature and health educator input rather than being directed by patient needs. This oversight may lead to neglecting to give patients the tools they need to successfully manage their illness or injury at home. Additionally, analysis of detailed notes from the focus groups showed that patients felt that effective communication at the time of discharge was a key factor in providing quality care (Buckley et al, 2013). North, Pollio, Devereaux, Hong, and Jain (2014) found that when speaking in focus groups, patients identified the information they were provided by physicians as important; however, patients rated other topics of higher interest. The groups identified a need to improve the relationship between patients and physicians which is significant in that encouragement and support from physicians has been shown to improve patient motivation for treatment (North, Pollio, Devereaux, Hong, and Jain, 2014). In semi-structured interviews of 20 older, African American adults with HIV, they reported that there are 4 important themes related to intervention development and design. These themes, individual learning needs, sex-specific

and mental health needs and delivery approaches, are necessary to improve management of disease and health outcomes (Gakumo, Enah, Vance, Sahinoglu & Raper, 2015).

One particular focus of information obtained from patients is what health information they want included in the health materials they are given. This focus addresses where health information is obtained as well as what information is included and how it is presented as written health material. In a study using focus groups consisting of 34 patients and 15 physicians, print size, diagrams, and clear and simple presentation of the information made the materials easier to use and understand (Davis, Armstrong, Dignan, Norling & Redmond, 2006). In a study about patient preferences of sources of health information using 9 focus groups of 45 adults with diabetes, the following five themes surfaced: 1) passive information is important, 2) patients tend to create their own path of information gathering depending on where they are in the disease process, 3) patients' personal relationships help them understand and use information, 4) patient-provider relationship is important to resolve complicated and conflicting information and 5) health literacy affects a patient's ability to understand and use health information (Longo, Schubert, Wright, Lemaster, Williams & Clore, 2010). Genuis (2012) interviewed 28 information seeking women and found that social context, information consistency, and source complementarity were important factors when using health information sources. Focus groups consisting of 12 participants evaluated a patient education website and recommended that all levels of health literacy and technology skill be considered when developing websites for patients (Diamantidis, Zuckerman, Fink, Hu, Yang & Fink, 2012). In a study using focus groups with a total of 27 participants, the participants preferred different information than what was initially provided. Participants experienced problems with the online information related to

comprehending medical terminology (Hopmans, Damman, Timmermans, Haasbeek, Slotman & Senan, 2014).

Qualitative studies done from the patients' perspective allows the patients to tell the researcher how they are impacted by inadequate health literacy. In a study interviewing 188 participants, results show that overall knowledge may mask patients' incorrect theories leading to poor decision-making (Holmes-Rovner, Price, Rovner, Kelly-Blake, Lillie, Wills & Bonham, 2006). Interviews involving 73 men and women revealed that higher health literacy levels are associated with higher perceived involvement in shared decision-making with their health care providers (Smith, Dixon, Trevena, Nutbeam & McCaffery, 2009). Peek, Wilson, Gorawara-Bhat, Odoms-Young, Quinn & Chin (2009) interviewed 24 participants and found that health literacy is a barrier to shared decision-making. In a study of 12 participants, interviews revealed that individuals felt insecure if they didn't receive enough or understand information (Modiq, Kristensson, Troein, Brorsson & Midlov, 2012). Interviews of 18 participants revealed that health literacy effects persons' abilities in seeking options and informed and shared decision making opportunities (Edwards, Wood, Davies & Edwards, 2012). In a study using focus groups, 50 participants revealed that deciding to participate in clinical trials is based on patients understanding research and science, patients being able seek out and evaluate health information, and providers communicating in a way that is appropriate for the populations served (Evans, Lewis & Hudson, 2012). In a study of 60 individuals having undergone hematopoietic stem cell transplantation, it was revealed that improving a patient's understanding using clearer forms, better communication, and reinforcement reduces risks for negative outcomes (Cohen, Jenkins, Holston & Carlson, 2013). After assessing for health literacy, cognitive function and functional health, interviews of 784 adults showed that cognitive function clarifies a significant association

between health literacy, physical health and depression (Serper, Patzer, Curtis, Smith, O'Connor, Baker & Wolf, 2014).

### **Benefits and limitations of patient perspective**

Research findings from the patient perspective validate the importance of health literacy in patient care, showing us that the patient population suffering from inadequate health literacy is significant. The research findings also support that patient and family involvement is paramount to positive patient outcomes. Patients should have input into what type of information is to be included in health materials they are given. Researchers inquiring as to patients' wants and needs are a good source to discovering that. Adequate health literacy is important in order to allow patients to be informed participants in their own plan of care.

There are some limitations to research studies that represent the patient perspective. The focus groups coordinated by Buckley et al (2013) consisted of a small sample from one clinic, so findings cannot be generalizable to other populations. The interview findings of Jordan, Buchbinder, and Osborne (2010) were gained from a sample of 48 Australian individuals, so may not be generalizable to other patient populations. North, Pollio, Devereaux, Hong, and Jain (2014) conducted focus groups with a unique population of hepatitis C patients, so their findings may not be generalizable to other patient populations. Even though these findings may not be generalizable to other patient populations, they are significant in that they are from the patient's perspective. Further research needs to be done to see if the findings are generalizable.

This critique of the implementation of health literacy initiatives show that a few key components are still missing. Patients need to know the importance of treatment plans and be able to access health care services to maximize chances for positive health outcomes. Accurate, linguistically-appropriate materials need to be provided and accessible to patients. But more

importantly, patients need to be a part of deciding what information physicians provide so that their information needs are met. Patients are telling us that they are not receiving information about the topics most important to them. In order to build a strong physician and patient relationship, physicians need to listen to the needs of their patients. When discussing care and treatment in focus groups, patients identified poor communication between doctor and patient as a barrier to care (North, Pollio, Devereaux, Hong, and Jain, 2014). Health literacy initiatives, if implemented effectively by using patient input, are a way to care for patients by empowering them to be involved in their health care. Soliciting patient feedback is an important step in creating written documents that meet the needs of the patients. Further research needs to be conducted to discover what patients want included and how they want their health information delivered.

### **Patient experience or perception of the discharge process**

In addition to the written health education materials, the perceptions patients have of the discharge process has the A second literature review using CINAHL and PubMed was conducted for the years 2005-2015 using the terms discharge process and patient experience or perception to attempt to discover factors other than the written materials that might be influential in the discharge process. The search was then limited to human adults, United States of America and no mental health or learning disabilities reducing the total number of articles The initial search yielded three articles that were from the patient's perspective. Two articles were qualitative and one was quantitative. These studies allow insight into the patients' experiences of the discharge process and to share their insights into what works and what doesn't work.

Knight, Thompson, Mathie and Dickin, (2011) when interviewing 12 caregivers and seven patients 75 and older, found that inadequate explanations and poor communication at

hospital discharge were barriers to effective medication management in adults taking four or more medications. A quantitative survey to evaluate the effectiveness of a change to an interprofessional discharge planning/teaching process with more patient and family engagement yielded that an interprofessional approach to discharge teaching improved patient satisfaction and the quality of teaching (Knier, Stichler, Ferber & Catterall, 2014). Koh, Barr & George (2014) conducted semi-structured telephone interviews to explore obstacles incurred during the discharge process that discourage patients from continuing stroke rehabilitation after hospital discharge. The themes that resulted from the study data were: the means to access rehabilitative services; lapse in discharge coordination; family members' views and actions; discrepancies in expectation; and the perception that rehabilitation is simple (Koh, Barr & George, 2014).

The findings from these studies revealed that although most of the focus on health literacy is about the written materials themselves, there are other important factors that influence the patients' experiences of the discharge process. Study findings yielded both positive influences as well as barriers perceived during the discharge process. Involving the patient and family in the discharge planning and teaching process was viewed as positive. Barriers to a successful discharge included poor communication between patients and providers as well as poor coordination of the discharge process. These findings, coupled with the scant literature in this area, support the need to further explore the experiences of patients during hospital discharge.

### **Factors influencing health literacy**

The review of literature identifies factors that influence a person's health literacy level. Two key factors identified include race and age. In a study of fifty four participants evaluated using the Newest Vital Sign, Blacks and Hispanics had significantly lower health literacy

(Heinrich, 2012). Surveys of 502 veterans in a primary care setting revealed that African Americans had lower health literacy and a greater dissatisfaction with their role in decision making (Rodríguez, Andrade, García-Retamero, Anam, Rodríguez, Lisigurski, Sharit & Ruiz, 2013). Additionally, Weekes (2012) found that African Americans have a lower health literacy when compared to Caucasians counterparts and that there is a scarcity of research on health literacy in the African American population. Older adults, effected by sensory changes, require unique strategies to address their health literacy needs (Speros, 2009). Billek-Sawney and Reicherter (2005) state that health providers need to be aware of health literacy among older adults and the need to employ effective strategies to address this issue. These findings support the need for further research involving these populations.

## CHAPTER 3 METHODOLOGY

### **Methodology**

The purpose of this chapter is to detail the methodology chosen for this study and explain why the particular approach was chosen. A general qualitative research approach utilizing a semi-structured interview was used to investigate the experiences that patients have when they receive health education materials in the inpatient setting, specifically written discharge information and instructions. This inductive approach was an exploratory study that allowed for new information to be discovered through the thoughts and insights of the patients themselves. The researcher is seeking to discover the experience of receiving written discharge information and the discharge process as a whole from the perspective of patients. A qualitative approach was employed in order to discover factors and variables which may not be captured in a standard questionnaire or survey containing a specific set of options as answers. This study was an attempt to “break new ground by revealing what had been concealed because” researchers had not previously explored this aspect (Munhall, 2012, p. 11).

The focus of this study was to explore the participants’ perspectives concerning health education materials and meanings that emerge with thematic data analysis of the interviews. This study was significant because patients hospitalized for a cardiac event are frequently given written information and instructions and are expected to have what they need to manage their illness at home and to decrease the chance of readmission. The intent of this chapter is to describe the methodology chosen for this study. Additionally, the research questions, population

studied, consent process, data collection process, research design and data analysis process are discussed.

### **Qualitative research**

Qualitative research is a method of inquiry used to explore the understanding of a phenomenon or event by exploring all aspects of the situation. The data collected from qualitative studies is most often in the form of words. As explained by Miles and Huberman (1994), these words are the result of observation, examination or inquiry. Data collection usually occurs with the researcher being in close proximity of the situation being studied for an extended period of time (Miles & Huberman, 1994). One thing to consider when using qualitative data is that words have different meanings for different people and measures to verify intended meaning must be employed.

