2007

An Examination of the Relationships Among Health Literacy, Social Support, and Patient Activation in Community Residing Older Adults

Brenda L. Harding Hage

DOCTORAL PROGRAM IN HEALTH RELATED SCIENCES
SCHOOL OF ALLIED HEALTH PROFESSIONS
VIRGINIA COMMONWEALTH UNIVERSITY

This is to certify that the dissertation prepared by Brenda L. Hage, entitled "*An Examination of the Relationships Among Health Literacy, Social Support, and Patient Activation in Community Residing Older Adults,*" has been approved by her committee as satisfactory completion of the dissertation requirement for the degree Doctor of Philosophy.

[redacted]

J. James Cotter, Ph.D., Dissertation Committee Chair
VCU School of Allied Health Professions

[redacted]

Constance L. Coogle, Ph.D., Dissertation Committee Member
VCU School of Allied Health Professions

[redacted]

Catherine M. Kelso, M.D., Dissertation Committee Member
VCU School of Medicine

[redacted]

James M. Calderone, Ed.D., Dissertation Committee Member
College of Misericordia, School of Professional Studies and Behavioral Sciences

[redacted]

Cecil B. Drain, Ph.D., Professor and Dean
VCU School of Allied Health Professions

[redacted]

F. Douglas Boudinot, Ph.D., Dean
VCU Graduate School

September 24, 2007
Date

AN EXAMINATION OF THE RELATIONSHIPS AMONG HEALTH LITERACY, SOCIAL SUPPORT, AND PATIENT ACTIVATION IN COMMUNITY RESIDING OLDER ADULTS

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University.

By

BRENDA L. HARDING HAGE
Master of Science, Nursing, College Misericordia, 1996
Bachelor of Science, Nursing, University of the State of New York, Albany 1994

Director: JOHN J. COTTER
DIRECTOR OF THE DOCTORAL PROGRAM IN HEALTH RELATED SCIENCE
ASSISTANT DEAN FOR DISTANCE EDUCATION

Virginia Commonwealth University
Richmond, Virginia
September, 2007

ACKNOWLEDGEMENTS

I would like to express my deep appreciation to the many individuals who assisted me in the completion of this research project. First, I would like to thank Dr. Jim Cotter for his guidance throughout my time at VCU. His enthusiasm and sense of humor did much to assist me through this challenging program. In addition I would like to thank the other members of my dissertation committee; Dr. Kathy Kelso for her geriatric expertise, Dr. Connie Coogle for her methodological and research wisdom, and Dr. Jim Calderone for his expertise in the social sciences and his gentle and encouraging insights.

To my friends, colleagues, and the cohort of 2003, thank you for your ongoing support and encouragement. Thanks to Dr. Chip Hunter for encouraging me to apply to VCU in the first place. I would also like to especially acknowledge my friend and colleague, Dr. Jean Steelman, for generously sharing her statistical and research expertise. I must express my sincere thanks and appreciation to the ever gracious Mrs. Lewis and Lucy Lewis for their friendship and for providing me with a home away from home in Richmond. Your family truly epitomizes the ideal of Southern hospitality.

Finally, I would like to dedicate this work to my husband Nafty, our sons David and Michael, and to my parents, Harold and Judith Harding. Your patience, love, encouragement and support during these last four years have been so important to my success; thank you all for believing in me. Mom and Dad; your help with this project was

invaluable (don’t forget to have fun!). Thank you for instilling in me the belief that just about anything’s possible with hard work and determination, and for loving me all these many years.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

AN EXPLORATION OF THE RELATIONSHIPS AMONG HEALTH LITERACY, SOCIAL SUPPORT, AND PATIENT ACTIVATION IN COMMUNITY RESIDING OLDER ADULTS

By Brenda L. Harding Hage, Ph.D.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2007

Major Advisor: John J. Cotter, Ph.D.
Director of the Doctoral Program in Health Related Science
Assistant Dean for Distance Education

This study examined the relationships among the variables health literacy, social support, and patient activation. The subjects were 90 elderly, community residing adults meeting the inclusion criteria and who volunteered to participate in the study and completed three survey instruments: the Short Form of Functional Health Literacy (Parker, Baker, Williams & Nurss, 1995); the Medical Outcomes Survey (MOS) Social Support Survey Instrument (Sherbourne & Stewart, 1991); the Patient Activation Measure (PAM) Short-Form (Hibbard, Mahoney, Stockard, & Tusler, 2005); and a demographic form.