Tesch (1990) explains qualitative research types using a graphic flowchart (Miles & Huberman, 1994, p.7) that flows from the research interest to the comprehension of the meaning. Using Tesch's flowchart, this study begins with language as communication leading to the discovery of regularities. The identified regularities are further explored in an effort to comprehend the meanings and discern themes (Tesch, 1990). Following the formation of themes, member checking for accuracy of meaning is performed using follow up contact with participants.

A qualitative approach was chosen for this study because it enables the researcher to explore a particular phenomenon or event from the participant's perspective. During the interview process, participants communicated their experiences through spoken words. Comparison of the collected data, words and phrases from the different participants, led to the discovery of regularities among them. Meanings were assigned to words and phrases and then

similar words and phrases were placed into themes. The meanings and themes were checked for accuracy by contacting the participants and verifying. The data collected was then further analyzed to evaluate if the research questions had been addressed or answered.

### **Research questions**

The purpose of this study is to explore what perceptions patients have of the healthcare materials that they receive or if there are other factors that influence the discharge process. The study will address the following questions:

- 1) How do patients experience the written information during discharge?
- 2) What, if any, other factors influenced the patient's experience of the discharge process?

### **Population**

The population chosen for this study was African American adult females recently discharged from the hospital for congestive heart failure. This particular patient population is being chosen because patients with cardiac events are among the top populations with the tendency to be readmitted to the hospital within 30 days of being discharged. African American females represent a specific population with a significant number being affected by cardiovascular disease.

### **Recruitment**

Participants for the study were recruited from the cardiac care unit. Potential participants were approached prior to discharge and given an informed consent form to read and ask questions. Potential participants were made aware that there would be no consequences for refusing to participate and that their care would not be altered in any way. Individuals that chose to participate signed the consent form and were given a copy to keep. Individuals that choose to

participate were informed that they had the right to leave the study at any time without fear of consequences.

### **Data collection**

Nine African American adult females, age 18 or older, hospitalized with a chronic cardiac diagnosis were interviewed between 48 hours to 10 days post hospital discharge. The purpose of the interview was explained, and then the participants who were interviewed were asked to think back on when they were recently discharged from the hospital and to share their thoughts about the experience. The interview was guided using the following open-ended prompts: 1) Tell me about when you received your instructions at discharge. 2) Did you feel like that situation was handled to your satisfaction? Why? 3) Was the information useful to your situation? Why? 4) Did the information you were given meet your needs? Why? The interviews were conducted using an open format, with interviewees being allowed to recall their experience and generate information spontaneously. Participants were refocused using the guided prompts if necessary. The interviewer audio recorded the interviews, transcribed them word-for-word and verified them for accuracy using follow-up interviews with each participant. Interviews lasted approximately 45 minutes each. One interview was conducted by telephone and the other eight were in person.

Data was collected from February 2017 through May of 2017. Data collection included nine 45-60 minute recorded face-to-face and telephone interviews with participants. Individual, semi-structured interviews allowed participants the opportunity to provide detailed personal accounts of their experiences of receiving written healthcare materials in the hospital setting, as well as the discharge process as a whole. This process allowed for participants to disclose their

perceptions of whether these materials are meeting their healthcare needs. Each interview consisted of four major open-ended prompts and the opportunity to share the experience openly. Initial interviews were conducted at a mutually agreed upon location that was convenient to both participant and researcher, providing an environment in which the participant felt free to speak openly and honestly and was conducive to allowing for an audiotaped interview. All interviews were audiotaped and transcribed by either the researcher or a transcription service following the interview. The audiotapes were securely stored until completion of the follow up interview and then destroyed.

Follow up interviews with participants were scheduled as transcripts were completed to verify interpretation of data. Follow up interviews were conducted by telephone. These interviews were shorter than the initial interviews and were used to verify interpretation of data, fill in gaps from the first interview and to explore concepts that surfaced from other interviews. In addition to transcribed interviews, a reflective journal was kept to minimize the possibility of researcher preconceptions being interjected and to ensure that the focus was on participant experiences.

Also, a copy of the written discharge instructions (Appendix) given to the patients at discharge was obtained from the nurse manager of the nursing unit. The Electronic Medical Record at this facility is managed by Cerner. The discharge instructions are chosen by the physician from the standard documents provided in the system. The document cannot be altered by the staff nurses. In all cases, discharge instructions and paperwork were given by the participant's nurse or nurse and nursing student on the day of discharge from the hospital. By comparing what the participants were able to recall from the discharge teaching, this document

allowed the researcher to verify that the participants were able to read and/or understand the instructions they were given during discharge from the hospital.

### **Data analysis**

Analysis of the qualitative data gathered from these transcribed interviews used an open coding strategy. The interviewer reviewed all the transcribed data, identifying similarities among interviewees in experiences and examples provided. The data analysis process, or coding, included the development of as many thematic categories as possible. A set of initial codes and subsequently the corresponding definitions to support those codes were developed through line-by-line coding. This process was used to develop themes from the perspective of the participants. The data was then organized according to the themes. Conceptually similar concepts were grouped together to form themes and sub-themes. These themes were organized into categories in order to address the research questions. Definitions of the themes were further developed as statements from participants were added. As themes were further developed, as many subthemes as needed were also developed. Phrases were added to the subthemes in order to demonstrate common themes among participants. Themes that are not common among a significant number of participants were eliminated. Additional themes were developed as needed as additional interviews were conducted.

### **Verification**

Strategies were used to ensure the validity of the data collection and analysis process. These strategies included providing rich, detailed descriptions, member-checking and reporting of researcher bias. The researcher provided a detailed description of the study's focus, the role of the researcher, the basis for selection of participants, and the situation surrounding data collection. Member-checking was employed by having participants verify interpretations and

meanings derived from data analysis. Finally, the researcher disclosed in writing in the dissertation proposal, under the heading “Role of the researcher,” any preconceptions held by the researcher. All data collection and analysis strategies were disclosed in detail in order to provide a correct portrayal of the methods utilized in this study.

### **Role of the researcher**

Due to previous and current experience of working closely with hospitalized patients, the researcher brought certain biases to the study. I embarked upon this study with the viewpoint that patients have plethora experiences related to receiving health education materials in the hospital setting. To control for the potential effects of preconceptions by the researcher sometimes present in the use of a qualitative approach, the researcher implemented strategies to lessen the effects of such preconceptions. The researcher wrote down what she knew about the subject prior to conducting interviews, kept a reflective journal, and asked for participant feedback (Hamill & Sinclair, 2010). Personal ideas about the subject were written down prior to interviewing to ensure that these ideas and values did not override those of the participants. A reflective journal was kept to allow the examination of positions throughout the data collection process. Participant feedback was obtained through the use of follow-up interviews to ensure that interpretation of the data was correct.

### **Bounding the study**

The setting of the study is a large academic medical center and Adult Level I Trauma Center with over 1,000 inpatient beds. The medical center has more than 16,000 employees and more than 1,000 physicians. The medical center is located in a city with a population of over 200,000. The sample in this study included African American female adults, age 18 or older, and recruited from an inpatient cardiac care unit. Participants were English speaking and were

hospitalized with an acute exacerbation of a chronic cardiac diagnosis. Potential participants, identified by the nurse manager of the nursing unit, were asked for permission to discuss possible participation in the study prior to or at the time of hospital discharge. They were given the opportunity to participate in the study if they were found to meet participant criteria.

Using a general qualitative approach, the patients were interviewed between 48 hours to 10 days post hospital discharge. The interviews took place at a mutually convenient time and location. All attempts were made to conduct face-to-face interviews; however, one of the interviews was conducted by telephone. Particular attention was paid to understand whether or not participants felt that health education materials met their needs and expectations.

Participants were asked to give examples of how they were able to use the information they received. Participants were asked how the information provided addressed or did not address their concerns. Also, open-ended questions were used to help identify participants' expectations of health education materials. Participants were allowed to share their experiences of the discharge process in an effort to discover if health education materials are meeting the needs of patients.

### **Ethical considerations**

To minimize the chance of ethical issues arising, certain preventive steps were taken. First, The American Nurses Association Code of Ethics was consulted. Because human participants were involved, informed consent, with the option to withdraw at any time, of the participants was obtained. Institutional Review Board approval from the institution and the university were obtained. Some ethical issues that could have arisen during my proposed study included patient privacy violations, institutional policy violations, and the discovery of improper patient care.

Precautions were taken to avoid violating the rights and privacy of any patient.

Participants were not pressured into being a part of the study, but were formally invited to participate and allowed to withdraw at any time during the study. The research objectives were articulated both verbally and in writing. The participants were informed of their role in the study and their rights as participants in language they could understand. Participants were informed of any data collection equipment and activities. The researcher was prepared to deal with cross-cultural issues among participants. Any participants from vulnerable populations had their needs addressed during the study. All patient information and any data collected for the study was secure and protected. Any personal information and identifiers were kept confidential. Personal identifying information was not included in the final report. Transcriptions were verbatim and interpretations were made available to and verified by participants.

The researcher did not exhibit any behaviors that might reflect poorly on the university or violate the policies of the institution where the study was being conducted. The researcher was aware of and familiar with the code of conduct at both entities. The researcher presented herself in a professional manner.

The interview process has the potential to reveal malpractice issues where patients did not receive written information when they should have. This possibility was discussed with the institutions involved. The researcher was aware of what steps to take had potential cases of poor patient care or possible malpractice arisen.

The researcher attempted to prepare for any foreseen ethical issues that might have arisen during the study. Also, the researcher was aware of how such issues should be reported if they had occurred. Additionally, the researcher watched for unforeseen ethical issues and was familiar with the protocol for reporting such occurrences.

## **Summary**

Qualitative research allows for the exploration of a particular phenomenon from the perspective of the individuals that are experiencing it. The researcher was seeking the personal experiences and perceptions of study participants with regards to the written health information that they received at hospital discharge as well as the discharge process as a whole. The interview process collected data in the form of communicated words which were assigned meanings and then further categorized into themes. Words and phrases with similar meanings were placed into the same theme. The meanings and themes were verified by the individual participants using follow up phone calls. The resulting meanings and themes give insight into the perceptions and experiences of the participants. Data analysis and discussion are in the following chapters.

## CHAPTER 4 RESULTS

### **Results**

The participants of this study consisted of nine African American adult females with a diagnosis of congestive heart failure. None of the nine participants were newly diagnosed. Demographic information, such as age, socioeconomic status, marital status, degree of education and literacy level were not collected. The group was treated as one population in and of itself.

Each participant was approached while a hospital inpatient and asked if they wished to participate in the study. Each signed an informed consent and were given a copy of the consent along with contact information should they have questions or change their minds. Participants were contacted after discharge from the hospital to set up a time and place for the interview.

Interviews took place 48 hours to 10 days post discharge. Six interviews occurred in the participants' homes. Two interviews occurred at mutually agreed upon public locations. One interview was conducted via telephone due to travel distance. Interviews lasted between 30 and 75 minutes and were audio recorded with the participants' consent. The interviews were transcribed verbatim. Analysis of the qualitative data gathered from these interviews used an open coding strategy. The interviewer reviewed all of the interview data, identifying similarities among interviewees in experiences and examples provided. As a result of this review process, 7 initial themes with brief descriptions were generated. In some cases, the name of the theme was provided by the interviewee, and in others the name of the theme emerged during the analytic process based on key similarities in descriptions across at least two interviews. The themes were

further elaborated and the 7 subthemes were organized into three overarching conceptual categories. Descriptions of categories and themes were then refined and relevant examples from the interview data were identified and interpreted. Finally, the findings were member checked by telephone conversation with each one of the interviewees to validate the results of the analysis.

The participant quotes supporting the 7 subthemes are shown in Table 1 below.

Table 1: Subthemes Supported by Participant Quotes

Participant Number	Understandable	Comprehensiveness	Patience	Patient-centered	Personal Touch	Professionalism	Communication
1	X	X			X		X
2	X	X	X	X	X		X
3	X	X	X	X	X	X	X
4	X	X	X	X	X	X	
5	X	X	X	X	X	X	X
6	X	X	X	X	X	X	X
7	X	X	X	X	X	X	
8	X	X	X	X	X	X	X
9	X	X	X	X	X	X	X

The three categories with their 7 subthemes are described in detail below. The categories and subthemes are further divided to address the research questions.

Research Question: 1) How do patients experience the written information during discharge?

1. Consumer-friendly Information and Materials: This category included examples of participants reporting that the information and materials that they were given were easy to use and/or understand. The participants conveyed that the materials were readable and helpful. To verify that the information was readable and understandable, participants' responses to what information they were given was

compared to the written discharge information they were given when they were discharged. They also reported that the staff supplied them with comprehensive information in order for them to better understand their diagnosis and allow them to be better prepared for self-care.

- a. Understandable: This subtheme referred to instances of participants conveying that the materials were able to be understood; intelligible. Participants reported that the written materials were easily understood and straightforward. None of the participants reported not being able to read the information that they were given. Additionally, when referring to the discharge instructions given to the patients at discharge (Appendix), patients demonstrated the ability to communicate, through spoken words, major points included in the instructions that they were given.

All participants reported having no difficulty reading and understanding the information they were given. They shared experiences of health care team members reviewing the information to make sure that the participants understood it prior to being discharged. All of the participants reported that they understood the discharge instructions prior to being discharged. Participant 1 said that the health education materials “made sense to me.” Participant 2 reported “everything was well. I had no problem with it. Everything was good.” Participant 3 felt the information “was useful for me uh staying on track of what the doctor told me to do.” Participant 4 remembered her experience of receiving discharge health education materials stating that the health care team “actually did a very well job. Yeah, they did a great job. They had a lot of information that I needed and all I have to do.” Participant 5 recalled her experience saying that her physician “had instructed me and he gave me the instructions of what I needed to do the day

out of the hospital. I understand, and they made sure I understand it because a nurse came around and she went over it with me and had me sign a sheet that I understood what I needed to do.”

Participant 6 reported that the information she was given “gave me great information on what the norm is for me and where I was.” Participant 7 stated that her paperwork “had information that helped. I didn’t have no complaints about it. I didn’t have any problems.” Participant 9 reported that the health care team “gave me instructions on what to do upon the discharge and everything. It was real helpful.” Participants reported feeling like they had been supplied with all of the information that they needed to successfully manage their health care at home.

In order to verify that the patients understood the written health information they were given, patient recall of information was compared to the information in the written instructions they were given. Quotes referring to instructions they were given were compared to the discharge instructions given by the hospital unit. The ability of the participants to spontaneously recall information in the discharge information, without having the paperwork in front of them, supports that knowledge transfer occurred. This also could be evidence supporting that if health care providers are patient, form good relationships and have good communication skills, patients can remember verbal instructions even if they are not able to read written instructions.

The five main points included in the discharge instructions given to the patients are: daily weights to monitor fluid retention, limited or no salt intake, fluid restrictions, medication adherence and symptoms to watch for. All participants recalled the need for daily weight monitoring. Six out of nine participants mentioned sodium and fluid restrictions. Eight out of nine participants talked about their medications. Seven of the participants mentioned symptoms they were supposed to watch for. Six participants referred to all five of the main teaching points included in the discharge information.

The importance of daily weighing to monitor for weight gain due to fluid retention was mentioned by all participants. Participant 1 shared “they want us to weigh ourself every day. That makes sense. They want you to weigh before you go to the bathroom. Before you go to the bathroom, weigh yourself. Make sure you don’t carry no excess weight.” Participant 2 explained that daily weighing is important “so I won’t be weighing more than I should be weighing with the fluid.” Participant 3 recalled that if she “had any swelling or gain any weight. Anything like that it’s important for me to call the doctor.” Participant 4 stated that “They told me to watch for weight gain, five pounds or more.” Participant 5 was told to “weigh myself everyday...check the pounds. More than 5 pounds. I’m supposed to check and make sure by weighing myself every morning.” Participant 6 stated “if you gain one or two pounds to alert their office or get in touch with your heart doctor and alert them immediately.” Participant 7 was instructed to “weigh myself every day. Watch for fluid gain. Call my doctor if more than 5 pounds.” Participant 8 recalled that “if I start to gain any weight, 2-3 lbs a day or 3-5 lbs a week, I need to call my doctor and see my doctor.” Participant 9 shared “I’m supposed to take my weight every day.” These responses support that all participants are aware of the need to weigh themselves daily.

The need to reduce or eliminate sodium intake was discussed by six of the nine participants. Participant 3 explained her understanding of the need to limit her sodium intake by stating “So, I cook it with no salt. I use Mrs. Dash and garlic powder and drink the amount of water that they told me to drink and I, I’m sticking close to the doctor ordered me to do.” Participant 4 discussed her understanding of sodium restrictions by sharing “I didn’t realize that I needed to clean that as well cause it’s too much salt. Too much sodium, yeah. 2000mg in my food intake throughout the day. I’m not supposed to go over that.” Participant 5 described a food label used to teach her about sodium restrictions saying “They gave on a sheet of paper. They

had a list of ingredients like one was canned beans, the gravy. They showed me how to read it and see how much sodium was in it then look on the other side and see how much sodium I'm supposed to take in. it was very helpful to me." Participant 6 discussed the changes she would make in order to comply with the sodium restriction stating "I didn't take a salt shaker to the table, but I added salt to my food. And now, they gave me a list of different seasonings I can use." Participant 8 explained her understanding of the need to restrict sodium in her diet by saying "Yes, ma'am. Instead of me using salt, they said I can use a salt substitute like Mrs. Dash, you know to season my food." Participant 9 discussed her strategies to eliminate sodium by sharing "Yes, I do have to look at them labels. That's the one thing the dietician really enforced. She said, "Look at the labels. You will get a lot of what you are looking for. Use basil, garlic, onion powder, garlic powder, not the salts." These quotes are evidence of the participants' understanding of the need to reduce or eliminate sodium in their diets.

Six of the nine participants were aware of the fluid restrictions that were mentioned in their discharge instructions. Participant 3 shared her understanding of the fluid restrictions by saying "I'm drinking an amount that they told me to drink." "That little cup what they had in the hospital. I can have that full of water and a half. Once a day, and that's it. And I figured that out too. It's a bottle and a half of water." Participant 4 demonstrated her knowledge of the fluid restrictions by sharing "I drink a cup of coffee and I got a can of soda which is like 355ml. So that's like give or take close to 600ml already I've taken in, which leaves me at 900 more and then I can't drink anything else today." Participant 5 shared that she "was still on restriction intake, of liquid restriction, and about the hospital cup they gave me. I use that cup all the time to make sure that I don't overdo it." Participant 6 explained that "There was a certain amount of liquids I was supposed to be drinking every day. I never knew that until I got to (this hospital

setting).” Participant 8 recalled that “They also told me about how I should stay on the fluid restriction diet on 1500 cc of water each day.” Participant 9 shared her understanding of the fluid restrictions by saying “I’m still having a hard time dealing with the intake of fluids cause it’s kinda hard to do like you know 1.5 liters.” These statements are evidence of the participants’ understanding of the fluid restrictions listed in their discharge information.

All but one of the participants mentioned their medications during the interview process. Participant 1 acknowledged the importance of medication by stating that she was “Keeping up with the days I take my medicine,” and that “the nurse came and check my medicine. Make sure that I ain’t...everything that I suppose to have.” Participant 2 shared that she had knowledge of her medications because “They explained the kinds of medicine that I would be taking, each one.” Participant 3 recalled the teaching she received by stating “after I got the medicine, she went over all the medication with me.” Participant 4 shared that “they gave me a new gout medication cause I have that in my feet. And everything else I been taking for a while and I know all my medication, milligrams I take and everything.” Participant 5 recalled that “They explained what I’m taking and why I’m taking it. They discarded two and put me on extra of what I did have. It was on paper for what I was supposed to take and what I was supposed to add onto. No taking medication but what the doctor told me.” Participant 6 remembered the teaching she received as “I had the medications list. She went over my medication list with me. One of the nurses even suggested to me to get a little box that has the little things like the time of day you’re supposed to take the medicine. That way, you won’t forget.” Participant 8 shared the instructions she received about her medications stating “They told me the medicine I need to take for my heart, for my high cholesterol, and for my diabetes. She did explain everything to me like they made some changes to my high blood pressure medicine, took me from using Plavix, which I had

been using for my heart. Now, I only have to take Aspirin instead of Aspirin and Plavix. It's like a blood thinner." Participant 9 explained her medication instructions by saying "It's the same medicines that I had before. The only difference was that they took me off of one of my blood pressure medicines. Everything else stayed the same. Still doing 80mg of Lasix twice a day." These quotes are examples of participants being able to recall the medication instructions they were given at discharge.