A correlational design was used to test the hypotheses that social support and health literacy are positively related to patient activation. Health literacy was significantly and positively related to patient activation. Multiple regression analysis was used to determine whether health literacy explained a significant proportion of the variance in patient activation. Neither health literacy or social support explained a significant proportion of the variance. Demographic variables of age, level of education, gender, marital status, and self-rated health accounted for a small, but statistically significant proportion of the variance. Implications of these findings include that social support did not have significant effects on patient activation. Health professionals should continue to explore additional directions to ameliorate the negative effects of low health literacy and activate patients, including reactions to health problems.

CHAPTER 1: INTRODUCTION

Preface

It is estimated that the number of Americans aged 65 years or older will reach 71 million, with one in five persons aged 65 or above by the year 2030 (US Department of Health and Human Services [USDHHS], 2004). Longevity does not necessarily correlate with enjoying better health in later years (Center for Disease Control [CDC], The State of Aging,, 2003). According to data by the Center for Disease Control (CDC), currently about 80 percent of all older Americans in the United States (U.S.) are living with at least one chronic illness such as asthma, diabetes and heart disease, and 50 percent have at least two (USDHHS, 2004). The average individual who is 75 years of age suffers from three chronic illnesses requiring five prescription medications for treatment. Overall, greater than two-thirds of all health care costs are spent on chronic illness in the U.S., however, for older Americans, chronic illness represents almost 95 percent of health care expenditures.

In an effort to contain health care costs for older adults with chronic illness, these individuals are expected to assume a greater role in maintaining their health and wellness by seeking out information and making informed health decisions (Guadagnoli & Ward, 1998; Neilson-Bohlman, Panzer, Hamlin, & Kindig, 2004).

Individuals with chronic illnesses often have complex medical treatment regimens requiring them to learn large amounts of medical information (Brown & Park, 2002). However, current research shows a disparity between people's reading and comprehension abilities and the expectations of the health care system that patients find and use information for decision making and self-care tasks (Rudd, Moeykens, & Colton, 2000; Parker, Ratzan, & Lurie, 2003). This mismatch between people's abilities and the high expectations of the health care system for patient decision making and self- care have made it difficult for individuals to take on a greater responsibility for their own health (Rudd, Moeykens, & Colton).

In total between 46 to 51 percent of American adults representing approximately 90 million in the U.S. population, have problems with literacy (Kirsch, Jungeblut, Jenkins & Kolstad, 1993), and may lack the necessary literacy skills needed to appropriate access and utilize resources available within the national health system effectively. Older adults are particularly at risk for low literacy (Kirsch et al., 1993) due to lower levels of formal education (U.S. Census Bureau, "Educational attainment..", 2003), and an increased incidence in altered cognition and visual deficits associated with aging (Kerka, 2003).

Health literacy has been defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (US DHHS, 2000, p.11-20). As with general literacy, older adults are also at increased risk for low health literacy (Gazmararian et al., 1999). Having a higher level of educational attainment is not a guarantee against low health literacy (Greenberg, 2001). It is possible for individuals with higher educational status to have low health literacy due to a lack of familiarity with medical jargon and terminology. Temporary situations such as illness, emotional trauma, and stress can also cause highly literate persons to have difficulty in understanding health information (Freebody & Frieberg, 1997).