Symptoms to watch for were mentioned by seven of the nine participants interviewed. When asked if she could remember any symptoms to watch for, Participant 3 said "Yeah, they uh went over like uh if I had any swelling or gain any weight. Anything like that it's important for me to call the doctor." Participant 4 recalled symptoms to watch for as "weight gain, five pounds or more. Um, chronic coughing, you know, difficulty breathing, swelling, um, what else? Chest pains, of course, you know, anything with regards to my heart failure." Participant 5 shared that she was instructed "if I start swelling, or get a fever or having chest pains or feel faint, that's when I supposed to call the emergency help. If I take my water pill, and I'm not passing the fluid the way I think I should, I should inform the doctor." When discussing medications, Participant 6 said she was told "if your blood pressure gets to this certain level, or if you gain one or two pounds to alert their office or get in touch with your heart doctor and alert them immediately." Participant 7 said that she was instructed "what I need to do for my congestive heart failure dependent on if I need to call someone. They gave me a number that I could call." Participant 8 explained that "As far as my congestive heart failure, if I get tired or starting to feel weak and stuff, I need to call and get an appointment to go to the doctor. If I start to gain any weight, 2-3 lbs a day or 3-5 lbs a week, I need to call my doctor and see my doctor." Participant 9 shared her understanding of symptoms to watch for as "If I gain 2-3 pounds in a

day, then I should be contacting my doctor. That’s how I should be able to tell: do I have fluid on me again? Shortness of breath again. Stuff like that. How far I can walk. The same stuff that be making me go in. They did tell me that.” The ability of the participants to recall symptoms to watch for due to their congestive heart failure is evidenced by these quotes.

Table 2 presents individual participant responses that refer to the five main teaching objectives of the discharge instructions.

Table 2: Participant Quotes Supporting Understanding of Teaching Objectives

Participant	Daily Weight	Sodium Intake	Fluid Intake	Medication	Symptoms to Watch for
1	X			X	
2	X			X	
3	X	X	X	X	X
4	X	X	X	X	X
5	X	X	X	X	X
6	X	X	X	X	X
7	X				X
8	X	X	X	X	X
9	X	X	X	X	X

- b. **Comprehensiveness:** This subtheme included experiences where participants felt that a healthcare team had access to information that covered all elements or aspects of their care. Participants reported that the health care team shared information with them that they needed to be able to understand their condition and to better take care of themselves. Participants felt that the information that was shared with them covered all of their health care needs.

All of the participants reported that the information and materials that they received was more comprehensive than they had received previously. They shared that the information was both everything that they needed and was better than information they had previously received. Participant 1 shared “I can’t think of one single thing what wasn’t gone over.” Participant 2 reported that the materials were comprehensive and that “there’s nothing I think they didn’t cover.” Participant 3 felt that she was given comprehensive information by stating “Yeah, they uh went over like uh if I had any swelling or gain any weight. Anything like that it’s important for me to call the doctor.” Participant 4 revealed that her discharge health education materials “had a paper in there showing me the dos and don’ts of what to stay, what to eat and what not to eat. So, it had a lot of extra information in there.” Participant 5 felt that the explaining of discharge information “was handled very well because before I left, the doctors all came around, and they gave me tests they had done. They gave me the results.” Participant 5 shared that during this hospitalization she “got better information this time. I feel like I’m more prepared than I was. It made me have better tools than I did, way more than I knew the first time.” Participant 6 shared that the information “gave me a breakdown of what my condition was. There was several things they gave me great information on. I have so much knowledge now regarding my condition.” Participant 7 felt that the information was comprehensive and that “I don’t have anything to say that I wish they would have put in there.” Participant 8 stated that the health care team “really did do a comprehensive study on what I need to do.” Participant 9 said that the health education materials included “stuff like what should I eat, what not to eat, what to do on a daily basis, watch my intake on fluids—what’s important for me not to go back into the hospital.” The participants felt as if they were given quality information covering their condition and, at times, more information than they had expected to receive.

The written discharge information given to the participants (Appendix) was consistent with the American Heart Association “Self-Care Guide for the Heart Failure Patient” (White, Kirshner & Hamilton, 2014). In the guide, patients are advised of disease symptoms, limiting salt and fluid, monitoring weight and medications they may be prescribed. The consistency between these two documents supports that the discharge information given to the participants on this nursing unit are standard best practices. In addition, readability statistics obtained from the proofreading option in Microsoft Office Word revealed that the discharge information was written at Flesch Kincaid Grade Level 5.1. For the Flesch-Kincaid Grade Level, scores are translated into an estimated reading grade level and estimated school grade completed (Charbonneau, 2013). The results of the evaluation of the discharge information show that it was written at a 5<sup>th</sup> grade level, which was consistent with what the nurse manager reported.

Research Question: 2) What, if any, other factors influenced the patient’s experience of the discharge?

2. Humanization: This category included three subthemes pertaining to the humanization of the participants. All of the participants reported that they were treated more as humans rather than just another patient or number. They communicated that they were treated as individuals with specific needs. Participants presented examples where the healthcare team members went above and beyond what they considered as the normal standard of care. The content of the subthemes in this category was almost entirely positive in nature and were the majority of the content of all the interviews.
  - a. Patience: This subtheme included experiences where the participants felt that the healthcare team members gave them all the time and attention that they

requested or needed. Participants noted that the nurses never rushed them and were willing to take all the time necessary to meet the needs of the participants. Participants were allowed to ask questions and the healthcare team took the needed amount of time to make sure that they were answered, explained and understood. Eight of the participants reported experiences where the healthcare staff showed willingness to spend as much time as needed when interacting with them.

Seven of the participants mentioned that the nurse read over the written discharge materials and took time to explain everything to them. Although none of the participants mentioned the nurse asking them to recall or teach-back the information, three participants gave examples of the nurses reading the entire discharge materials to them. Participant 3 mentioned that the nurse “went over the discharge paper with me. Everything what was in the discharge paper,” emphasizing that the nurse took the time needed to review everything. Participant 4 also emphasized that the nurse went over everything by stating “she read everything page, page thoroughly.” Participant 6 noted her nurse reading the discharge materials to her by mentioning that “she went step-by-step, page-by-page, explained everything to me.” Examples of taking time to explain the instructions were noted in quotes from five participants. Participant 2 noted the health care team explaining instructions to her by stating “they went over my medical record. They explained the kinds of medicine that I would be taking, each one.” Participant 3 explained how the nurse made sure that she understood the instructions by stating “she made sure that I understood what was on the discharge paper” and “she went over all the medication with me.” Participant 5 described how the health care team explained her instructions by saying “they explained what I’m taking and why I’m taking it.” Participant 7 remarked that her nurse

explained her medications to her by stating that “she went over my medication list with me.” Participant 8 conveyed that her nurse explained everything to her by sharing that “she started going over everything around 11, and by 3, we had everything down pat for what I was asking questions about.” Participants conveyed that this behavior demonstrated that the nurse was willing to take the time and effort to ensure that the information was thoroughly reviewed.

Two participants made a point to mention that the nurse sat down with them while going over the discharge instructions. Participant 5 stated “she sat down, and she really went in depth, and I appreciate that.” Participant 9 shared that her nurse “sat there for a while reading.” They felt that this was an added touch that was worthy of noting as it demonstrated a willingness on the part of the nurse to spend as much time as needed to review the information and improved their overall perception of the discharge process.

Instances of nursing staff showing unusual patience were noted by five participants. These acts are described using quotes from interviews. Participant 5 described patience in her nurse noting she was “just showing patience with the patient. Not making me wait an hour and a half for my discharge papers. They actually escorted me down.” Participant 6 noted a difference in patience at this hospitalization stating “the thing I liked about this time around is the patience and kindness of the staff.” Participant 7 explained that her nurses showed unusual patience by saying “Whatever I needed, they were just friendly enough to do that for me. No problem at all. You could tell they didn’t mind.” Participant 8 noted that her nurse told her that “there was no rush. There was no rush to be gone at a certain time of the day” which was perceived as showing patience. Participant 9 also noted that her nurse showed unusual patience by reporting that “when she actually discharged, she was like don’t rush.” The patience expressed by the nurses made the

participants feel like they were willing to take time to care for them and that the participants were not a burden to them.

- b. Patient-centered: This subtheme referred to the concept that health care and health information is customized and reflects patient needs, values and choices. Knowledge and information are freely shared between and among patients, care partners, physicians and other caregivers. Many participants remarked that they felt that their care and information was tailored to them and their specific needs. The nurses were accepting and tolerant of the participants' preferences. Eight of the nine participants shared experiences of feeling that the healthcare team showed a patient-centered approach to their care. This subtheme involves experiences of nurses asking or allowing the participants to make decisions according to their needs and preferences. It also includes examples of patient care and health care instructions meeting the individual participant's needs and instances where participants felt that their care had been customized to meet their needs.

Three participants described instances where they felt like they were allowed to have input into decisions regarding their care. Participant 2 described this experience noting that her nurse "asked me a lot of different question. You know, what would I like." Participant 5 mentioned that "It was up to me if I felt like I was feeling better... then I could go home." Participant 6 felt that she was allowed to be part of the decision-making process because "they asked me did I wanna walk or did I wanna be wheeled down." These experiences made the participants feel like they were a part of the decision making process and that they had some control in the decisions made concerning their care.

All but two of the participants shared experiences where the care they were given or the health care instructions they were given met their needs as an individual. Participant 3 described this experience as “it met my needs. It’s working well with my routine.” Participant 4 shared that “they had a lot of information that I needed and all I have to do. I asked the nurse and they made sure I got in contact with whoever, nutrition.” Participant 5 shared that her nurse gave her information that met her needs by saying that “he had instructed me and he gave me the instructions of what I needed to do the day out of the hospital. Oh yes, it helped me a lot.” Participant 6 described how the information she was given met her needs as an individual by sharing that the information “gave me a breakdown of what my condition was. There was several things they gave me great information on. I have so much knowledge now regarding my condition. They gave me everything I needed. Everything.” Participant 7 described that the discharge information met her needs by stating that “It had information that helped.” Participant 8 reported that “They really did do a comprehensive study on what I need to do instead what some other patient or other patient may need to do, but what I need to do for me” which highlights the feeling that her information met her specific needs. Participant 9 felt that her needs were met noting that “They gave me stuff like what should I eat, what not to eat, what to do on a daily basis, watch my intake on fluids—what’s important for me not to go back into the hospital. Yeah, it met my needs.” These experiences shared by the participants support the concept of patient-centered care.