Low health literacy is associated with less knowledge of chronic disease (Gazmararian, Williams, Peel & Baker, 2003) decreased self- management skills and poorer health outcomes (Bennett et al., 1998; Williams, Baker, Parker, & Nurss, 1998; Gazmararian et al., 1999; Schillinger et al., 2002). Individuals with low health literacy are also less likely to engage in preventative health screenings (Bennet et al., 1998; Scott, Gazmararian, Williams, & Baker, 2002; Berkman et al., 2004) and preventative services such as immunizations (Scott et al., 2002). These findings are consistent with those by Williams, Davis, Parker, and Weiss (2002) who found that increased health care costs, use of an inefficient mix of health care services and increased rates of hospitalization are associated with low health literacy. Longer hospital stays and higher health care costs have been linked to low health literacy (Baker et al., 2002) and it has been estimated that this problem adds an additional $73 billion dollars in annual health care expenditures (National Academy on an Aging Society [NAAS], 1998).

Because of changes in traditional family structure, it is unrealistic to expect that Baby Boomers will be able to rely solely on family support to meet their care-giving needs (Kutza, 2005). Societal departure from a more traditional family make-up has forced older adults to expand their social networks and social support. These networks may be comprised of friends, neighbors and members of religious organizations and community groups rather than immediate family. Limited research has been done on how, when and why older adults extend these networks (Martire, Schultz, Mittlemark, & Newsom,1999; Katz, Kabeto, & Langa, 2000). More information is needed on circumstances that lead older adults to seek to enlarge their social networks in order to better meet the complex needs of this rapidly expanding population (Feld, Dunkle, & Schroepfer, 2005).

Little is currently known about factors that may ameliorate the negative effects of low health literacy (Lee, Arozullah, & Cho, 2004). Lee et al. (2004) suggest that social support may act as a moderator on the problem of low health literacy, on health status and on the use of an inefficient mix of health services by those with low health literacy. Social support refers to the impact of social relationships and interactions that can influence health (Dolbier & Steinhardt, 2000) and can take the form of informational or instrumental support in response to the individual's needs. Family members and friends may assist in making health care arrangements for older adults or offer assistance in day to day activities such as chores (instrumental support) or offering information or advice on health related matters (information support) (Lee, Gazmararian, & Arozullah, 2006). Older adults frequently report receiving help with tasks such as completing forms, performing math operations and understanding written information from family or friends (Kirsch et al., 1993). Social support may be beneficial for individuals who are negotiating the health system and may help those with low health literacy to compensate for this problem. Lee et al. (2004) further assert that social support has not previously been considered as a possible resource that could help individuals with low health literacy to better manage their own health. The ability to self-manage health has taken on greater significance due to the increasing number of individuals affected by chronic illness and associated increases in health care utilization and costs. In fact, chronic disease has been cited as the major reason for seeking health care and has been estimated to account for 70 percent of overall health expenditures (Hoffman, Rice, & Sung, 1996). Lorig (1996) identified three distinguishing features of a self-management model to include dealing with the consequences of disease, rather than the actual disease itself; being concerned with problem solving, decision making, and patient confidence; and forming partnerships between health professionals and patients where the health professional assumes the medical management of the disease and the patient assumes the day-to-day illness management. Lorig et al. (2001) studied 489 patients who participated in the Chronic Disease Self-Management Program, a seven-week, small group intervention. One year following completion of the program, most patients experienced statistically significant improvements in health outcomes and had fewer emergency room visits. In a two year follow-up, self-management program participants showed a decrease in ambulatory health care utilization and significant improvements in health distress during each year of the two year period.

Patient confidence is a key component in self-management (Lorig, 1996). Individuals must be confident that they can carry out a specific task or course of action to achieve a desired result. The more successes an individual achieves, the greater the individual's confidence becomes (Bandura, 1997). Arnold et al. (2005) examined whether self-reported physical functioning was explained by illness-specific differences related to diagnosis and whether certain generic factors also contributed to reported physical functioning in middle aged and older adults with congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD). While diagnosis and illness severity did not explain self-reported physical functioning, the study found that individuals with greater self-efficacy (confidence in ability to undertake specific health related tasks) reported better physical functioning. Studies has shown that self-efficacy has been linked a positive relationship with good disease self-management skills and is negatively correlated to utilization of hospital service rates (Clark & Dodge, 1999; Lorig, Ritter, & Stewart, 2001) Self-efficacy (confidence) plays a critical role in self-management which is key in the reduction of health care costs and better health care outcomes. However, in addition to confidence, individuals must also have the knowledge, skill and beliefs needed to be successful in self-management of health. These key aspects, knowledge, skills, beliefs, and confidence in ability to manage personal health collectively comprise the concept of patient activation (Greene, Hibbard & Tusler, 2005). Older adults tend to have lower levels of patient activation which is predictive of health care outcomes such as preventative health behaviors. Individuals who are more highly activated are more likely to make good health decisions and promote their own health (Lorig, 1996, Von Korff, et al., 1997, Lorig et al., 1999).