Four participants felt that the care and instructions they were given were specifically tailored to meet their personal needs. Participant 4 demonstrated that she felt that her care was tailored to meet her specific needs by sharing that “they did set up meals on wheels through my insurance” and “I spoke with the dietician briefly and she gave me about a few recipes that she

had in a little booklet.” Participant 5 explained that her care was specific to her needs by stating that “He had instructed me and he gave me the instructions of what I needed to do the day out of the hospital. They explained what I’m taking and why I’m taking it.” Participant 6 shared that she felt as if the instructions she was given were created to meet her specific needs sharing that the health care team “gave me a breakdown of what my condition was. There was several things they gave me great information on.” Participant 8 noted that “They had the paperwork, the prescriptions, referrals, anything I need to do for later on like setting up appointments after I was discharged out of the hospital. It told me how to control my high cholesterol, how to control my diabetes, what I need to do for my congestive heart failure dependent on if I need to call someone. Every day there was a group of doctors who would come around and assess me for my part and my health.” The information provided and the behaviors of the health care team led the participants to feel that the care and information they received was compiled specifically for them.

- c. **Personal Touch:** This subtheme included experiences where the participants felt like they received special treatment outside of the normal standard of care. All of the participants conveyed that health care team members went out of their way to do special tasks just for them. There were examples of the health care team going above and beyond to meet both medical needs and personal needs. The participants felt that these experiences facilitated a personal connection with members of the health care team.

Five of the participants mentioned that health care team went out of their way to make sure that their medical needs were met. Participant 1 explained that her nurse gave extra effort to make sure her medical needs were met by stating “the nurse came and check my medicine. Make

sure that I have everything that I suppose to have.” Participant 4 pointed out that the health care team went out of their way by recounting that she “asked the nurse and they made sure I got in contact with whoever, nutrition. People came, they came to see me.” Participant 5 shared that the discharge process met her needs by saying “That was handled very well because before I left, the doctors all came around, and they gave me tests they had done.” Participant 5 also reported that her nurse “had a list of things: chips, peanuts, and all that kind of stuff, which I shouldn’t eat, canned food, lunch meat, salad dressing, gravies out of the cans. That was real understanding to me. They not only tell me, but they had it written down so I could see it—what I wasn’t supposed to be using. They just came in there and talked to me. I really appreciate that.” Participant 8 noted how the health care team met her needs sharing that “It was totally different than any hospital I’ve ever went to than when I first got here. That was a team of doctors and nurses there for me. Even with my illness, I’d never had that before. Every day there was a group of doctors who would come around and assess me for my part and my health.” Participant 9 felt that her nurse went out of her way recalling that “I had one nurse who came in, and she just was like, ‘You know, I know your condition.’ She brought a whole ‘nother booklet for me. She was just telling me, ‘Your condition is really serious and stuff. I’m just your nurse for the day, but I wanted you to know a little more about your condition. I want you to read this book and follow what you can do. It’s all about getting the weight down.’” Participant 9 was impressed that the health care team was willing to address her other medical needs recalling that “They were working with me. I appreciate them on that. I also appreciate them because I was having trouble with my knee. They connected me with a rheumatoid doctor who came around did their x-rays. They fixed that problem. I appreciated the medical staff, really.” These examples of health care

team members making effort to give them comprehensive care was perceived as a gesture of adding a personal touch to their care.

Five of the participants described examples of how health care members acted in a way to make sure that they met their physical wants and needs. Participant 2 shared how health care members made sure that her physical needs or wants were met describing that “They assisted me to the car. You know, in the wheelchair.” Participant 3 described her care as being “just like a rainbow of my family taking care of me.” Participant 6 recalled that the health care team met her physical needs sharing that she previously “had the experience of waiting forever to be discharged, but they went ahead and got it done. I just appreciate it you know this time around how nice the nurses were. Not making me wait an hour and a half for my discharge papers. They actually escorted me down, they had went ahead and called my medicines into my pharmacy. I appreciate that.” Participant 7 described how her nurse was willing to meet her physical needs stating that “Whatever I needed, she got it and did it. I didn’t have any complaints. Whatever I needed, they were just real nice to me. I needed cream rubbed on my back, no problem. They were just friendly enough to do that for me. No problem at all. You could tell they didn’t mind. They were just real nice and doing whatever they can to help you.” Participant 9 reported that “Everybody came into there to check. They all asked if I needed anything. I appreciate that. It made you feel welcome.” These acts of health care team members adding a personal touch to make sure that physical wants and needs were met were actions that promoted humanization.

One third of the participants made reference to being contacted by telephone by a member of the healthcare team after they had been discharged home. These instances of telephone contact were captured through quotes from the interviews. Participant 2 stated “I had someone to call me. They asked did I need a nurse or anything like that to come out and help.

They asked me a lot of question and, you know, did I need a nurse?” Participant 3 shared that “Someone call me every day for follow up. Someone have call me every day. Every day I have had a follow up call.” Participant 5 reported “Well, I get a call every day.” These telephone calls made the participants feel as if they had a connection to the health care team and that the health care team cared about them after being discharged.

3. Expertise of Healthcare Team: This category referred to instances where the healthcare team demonstrated both a breadth and depth of knowledge that covered all of the participants’ health care needs. It also referred to how the healthcare team presented themselves to the participants. Participants communicated that the health care team demonstrated a degree of knowledge that they had not experienced at other institutions. They also reported that the staff was competent in communicating their health care instructions.

a. Professionalism: This subtheme referred to instances where the participants felt that a member of the healthcare team demonstrated the demeanor and/or the competence of someone with the knowledge and skill of a professional. Participants reported that members of the health care team had the qualities and characteristics of a professional. These characteristics of professionalism were supported both by the actions of the health care team and by the quality of information that they shared with the participants.

Seven of the participants gave examples of members of the health care team demonstrating behavior reflective of professionalism. Participant 3 felt that her nurse exhibited professionalism because “she made sure that I understood what was on the discharge paper.” Participant 4 recalled that her nurse “read everything page, page thoroughly.” Participant 5

reported that her nurse “came around and she went over it with me and had me sign a sheet that I understood what I needed to do. She explained what I’m taking and why I’m taking it.”

Participant 6 remembered that her nurse “went step-by-step, page-by-page, explained everything to me.” Participant 7 stated that the health care team was “doing whatever they can to help you.”

Participant 8 shared that she “never had as good of care” as she had at this hospitalization.

Participant 9 differentiated this hospitalization by stating “the nurses are different; the nurses were attentive.” According to the participants, these behaviors demonstrated by the health care team members were characteristics of a professional.

A majority of the participants described feeling that the information that they received was of a professional quality and some reported it as better than they had previously received. Participant 4 described the information she received as “a lot of information that I needed and all I have to do.” Participant 5 felt that she “got better information this time.” Participant 6 stated that she was “equipped with all the knowledge.” Participant 7 noted that “It’s really great the way they have that system set up because you get every bit of knowledge you meant to have.” Participant 8 pointed out that the information she received “was totally different than any hospital I’ve ever went to.” The participants conveyed that the information they received covered all of their needs and was of a more professional quality than they had previously received.

- b. Communication: This subtheme referred to participants experiencing that members of the health care team were successful in communicating both general health care information as well as information specific to their individual needs. Participants felt that the staff supplied them with all of the information that they needed to be able to care for themselves after leaving the

hospital. Participants also stated that the health care team was proficient in explaining the information that was given to them in written form.

Seven of the nine participants shared that the health care team was proficient at communicating information that they needed to manage their condition and be able to care for themselves. Participant 1 thought that the nurses had proficient communication skills noting that she “understood everything they said.” Participant 2 shared that “the nurse that went over it with me, she, she was very clear. I understood her very well. She was very straight with me.” Participant 3 stated that her nurse “asked me did I understand it and she made sure that I understood what was on the discharge paper.” Participant 5 described the communication of information by sharing that “they made sure I understand it because a nurse came around and she went over it with me.” Participant 6 stated “The actual nurse explained everything to me—what the doctor said I should be doing, she went over my medication list with me. They gave me everything I needed. Everything.” Participant 8 reported that her nurse “did explain everything to me and we had everything down pat for what I was asking questions about.” Participant 9 shared that “This is the first time it was like really detailed cause like the first time I really wasn’t involved. It was the same information, but I wanted to listen this time.” These participants felt that the information they were provided with was communicated effectively and made them prepared to care for themselves.

## CHAPTER 5 DISCUSSION

### **Discussion**

The review of literature on the subject of health literacy tells us that both hospitals and payers believe that better organization of post-discharge care, including health education materials, is key to reducing readmission. Patients are most often given health information in written form; therefore, the main focus of health literacy initiatives has been on creating written information at the appropriate literacy level. Health literacy professionals argue that improved health literacy will lead to greater patient involvement, which, in turn, should lead to better patient outcomes (Johnson, 2014). In addition to the written materials, the patient-provider relationship, including communication and information sharing, is a significant factor in determining patient health outcomes. When discussing care and treatment in focus groups, patients identified poor communication between doctor and patient as a barrier to care (North, Pollio, Devereaux, Hong, and Jain, 2014). In a study about patient preferences of sources of health information, patient-provider relationship and health literacy affects a patient's ability to understand and use health information (Longo, Schubert, Wright, Lemaster, Williams & Clore, 2010). Inadequate health literacy and insufficient patient-provider communication are associated with poor patient outcomes; therefore, initiatives to improve patient involvement and initiatives to improve practitioner involvement should be a focus.

Three current health literacy initiatives promoting the push from health professionals deciding what information patients need to shared decision making which are showing significant health outcome improvements are: 1) simplifying written materials and making it

easier to understand; 2) improving providers' communication skills; and 3) improving patients' self-management skills (Koh, 2012). Patient education, which is an important aspect in providing care, is essential for good patient outcomes (Chang and Kelly, 2007). In order to successfully navigate the health care system and to realize positive health outcomes, patients need to be able to understand the health education materials with which they are provided. Because literacy is an integral part of health literacy, making sure that written health education materials are created using an appropriate literacy level has been at the forefront of the health literacy movement. Hospitals, health literacy professionals and health care workers continue to focus on the patient's ability to read and understand the written information they are given. The results of this study support that, in this specific health care setting, this has been achieved and that there are other factors that influence the success of the discharge process.

By using a qualitative approach, interviews using open-ended questions, this study focused on the perceptions of the individual participants. During the interview process, the participants were able to freely share their experiences of receiving written health education materials at the time of discharge from the hospital. Participants were encouraged to share what they thought went well, what went wrong and what they wish had been included in the discharge process. The data collected from the transcribed interviews revealed that the patients were able to read, understand and recall the information they were given, evidence that the materials supplied were written using an appropriate literacy level. The experiences shared by the participants reveal that the written health education materials were only a portion of what was perceived as important to the participants. Participants felt that the actions and expertise of the health care team were key factors influencing their perceptions of the discharge process.