Theoretical Model

In order to analyze the relationships between health literacy, social support and patient activation, Bandura's social cognitive theory (Bandura, 1997) was used. Social cognitive theory (SCT) has been used to explain human behavior and has been characterized as "…a triadic, dynamic and reciprocal interaction of the environment, personal factors and behavior" (McCormack Brown, 1999, p. 4). The major constructs of SCT have been known as 'determinants of human functioning' and include behavior, personal and environment. Behavior or behavioral capacity relates to the knowledge and skills needed to perform a given behavior or task; personal, which includes cognitive, affective and biological events; and environmental, which refers to physical and social networks that can affect an individual's behavior such as family and friends, or factors related to the physical environment such as heat, cold, or room size. Self-efficacy is the belief in one's capacity to perform actions or tasks needed to achieve a desired outcome (Bandura, 1997). The term confidence has historically been used synonymously with self-efficacy in the literature. (Bandura, 1997; Pintrich & Schunk, 1996). Confidence in one's ability to perform specific tasks can be viewed as analogous to beliefs or perceptions of self-efficacy regarding performance of the task (Wongwiwatthananukit, 2002). Health beliefs are an important personal factor. Human functioning is viewed as a dynamic interaction between these personal, behavioral and environmental factor constructs (Bandura, 1986). The reciprocity of these constructs is not of equal strength nor does reciprocity occur simultaneously but instead varies with situations and circumstances. Personal factors encompass health literacy (cognitive), beliefs and confidence (components of patient activation) while environmental factors includes social support. Behavior encompasses the notions of self-management, knowledge and skills (components of patient activation) and health outcomes.

Problem Statement and Study Significance

Low health literacy is a national problem affecting nearly half the adult population in the U.S. (Neilson-Bohlman et al., 2004) and the elderly are particularly at risk for this problem (Gazmararian et al., 1999). Low health literacy is associated with higher health care costs (Williams et al., 2002) and poorer health care outcomes (Bennett, Ferriera, Davis et al., 1998; Williams et al., 1998; Gazmararian et al., 1999; Schillinger et al., 2002). Developing a better understanding of the factors that may positively impact on the problem of low health literacy in older adults is critical to effectively addressing this issue and to the containment of health care costs. Past studies have helped to describe the scope and breadth of this issue but limited research has been done on related factors that might mediate the effects of low health literacy.

Statement of Purpose

The purpose of this study is to examine the relationships among the factors health literacy, social support and patient activation. The diagram in Figure 1 illustrates the relationships between the predictor variables of health literacy and social support and their relationship to the outcome variable, patient activation which is based on Bandura's SCT theory (1997). The figure also shows how these variables are organized in determinants of human functioning categories (environmental, personal and behavioral) according to SCT. Since patient activation encompasses the knowledge, skills, attitudes and beliefs needed to manage an individual's health, it is included under both behavioral and personal factors.