All participants reported having no difficulty reading and understanding the information they were given. All of the participants reported that they understood the discharge instructions prior to being discharged. All of the participants reported that the information and materials that they received were more comprehensive than they had received previously. Participants reported feeling like they had all of the information that they needed to successfully manage their health care at home. Participants reported that the health care team shared information with them that they needed to be able to understand their condition and to better take care of themselves. Participants felt that the information that was shared with them covered all of their health care needs.

Participants were able to demonstrate their understanding, through quotes obtained during the interviews, of the information given to them in the discharge paperwork. Six of the nine participants were able to recall all five of the major factors listed in the discharge information: weighing themselves daily; eliminating sodium intake; fluid restriction; medications; and symptoms to watch for. All nine of the participants mentioned both the importance of weighing themselves daily and knowledge of their medications. The majority of participants mentioned the elimination of sodium, fluid restrictions and symptoms to watch for that need physician notification. The findings revealed in the interviews support the participants' claims that they were able to read and understand the written health information they were given at discharge. In addition to reporting the ability to read and understand the written information, all of the participants reported that the health care team had good communication skills when it came to explaining the discharge information.

The findings from this study, using this participant population and setting, revealed that the majority of participants are able to understand and recall the major points covered in their

discharge instructions. In addition, the discharge information was written at Flesch Kincaid Grade Level 5.1, suggesting that providing written materials at the appropriate literacy level may not be the only positive influence on the discharge process. Of note, seven of the nine participants shared that the health care team was proficient at communicating information that they needed to manage their condition and be able to care for themselves. The participants' ability to recall information from their discharge paperwork coupled with the perception that the health care team possessed good communication skills supports that this particular nursing unit is showing evidence of being successful in providing information at the appropriate literacy level and in communicating health information to its patients during the discharge process. These results support that efficient communication skills and spending time with patients during the discharge process may positively influence patients' willingness to accept and ability to understand health education information.

In addition to the quality of the materials themselves, the perception of individual patients is also important. In order for patients and families to become active participants in healthcare, they need to have the perception that their needs and desires are viewed as important to healthcare providers. In order to evaluate whether or not patients perceive that members of the health care team are meeting their needs, communication must exist between the patients and the health care team. Health care team members need to inquire of their patients if their needs are being addressed and met. Determining if patients perceive that we are meeting their needs is an important endeavor and evidence of efforts to do so is lacking in current literature.

In this study, all of the participants reported having an overall positive experience during the discharge process. During the interviews, they communicated that the health care team members exhibited both personable and professional behavior. Five out of the seven subthemes

are about the behavior and competence portrayed by the health care team. Participants valued the behavior and competency of the health care team members as well as the relationship they formed between themselves and the health care team members. All of the participants reported that the health care team treated them like individuals. Eight of the participants communicated that the health care team portrayed both patience and patient-centered care. All nine of the participants experienced a personal touch from the health care team. The category of humanization was found to be significant in all participants. Participants also reported that the health care team was professional, knowledgeable and had excellent communication skills. Seven participants reported that health care team members exhibited professionalism and quotes from seven participants supported that health care team members had proficient communication skills. All of the participants contributed quotes that supported the category of expertise of health care team. Also of note, five of the participants supplied quotes to support all seven subthemes.

The experiences of the participants interviewed for this study suggest that the most optimal approach to successful communication of discharge health information and instructions to patients is to first humanize the patient using patience, personal touch and patient-centered care. Although not previously seen as important to the health literacy discussion, participants from this study reported that nurses who took extra time with them or went out of their way to help them made them feel like individuals. Humanization of the participants led all of the participants to feel that they had a personal relationship with the health care team members. This feeling of having a personal relationship fostered trust in the participants. Trusting in the health care team persuaded the participants to be more accepting of information and instruction from the health care team.

All of participants also reported that the expertise of the health care team members was a key factor in how they perceived the care and information that they received. All of the participants had quotes supporting either professionalism or communication; five participants had quotes supporting both subthemes. The knowledge of the staff and their ability to communicate effectively influenced the willingness of the participants to accept the instructions they were given along with the overall impression they had of the entire discharge experience. All of the study participants felt that the quality of care and information they received were far superior to what they had received during past experiences. Therefore, knowledge base and behavior of health care team members are influential in patients' perceptions of health education materials and their delivery

The implementation of this approach of humanization of patients combined with a professional and competent health care team fosters a feeling of a personal connection for the patient. Even though all of the participants reported that the health education materials were understandable and comprehensive, the feeling of having a personal connection with the health care team promoted trust and willingness to accept instruction and information in the participants. This personal connection between patients and health care team members allows for information sharing which aids the health care team in understanding and meeting the needs of the patients. Allowing the patients to have input into the content of discharge information and having the information disseminated by a knowledgeable and competent health care team produces quality, usable, patient-centered health care education materials which leads to better patient outcomes.

The National Institutes of Health (2014) tells us that communication between physician and patient is an important piece in achieving adequate health literacy. Patients need to be active

participants in deciding what information the health care team provides to make certain that their information needs are met. To provide patient-centered care, patient input must be solicited and taken seriously by health care professionals. This approach requires a trusting relationship between patients and health care team members. In order to build a strong, trusting relationship between patients and health care team members, health care team members need to listen to and address the needs of their patients. Quality communication between health care team members and patients will assist health care team members to better understand the wants and needs of the patients. A trusting relationship also increases a patient's willingness to listen to and accept the information they are given.

### **Recommendations**

Based on the findings of this study, three components for achieving successful communication of health education materials from health care professionals to patients have emerged:

1. Health care team members need to foster the feeling of humanization in their patients.

Using correct communication skills and behaviors gives patients the feeling that health care team members value them as individuals. Showing patience and spending time with patients promotes the perception of a personal relationship between patients and health care team members. This sense of having a personal relationship brings about the feeling that the health care team member cared about them and their individual needs. A personal relationship promotes trust between the patients and the health care team members. Trust has a positive influence on the flow of information between patients and health care team members. This trust allows patients to communicate their needs and for health care team members to address them. Trust also increases the patients' willingness to accept the information given to them by health care team members.

2. Possessing comprehensive health care knowledge and having the ability to effectively communicate are qualities that patients desire health care team members to possess. Participants reported that they were impressed with the level of knowledge that their health care team members had. They appreciated that the health care team was able to address all of their health care needs. Participants also shared that the health care team members were effective in communicating health information to them. They stated that health care team members were patient, thorough and took steps to ensure that patients understood the information they were giving to them. Most participants remarked that the level of knowledge and quality of information were far superior to what they had received during past experiences. The feeling that they were receiving superior information from someone that is better educated made them more accepting of the information. Participants also remarked that the health care team members were proficient in explaining the health education materials to them. The expertise of the health care team members and the communication skills they exhibited were key factors in achieving a successful delivery of health care information at discharge.
3. Health care team members need to provide consumer-friendly health care education materials to their patients. Inadequate health literacy is a barrier to patient involvement in health care decisions and is a contributor to poor patient outcomes. The written health education materials provided need to be both readable and understandable in order for the patients to be active participants in their health care. In order for patients to be able to follow their plan of care, they must be able to read, understand and use the information they are given. In addition, the materials provided must contain all information needed for the patients to be able to achieve a positive health outcome.

In this study, the nursing unit was successful in supplying their patient population with discharge information that both meets the standard best practice and is written at the appropriate literacy level. In addition to offering appropriate discharge materials, this study highlights the need to include relationship and expertise as a way to eliminate barriers to an individual's ability to understand and willingness to accept health care information. The patient-provider relationship is an important factor in how successful patients are able to utilize and navigate the healthcare system. Patients need to be active participants in health care decisions pertaining to their plan of care. Humanization of patients and expertise of health care team members coupled with consumer friendly health education materials help remove the barriers to care that individuals with inadequate health literacy may experience. This approach will lead to individuals actively participating in their health care and ultimately better health outcomes.

### **Implications**

The findings of this study lead to the critical evaluation of how the health care workforce is currently being trained. The results reveal a need to scrutinize the implications of using these recommendations in the training of current health care professionals and the instruction of pre-licensure students. With examples of patients reporting that humanization and expertise are as important as consumer-friendly materials in obtaining successful communication of health care instructions, it is imperative that training of health care team members focus on these key factors. In addition to providing patients with health education materials that they can read, understand and utilize, health care professionals need to strive to form trusting relationships with their patients. Results from this study disclose that humanization of patients and expertise of health care workers promotes acceptance and understanding of health care education by the patients.

Pre-licensure programs provide education on different disease processes and appropriate health care interventions. In addition, pre-licensure programs for the health care workforce should include humanization and communication skills in the curriculum. The results of the data collected in this study support that these are important factors influencing how patients experience the discharge process. Evaluating the curriculum of pre-licensure programs would identify programs that lack proper and thorough training in the areas of humanization and communication. Identification of these institutions could lead to curriculum changes which would better prepare the students to interact with patient populations. Inclusion of these key elements of relationship building could be addressed through being interwoven throughout the entire curriculum or addressed in a single course. This is important because results showed that using humanization and effective communication skills fosters a trusting relationship between patients and health care workers. The ability to positively interact with patients is shown to influence the patient's ability to understand and willingness to accept health care information.

Based on the results of this study, competencies required by current health care professionals should include classes and/or training modules which focus on humanization of patients and effective communication skills. The modules and/or classes should be provided during the orientation process as well as provided on a yearly basis. Providing health care professionals with training needed to cultivate relationships with their patients encourages an environment of trust and communication. In addition to providing training, competencies in humanization and communication should be evaluated regularly to ensure that health care workers have mastery of these skills. Investing in skills to promote relationship building between patients and health care team members will lead to better communication of health education materials and possibly improved patient outcomes.

## **Further Research**

The findings of this study uncover the need to conduct further research in the area of health literacy. Firstly, there needs to be similar studies using qualitative interviews with other populations and in other health care settings, as well as patients' caregivers and parents of minor children. Second, the curricula of pre-licensure programs for health care workers needs to be evaluated for the inclusion of humanization and effective communication skills. Finally, current health care workers need to be provided training and be evaluated for competencies in humanization and communication.

A main limitation to this study was its reliance on African American females with a diagnosis of congestive heart failure that were recently discharged from the hospital. Future studies should look into other populations in the hospital setting. Secondly, populations in other health care settings should be studied. Interviews from other populations being recently discharged from the hospital could add evidence to support the findings that humanization and expertise are key factors that influence the successful communication of health care education materials at discharge. Thirdly, the perceptions of patients' caregivers and parents of minor children would be beneficial. Finally, documenting observations made during the discharge process followed by interviews of both patients and nurses would allow for comparison of the experience of the discharge process from both perspectives.