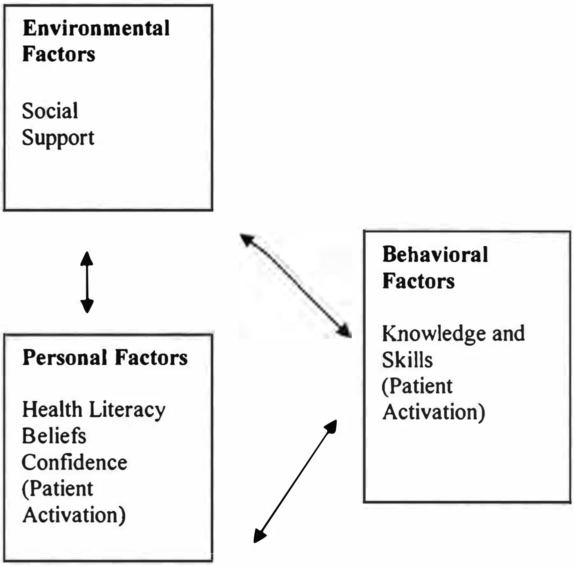

Figure 1. Social Cognitive Theory

Research Questions

This study seeks to examine relationships among health literacy, social support and patient activation in community residing older adults. The study also seeks to examine which of the two predictor variables account for the greatest proportion of the variance.

Research Hypotheses

The research hypotheses for the study include the following:

Hypothesis One- Social support is positively related to patient activation.

Hypothesis Two- Health literacy is positively related to patient activation.

Hypothesis Three- Health literacy will account for the greater amount of

the variance in patient activation.

Delimitations

The time of the study is (May 2007- August 2007). The study was limited to older adults residing in subsidized and unsubsidized senior housing centers in Luzerne County, in northeastern Pennsylvania. Permission was received from Ecumenical Enterprises, which manages six large elder housing complexes with a combined total of 369 apartment units in five different cities in Luzerne County. The study sample included community residing, older adults aged 62 years and above. Only those subjects matching the selection criteria established for the study were included.

Assumptions

A key assumption of this study was that higher levels of patient activation leads to better self-management skills and ultimately better health outcomes. The sample for study is representative of the total population of community residing older adults residing in subsidized housing in Luzerne County, which is in northeastern Pennsylvania.

Definition of Terms

- Literacy: the ability to read, comprehend and apply written information.
- Document literacy: searching, comprehending and using information from non-continuous texts (NCES, 2006).
- Health literacy: "..the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (US DHHS, 2000, p.11-20).
- Instrumental support: assistance in everyday activities.

- Information support: offering information or advice.
- Numeracy or numeric literacy: the ability to perform computations using numbers in printed materials (NCES, 2006).
- Patient activation: knowledge, skills, beliefs, and confidence required to move individuals to better health and well-being (Hibbard, Stockard, Mahoney, & Tusler, 2004; Greene, Hibbard, & Tusler, 2005).
- Prose literacy: "the knowledge and skills used to perform prose tasks (i.e., to search, comprehend, and use of information from continuous texts)" (National Center for Education Statistics [NCES], 2006, p.2).
- Self-efficacy: belief in one's capacity to perform actions or tasks needed to achieve a desired outcome (Bandura, 1997). Confidence is often used synonymously with self-efficacy in the literature (Wongwiwatthananukit, 2002; Bandura, 1997; Pintrich & Schunk, 1996).
- Social network: ties that connect a specific set of individuals or groups
- Social support: "..any process through which social relationships might promote health and well-being" (Cohen, Underwood, & Gottlieb, 2000, p.4).

Organization of the study

A cross-sectional, descriptive, correlational design was used to analyze the predictive factors of health literacy and social support and whether or not these factors accounted for a significant part of the variance in community residing, older adults' patient activation.

Summary

In summary, this chapter provided a brief review of the problem of low health literacy and its impact on health. An overview of the literature indicates that low health literacy is highly prevalent in the U.S. and has been associated with higher health care costs and poorer health outcomes. More information is needed on factors that may help ameliorate the negative effects of low health literacy. Social cognitive theory was offered as the framework for this study. The remainder of the study is organized into four additional chapters which consist of a review of the literature (Chapter Two), methodology (Chapter Three), results including data and analysis (Chapter Four), and finally, discussion of results and directions for future research (Chapter Five).

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Background and Significance

This section addresses four major related issues: 1) the problem and societal impact of low health literacy; 2) the role of social support; 3) chronic disease; 4) patient self-management of health and; 5) patient activation.