Other future research could involve a more focused analysis based on additional demographics or a longitudinal study following a patient population to assess for effectiveness of teaching and knowledge retention. Patient responses could be compared according to socioeconomic status or educational level, for example. Also, a particular patient population

could be compared for patients that had been readmitted within 30 days versus those who had not been readmitted within 30 days to see if the groups had significant differences.

The findings of this study support the need to incorporate humanization and communication skills into pre-licensure curricula. An evaluation of pre-licensure programs would reveal if humanization and communication are part of the existing curriculum. Once the evaluation process has been conducted, institutions can be made aware that education addressing humanization of patients and effective communication skills are lacking or minimally present in the pre-licensure curriculum. The institutions should be made aware of the findings of this study and how humanization and communication influence patients' perceptions of interactions with health care workers. Institutions should be encouraged to include humanization and effective communication skills into their pre-licensure curriculum. Course development and/or changes to course content should contain objectives to train and educate health care professionals to use humanization of patients and effective communication skills to foster relationship building between patients and health care workers.

The evidence from this study supports that, according to patients, humanization of patients and effective communication skills are important characteristics in health care professionals. Because the presence of these characteristics influence how patients experience the delivery of health education materials, competencies in these areas need to be addressed. This study found that when patients believed that they had a personal relationship with members of the health care team, they were better able to understand and were more willing to accept the health care education information provided to them. The data from this study supports that proficiency in these two areas fosters relationship building between patients and health care workers. Findings support that there is a need to develop a training module and/or class that

includes humanization of patients and effective communication skills. Achieving this goal warrants development of the concepts further through interviewing of patients in other populations and settings. After further concept development, an intervention to train nurses in hospitals should be constructed and implemented. The significance of implementing humanization and effective communication training should be evaluated through clinical trial. Evaluation methods should compare outcome measure between discharges using the usual procedures versus the addition of the intervention. Outcome measures could look at effects on avoidable recidivism and long term health outcomes. If findings from clinical trial evaluation substantiate that the intervention reduces avoidable recidivism and improves long term health outcomes, health care costs and individual patient health status could be effected in a positive way on a large scale.

## **Conclusion**

The findings of this study revealed that the patients hospitalized on this particular nursing unit had a perception of having a personal relationship with the health care team, an increased willingness to accept health care education information and described the overall discharge experience as positive. Although the health education materials were written at an appropriate literacy level, the participant interviews revealed other factors that influence the success of communicating health education. The willingness to accept health care education enabled the patients to better understand and follow their health care plan. This strategy of combining humanization with expertise has led to positive outcomes with respect to the patients' willingness to receive and ability to understand the health information they are given at discharge. The ability for patients to read, understand and use health education materials results in improved patient outcomes and a reduction in avoidable hospital readmissions. Therefore,

evidence supports implementation of training and evaluation of humanization and communication competencies in both pre-licensure programs and in the health care workplace.

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APPENDIX

DISCHARGE INSTRUCTIONS

**Daily Weight Record**

It is important to weigh yourself daily. Keep this daily weight chart near your scale. Weigh yourself each morning at the same time. Weigh yourself without shoes, and wear the same amount of clothing each day. Compare today's weight to yesterday's weight. **Bring this form with you to your follow-up appointments.**

**Call your health care provider if you have concerns about your weight, including rapid weight gain or rapid weight loss.**

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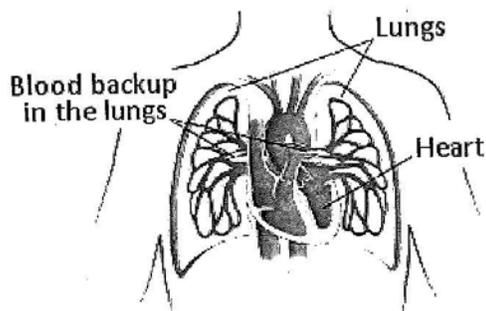
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This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.

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## Heart Failure

Heart failure means your heart has trouble pumping blood. This makes it hard for your body to work well. Heart failure is usually a long-term (*chronic*) condition. You must take good care of yourself and follow your doctor's treatment plan.



### HOME CARE

- Take your heart medicine as told by your doctor.
  - **Do not** stop taking medicine unless your doctor tells you to.
  - **Do not** skip any dose of medicine.
  - Refill your medicines before they run out.
  - Take other medicines only as told by your doctor or pharmacist.
- Stay active if told by your doctor. The elderly and people with severe heart failure should talk with a doctor about physical activity.
- Eat heart-healthy foods. Choose foods that are without *trans* fat and are low in saturated fat, cholesterol, and salt (*sodium*). This includes fresh or frozen fruits and vegetables, fish, lean meats, fat-free or low-fat dairy foods, whole grains, and high-fiber foods. Lentils and dried peas and beans (*legumes*) are also good choices.
- Limit salt if told by your doctor.
- Cook in a healthy way. Roast, grill, broil, bake, poach, steam, or stir-fry foods.

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- Limit fluids as told by your doctor.
- Weigh yourself every morning. Do this after you pee (*urinate*) and before you eat breakfast. Write down your weight to give to your doctor.
- Take your blood pressure and write it down if your doctor tells you to.
- Ask your doctor how to check your pulse. Check your pulse as told.
- Lose weight if told by your doctor.
- Stop smoking or chewing tobacco. **Do not** use gum or patches that help you quit without your doctor's approval.
- Schedule and go to doctor visits as told.
- Nonpregnant women should have no more than 1 drink a day. Men should have no more than 2 drinks a day. Talk to your doctor about drinking alcohol.
- Stop illegal drug use.
- Stay current with shots (*immunizations*).
- Manage your health conditions as told by your doctor.
- Learn to manage your stress.
- Rest when you are tired.
- If it is really hot outside:
  - Avoid intense activities.
  - Use air conditioning or fans, or get in a cooler place.
  - Avoid caffeine and alcohol.
  - Wear loose-fitting, lightweight, and light-colored clothing.
- If it is really cold outside:
  - Avoid intense activities.
  - Layer your clothing.
  - Wear mittens or gloves, a hat, and a scarf when going outside.
  - Avoid alcohol.
- Learn about heart failure and get support as needed.
- Get help to maintain or improve your quality of life and your ability to care for yourself as needed.

#### **GET HELP IF:**

- You gain weight quickly.
- You are more short of breath than usual.
- You cannot do your normal activities.
- You tire easily.
- You cough more than normal, especially with activity.
- You have any or more puffiness (*swelling*) in areas such as your hands, feet, ankles, or belly (*abdomen*).
- You cannot sleep because it is hard to breathe.
- You feel like your heart is beating fast (*palpitations*).
- You get dizzy or light-headed when you stand up.

#### **GET HELP RIGHT AWAY IF:**

- You have trouble breathing.
- There is a change in mental status, such as becoming less alert or not being able to focus.
- You have chest pain or discomfort.

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- You faint.

**MAKE SURE YOU:**

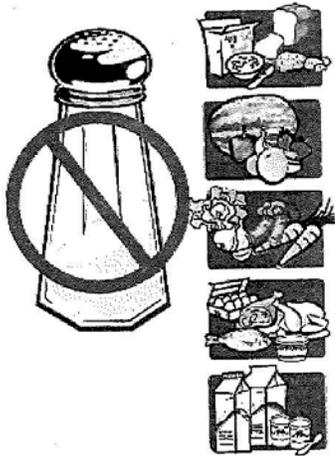
- Understand these instructions.
- Will watch your condition.
- Will get help right away if you are not doing well or get worse.

This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.

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## Low-Sodium Eating Plan

Sodium raises blood pressure and causes water to be held in the body. Getting less sodium from food will help lower your blood pressure, reduce any swelling, and protect your heart, liver, and kidneys. We get sodium by adding salt (*sodium chloride*) to food. Most of our sodium comes from canned, boxed, and frozen foods. Restaurant foods, fast foods, and pizza are also very high in sodium. Even if you take medicine to lower your blood pressure or to reduce fluid in your body, getting less sodium from your food is important.



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**WHAT IS MY PLAN?**

Most people should limit their sodium intake to 2,300 mg a day. Your health care provider recommends that you limit your sodium intake to 2,000 mg a day.

**WHAT DO I NEED TO KNOW ABOUT THIS EATING PLAN?**

For the low-sodium eating plan, you will follow these general guidelines:

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- Choose foods with a % Daily Value for sodium of less than 5% (as listed on the food label).
- Use salt-free seasonings or herbs instead of table salt or sea salt.
- Check with your health care provider or pharmacist before using salt substitutes.
- Eat fresh foods.
- Eat more vegetables and fruits.
- Limit canned vegetables. If you do use them, rinse them well to decrease the sodium.
- Limit cheese to 1 oz (28 g) per day.
- Eat lower-sodium products, often labeled as "lower sodium" or "no salt added."
- Avoid foods that contain monosodium glutamate (MSG). MSG is sometimes added to Chinese food and some canned foods.
- Check food labels (Nutrition Facts labels) on foods to learn how much sodium is in one serving.
- Eat more home-cooked food and less restaurant, buffet, and fast food.
- When eating at a restaurant, ask that your food be prepared with less salt, or no salt if possible.

### **HOW DO I READ FOOD LABELS FOR SODIUM INFORMATION?**

The Nutrition Facts label lists the amount of sodium in one serving of the food. If you eat more than one serving, you must multiply the listed amount of sodium by the number of servings.

Food labels may also identify foods as:

- Sodium free—Less than 5 mg in a serving.
- Very low sodium—35 mg or less in a serving.
- Low sodium—140 mg or less in a serving.
- Light in sodium—50% less sodium in a serving. For example, if a food that usually has 300 mg of sodium is changed to become light in sodium, it will have 150 mg of sodium.
- Reduced sodium—25% less sodium in a serving. For example, if a food that usually has 400 mg of sodium is changed to reduced sodium, it will have 300 mg of sodium.

### **WHAT FOODS CAN I EAT?**

#### **Grains**

Low-sodium cereals, including oats, puffed wheat and rice, and shredded wheat cereals. Low-sodium crackers. Unsalted rice and pasta. Lower-sodium bread.

#### **Vegetables**

Frozen or fresh vegetables. Low-sodium or reduced-sodium canned vegetables. Low-sodium or reduced-sodium tomato sauce and paste. Low-sodium or reduced-sodium tomato and vegetable juices.