Health Literacy

Healthy People 2010, a national strategic plan for disease prevention and wellness, has identified health literacy as a high priority area for national improvement of health and wellness (USDHHS, 2000). Health literacy encompasses many of the tasks needed to maintain health and wellness such as making appointments, completing health information and insurance forms, reading medication labels and following treatment instructions. Inability to perform these tasks due to low health literacy can exacerbate disparities related to access to health information and services.

The Institute of Medicine developed a comprehensive report, "Health Literacy; a Prescription to End the Confusion", which addresses the multifaceted issue of low health literacy. The report found that due to the demands of chronic disease management, increased use of new technologies, legal and regulatory requirements and less time for patient/provider interactions, low health literacy is currently, and will continue to be a growing problem for many individuals using the health care system (Neilson-Bohlman et al., 2004). The issue of low health literacy must be examined by providers, insurers within the health care delivery system.

Understanding health information is crucial to the development of self-management skills and informed participation in health care decision making which are essential to controlling the progression of chronic disease (Schloman, 2004). Low health literacy can make these activities difficult. Certain segments of the population are at increased risk for this problem including older adults (Kirsch et al.,1993; Williams, et al., 1998; Gazmararian et al., 1999; Beers et al., 2003), racial and ethnic minorities and those with fewer years of formal education. Individuals who are poor, unemployed, incarcerated, recent immigrants or working in seasonal jobs are also at increased risk (Kirsch et al., 1993). Gazmararian et al. (1999) surveyed 3260 new Medicare enrollees 65 years of age and above in Ohio, Texas, and Florida. The focus of this cross-sectional study was to determine the prevalence of low functional health literacy among community dwelling Medicare enrollees in a national managed care organization. Functional health literacy was assessed by the Short Test of Functional Health Literacy (S-TOFHLA) (Parker, Baker, Williams, & Nurss, 1995) which measures health literacy, scoring responses into three levels, adequate, marginal and inadequate. The study found that 33.9 percent of English-speaking and 55.9 percent of Spanish speaking participants had inadequate or marginal health literacy (Gazmararian et al.).

Multivariate analysis showed variables of study location, race/language, age, years of formal education, occupation and cognitive impairment were significantly associated with inadequate or marginal health literacy.

Although the concept of health literacy was first introduced in the literature by Simonds in 1974 and it has been widely written about since that time, major barriers still exist regarding this problem. Health related materials such as medical education brochures, discharge instructions and consent forms are frequently written at levels far above patient reading abilities (Gazmararian et al., 1999). Health insurance, health information and instructions require a high reading level to comprehend however, higher educational attainment does not guarantee an understanding of these materials. Even those with a college education may experience difficulty understanding health information and insurance forms (Greenberg, 2001).

Individuals may experience difficulty retaining verbal health information. Cohen-Cole (1991) found that patients remembered less than 50 percent of critical information given to them about own care immediately after leaving their physicians' office. Other studies provide data that indicate individuals with low health literacy may not be able to recall diagnoses and procedures they were informed of or had done immediately following a health care visit (Baker, 1999). This has negative implications for individuals with low health literacy and their ability to manage health.

Kellerman and Weiss reviewed patient education materials available from the Journal of the American Medical Association (1999). The reading level of 39 patient education handouts was analyzed used the Flesch-Kincaid (1948) grade reading level score and the Simplified Measure of Gobbledygoop (SMOG) readability formula (McLaughlin, 1969). All 30 handouts were found to be written at a 10th grade reading level or higher and the mean of all the handouts was a 12th grade level (Kellerman & Weiss). A more recent study of randomly selected patient educational information available the American Academy of Family Physician's website found that the majority of the materials were written at a 9th grade level or higher when almost 25 percent of patients are expected to be able to read only at a 5th grade level (Silver Wallace & Lennon, 2004).

An analysis of 250 studies in public health and medical periodicals showed that printed health information are written at levels much higher than the average adult's reading skills and abilities (Rudd, Moeykens, & Colton, 2000). In a Rand study of the language level of online health information available on health Web sites, 100% of the English-language websites were found to be written at a ninth-grade level or higher. Seven Spanish language Web sites were also evaluated and of these, six offered information at a high school level or above (Berland et al., 2005).

Impact of Low Health Literacy on Health

Berkman et al. (2004) conducted a meta-analysis of abstracts on health literacy identified from literature searches. The analysis focused on examining two key question areas: 1) the relationship of literacy skills to health care services, outcomes, and disparities in health outcomes, and 2) identification of effective interventions for those with low literacy skills. Three thousand fifteen abstracts from 1980 to 2003 were identified. Of those, 684 articles were given a full review and 73 met the rigorous inclusion criteria and were retained. Forty-four articles related to key question one and 29 articles addressed key question two (Berkman et al., 2004).

Low Literacy and Knowledge of Health Care Services

Six of the studies examined the relationship between literacy and knowledge of health care services such as mammography, cervical cancer screening, informed consent, childhood health maintenance, parental understanding of emergency room discharge instructions, and knowledge of cardiac health. With the exception of one, all of these studies showed statistically significant associations between higher literacy level and knowledge of matters related to use of these health care services (Berkman et al., 2004).

Literacy and Patterns of Health Care Service Usage

A positive relationship was found between literacy levels and cancer screenings (Pap smear and mammogram) among women aged 65 years and older in a Medicare managed care health insurance plan (Scott et al., 2002) . Individuals with low health literacy were less likely to have had a Pap smear or mammogram over two year period (Scott et al., 2002). In a study of low income patients with prostate cancer, later diagnosis was associated with low health literacy irrespective of subjects' race (Bennett, Ferreira, & Davis et al., 1995). The study also examined the relationship between literacy and adult immunization rates. After controlling for age, sex, race, education and income, those subjects with inadequate literacy had 1.4 (95% CI 1.1, 1.9) times the odds of not having received an influenza vaccine and 1.3 (95% CI 1.1, 1.7) times the odds of not have received pneumococcal immunization compared with subjects who had adequate literacy. No significant differences were found in subjects with marginal or adequate literacy (Scott et al., 2002).

In a study examining sexually transmitted disease screening, a literacy level at or greater than the ninth grade was associated with a 10 percent increase in the probability of adults undergoing gonorrhea testing in the past year (Fortenberry et al., 2001). Several studies have shown that poorer self-rated health (Weiss, Hart, McGee, & D'Estelle, 1992) and higher use of health care services (Baker et al., 1997; Baker, Parker, Williams, & Clark, 1998) have been independently associated with low health literacy.

Decreased health literacy is common in individuals with chronic medical problems such as high blood pressure, AIDS, asthma, and non-insulin dependent diabetes mellitus (Williams et al., 1998; Kalichman, Ramachadran, & Catz, 1999; Kalichman & Rompa, 2000). In a study of 653 Medicare enrollees with chronic health disease, researchers found that subjects with inadequate health literacy knew significantly less about their disease than those with adequate health literacy.
Disease knowledge was independently related to health literacy in a multivariate analysis (Gazmararian et al., 2002).

Role of Health Literacy in Patient/Physician Communication

Another problem associated with low health literacy is a lack of adequate health vocabulary. During patient interviews, individuals with low health literacy may not report key symptoms or important information needed for diagnostic decision making by health providers which can interfere with accurate medical diagnosis. Low health literacy can also impact the validity of medical testing. For example, screening for cognitive impairment may be inaccurate since the scoring of such tools is affected by patients' literacy and their understanding of written directions (Williams, David, Parker, & Weiss, 2002). Low health literacy may also lead to missed appointments with health providers, lack of informed consent, trouble accessing needed services from the health care system and medications errors such as wrong dosages or missed medication administration times (Williams et al., 2002) due to patients' inability to read medication labels since this population tends to rely on visual clues, oral explanations and demonstrations of new tasks (Baker et al., 1996).