#### **Fruits**

Fresh, frozen, and canned fruit. Fruit juice.

#### **Meat and Other Protein Products**

Low-sodium canned tuna and salmon. Fresh or frozen meat, poultry, seafood, and fish. Lamb. Unsalted nuts. Dried beans, peas, and lentils without added salt. Unsalted canned beans. Homemade soups without salt. Eggs.

#### **Dairy**

Milk. Soy milk. Ricotta cheese. Low-sodium or reduced-sodium cheeses. Yogurt.

#### **Condiments**

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Fresh and dried herbs and spices. Salt-free seasonings. Onion and garlic powders. Low-sodium varieties of mustard and ketchup. Fresh or refrigerated horseradish. Lemon juice.

**Fats and Oils**

Reduced-sodium salad dressings. Unsalted butter.

**Other**

Unsalted popcorn and pretzels.

*The items listed above may not be a complete list of recommended foods or beverages. Contact your dietitian for more options.*

**WHAT FOODS ARE NOT RECOMMENDED?**

**Grains**

Instant hot cereals. Bread stuffing, pancake, and biscuit mixes. Croutons. Seasoned rice or pasta mixes. Noodle soup cups. Boxed or frozen macaroni and cheese. Self-rising flour. Regular salted crackers.

**Vegetables**

Regular canned vegetables. Regular canned tomato sauce and paste. Regular tomato and vegetable juices. Frozen vegetables in sauces. Salted French fries. Olives. Pickles. Relishes. Sauerkraut. Salsa.

**Meat and Other Protein Products**

Salted, canned, smoked, spiced, or pickled meats, seafood, or fish. Bacon, ham, sausage, hot dogs, corned beef, chipped beef, and packaged luncheon meats. Salt pork. Jerky. Pickled herring. Anchovies, regular canned tuna, and sardines. Salted nuts.

**Dairy**

Processed cheese and cheese spreads. Cheese curds. Blue cheese and cottage cheese. Buttermilk.

**Condiments**

Onion and garlic salt, seasoned salt, table salt, and sea salt. Canned and packaged gravies. Worcestershire sauce. Tartar sauce. Barbecue sauce. Teriyaki sauce. Soy sauce, including reduced sodium. Steak sauce. Fish sauce. Oyster sauce. Cocktail sauce. Horseradish that you find on the shelf. Regular ketchup and mustard. Meat flavorings and tenderizers. Bouillon cubes. Hot sauce. Tabasco sauce. Marinades. Taco seasonings. Relishes.

**Fats and Oils**

Regular salad dressings. Salted butter. Margarine. Ghee. Bacon fat.

**Other**

Potato and tortilla chips. Corn chips and puffs. Salted popcorn and pretzels. Canned or dried soups. Pizza. Frozen entrees and pot pies.

*The items listed above may not be a complete list of foods and beverages to avoid. Contact your dietitian for more information.*

This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.

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## Fluid Restriction

Some health conditions may require you to restrict your fluid intake. This means that you need to limit the amount of fluid you drink each day. When you have a fluid restriction, you must carefully measure and keep track of the amount of fluid you drink. Your health care provider will identify the specific amount of fluid you are allowed each day. This amount may depend on several things, such as:

- The amount of urine you produce in a day.
- How much fluid you are keeping (*retaining*) in your body.
- Your blood pressure.

### WHAT IS MY PLAN?

Your health care provider recommends that you limit your fluid intake to 1,500 mL per day.

### WHAT COUNTS TOWARD MY FLUID INTAKE?

Your fluid intake includes all liquids that you drink, as well as any foods that become liquid at room temperature.

The following are examples of some fluids that you will have to restrict:

- Tea, coffee, soda, lemonade, milk, water, juice, sport drinks, and nutritional supplement beverages.
- Alcoholic beverages.
- Cream.
- Gravy.
- Ice cubes.
- Soup and broth.

The following are examples of foods that become liquid at room temperature. These foods will also count toward your fluid intake.

- Ice cream and ice milk.
- Frozen yogurt and sherbet.
- Frozen ice pops.
- Flavored gelatin.

### HOW DO I KEEP TRACK OF MY FLUID INTAKE?

Each morning, fill a jug with the amount of water that equals the amount of fluid you are allowed for the day. You can use this water as a guideline for fluid allowance. Each time you take in any form of fluid, including ice cubes and foods that become liquid at room temperature, pour an equal amount of water out of the container. This helps you to see how much fluid you are taking in. It also helps you to see how much of your fluid intake is left for the rest of the day.

The following conversions may also be helpful in measuring your fluid intake:

- 1 cup equals 8 oz (240 mL).
- $\frac{3}{4}$  cup equals 6 oz (180 mL).
- $\frac{2}{3}$  cup equals 5 $\frac{1}{3}$  oz (160 mL).
- $\frac{1}{2}$  cup equals 4 oz (120 mL).
- $\frac{1}{3}$  cup equals 2 $\frac{2}{3}$  oz (80 mL).
- $\frac{1}{4}$  cup equals 2 oz (60 mL).

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- 2 Tbsp equals 1 oz (30 mL).

#### **WHAT HOME CARE INSTRUCTIONS SHOULD I FOLLOW WHILE RESTRICTING FLUIDS?**

- Make sure that you stay within the recommended limit each day. Always measure and keep track of your fluids, as well as any foods that turn liquid at room temperature.
- Use small cups and glasses and learn to sip fluids slowly.
- Add a slice of fresh lemon or lemon juice to water or ice. This helps to satisfy your thirst.
- Freeze fruit juice or water in an ice cube tray. Use this as part of your fluid allowance. These cubes are useful for quenching your thirst. Measure the amount of liquid in each ice cube prior to freezing so you can subtract this amount from your day's allowance when you consume each frozen cube.
- Try frozen fruits between meals, such as grapes or strawberries.
- Swallow your pills along with meals or soft foods, such as applesauce or mashed potatoes. This helps you to save your fluid allowance for something that you enjoy.
- Weigh yourself every day. Keeping track of your daily weight can help you and your health care provider to notice as soon as possible if you are retaining too much fluid in your body.
- Weigh yourself every morning after you urinate but before you eat breakfast.
- Wear the same amount of clothing each time you weigh yourself.
- Write down your daily weight. Give this weight record to your health care provider. If your weight is going up, you may be retaining too much fluid. Every 2 cups (480 mL) of fluid retained in the body becomes an extra 1 lb (0.45 kg) of body weight.
- Avoid salty foods. These foods make you thirsty and make fluid control more difficult.
- Brush your teeth often or rinse your mouth with mouthwash to help your dry mouth. Lemon wedges, hard sour candies, chewing gum, or breath spray may also help to moisten your mouth.
- Keep the temperature in your home at a cooler level. Dry air increases thirst, so keep the air in your home as humid as possible.
- Avoid being out in the hot sun, which can cause you to sweat and become thirsty.

#### **WHAT ARE SOME SIGNS THAT I MAY BE TAKING IN TOO MUCH FLUID?**

You may be taking in too much fluid if:

- Your weight increases. Contact your health care provider if your weight increases 3 lb or more in a day or if it increases 5 lb or more in a week.
- Your face, hands, legs, feet, and belly (*abdomen*) start to swell.
- You have trouble breathing.

This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.

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Tobacco is the single greatest cause of disease and premature death in America today. University Hospital is an institution dedicated to the preservation of health and prevention of disease. If you are currently a non-smoker, we hope you will endeavor to remain smoke free. If you are currently a smoker, or have been during the last 12 months, University Hospital would like to encourage you to stop smoking. For help: contact the Smoking Quit-Line of the National Cancer Institute toll free at (877) 44U-QUIT or (877) 448-7848.

It is important for all patients with chronic illness such as diabetes, COPD, high blood pressure or congestive heart failure (CHF) to:

1. take your medications as prescribed
2. increase activity slow and steadily
3. go to your doctor's appointments as scheduled.

If you have congestive heart failure (CHF) you should also:

1. eat a low sodium diet
2. weigh every day
3. call your doctor if your weight goes up 2 pounds in one day or 5 pounds in one week
4. call your doctor if you have swelling, shortness of breath, cough, tiredness, or cannot perform your normal activities.

National Suicide Prevention Lifeline at 800-273-TALK (8255)  
[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

I have received a copy of the Discharge Instructions.

I have had the opportunity to ask questions.

I understand the Discharge Instructions and information given to me.

I have received my personal belongings and/or valuables claim check (to obtain valuables from the hospital safe).

I understand that I am to bring this sheet with me to my follow-up Clinic visits.

Thank you for allowing us to care for you during this time. Should you again have health care needs, we hope that you will allow us to be of assistance to you.

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Signature: Patient

Date

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INSTITUTIONAL REVIEW BOARD LETTERS OF APPROVAL

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Office of the Vice President for  
Research & Economic Development  
Office for Research Compliance

December 21, 2016

E. Whitney Simpson, MSN, RN  
DNP Program  
Capstone College of Nursing  
The University of Alabama  
Box 870358

Re: IRB # 16-OR-421 (Revision) "Health Education Materials: Where Are The Patients?"

Dear Ms. Simpson:

The University of Alabama Institutional Review Board has reviewed the revision to your previously approved expedited protocol. The board has approved the change in your protocol.

Please remember that your approval period expires one year from the date of your original approval, December 7, 2016, not the date of this revision approval.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants.

Good luck with your research.

Sincerely,

A rectangular box with a black border, used to redact the signature of the Director &amp; Research Compliance Officer.

Carrijo T. Myles, MSM, CIM, CIP  
Director & Research Compliance Officer  
Office of Research Compliance

358 Rose Administration Building | Box 870127 | Tuscaloosa, AL 35487-0127  
205-348-8461 | Fax 205-348-7189 | Toll Free 1-877-820-3066



Institutional Review Board for Human Use

Form 4: IRB Approval Form  
Identification and Certification of Research  
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on November 8, 2021. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: SIMPSON, ELIZABETH WHITNEY  
Co-Investigator(s):  
Protocol Number: X161209001  
Protocol Title: Health Education Materials: Where Are The Patients?

The IRB reviewed and approved the above named project on 12/28/16. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 12/28/16  
Date IRB Approval Issued: 12/28/16  
IRB Approval No Longer Valid On: 12/28/17



Expedited Reviewer  
Member - Institutional Review Board  
for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

470 Administration Building  
701 20th Street South  
205.934.3789  
Fax 205.934.1301  
irb@uab.edu

The University of  
Alabama at Birmingham  
Mailing Address:  
AB 470  
1720 2ND AVE S  
BIRMINGHAM AL 35294-0104