Financial Implications of Low Health Literacy

Although there is a limited amount of research data on the financial associations with low health literacy, available information suggests that an association exists between health literacy, utilization of health care services, and the cost of health care (Neilson-Bohlman et al., 2004). According to an analysis of nationally representative data conducted by the National Academy on an Aging Society [NAAS], individuals with low health literacy used more health care services that those with adequate health literacy (1998). A major finding of the study was that the primary reason for higher health care costs for those having low health literacy was longer hospital stays. An estimated $73 billion dollars in health care costs was spent in 1998 due to low health literacy. The majority of these expenditures, or 39 percent were incurred by Medicare. It has been estimated that while about 17 percent of these additional costs may be financed by employers of individuals with low health literacy skills, patients with low literacy patients are estimated to spend an additional $11 billion or 16 percent of these additional health care costs themselves (NAAS, 1998).

Baker et al. (2002) found that patients in public hospitals who were Medicare managed care enrollees with limited health literacy, had higher hospitalization rates compared with patients who possessed adequate health literacy A secondary data analysis showed that predicted health spending for a single patient with inadequate health literacy was $993 more than a patient with adequate reading skills. After controlling for health status, a difference of $450 remained. Among elderly managed care enrollees, low health literacy was found to be an independent risk factor for hospital admission. Over a two year period, one study found that in a pool of 95 low-income patients, those with inadequate health literacy were more than twice as likely to have required hospitalization in the previous year (Williams et al., 2002). In a study of English-speaking and Spanish-speaking Medicaid recipients, subjects with the lowest reading levels had annual health care costs of $12,974. In comparison, the overall population in the study had an average health care cost of only $2969 annually.

A large scale study of 3260, community residing elders from three states who were enrolled in Medicare managed care programs found that subjects with low health literacy were more likely to use inpatient care than subjects whose health literacy was adequate (Howard, Gazmararian, & Parker, 2005). The study measured levels of health literacy (adequate, marginal and inadequate) in older adults with chronic conditions. The study found that although subjects with marginal and inadequate health literacy had more chronic conditions than those whose health literacy was adequate, subjects with marginal and inadequate health literacy were found to have the same likelihood of using outpatient care or having prescriptions filled as those with adequate health literacy having less chronic conditions. Respondents with adequate health literacy had mean total costs of $9614 while those with marginal health literacy had costs of $8484. Those with inadequate health literacy had mean total costs of only \$7246. Inversely, individuals with inadequate health literacy had significantly greater emergency department costs (\$108; 95% CI: \$62 to \$154; $p < 0.0001$) compared to subjects whose health literacy was adequate. In subjects with marginal health literacy, total health care costs were higher (\$1543; 95% CI: -\$89 to \$3175; $p = 0.006$) however, this was not a statistically significant difference. The study concluded that individuals with inadequate health literacy tended to under utilize outpatient services and over utilize inpatient services leading to use of an inefficient mix of health care services and higher health care costs.

Review of Health Literacy Interventions: Strength and Weaknesses

The Institute of Medicine outlined a framework with three main points of potential intervention to improve national health literacy (Neilson-Bohlman et al., 2004). Limited information and conclusions about causality and health literacy are available so this framework is currently seen as a model around which interventions can be structured to help guide future research efforts. Individuals' interactions with culture and society, the educational system, and the health care system, whether positive or negative, have the potential to affect health care outcomes and costs. More research is needed to identify the types of causal relationships that exist within these interactions (Neilson-Bohlman et al., 2004). This knowledge could then direct the development of evidence-based interventions that could impact on the problem of low health literacy.

Teaching health professionals how to identify and screen individuals at risk for low health literacy is an important first step in diagnosing the problem (Davis & Wolf, 2004) however, many health professional are uncomfortable asking patients about literacy. In a recent survey, medical residents were questioned about their comfort level in asking patients' about their literacy abilities and the residents reported that they were more at ease asking about illicit drug use compared to literacy (Rosenthal, Werner, & Dubin, 2004). Although much information on the problem of low health literacy has been published in the health professions literature, there has been a lack of widespread progress in addressing this issue due to the shame and stigma linked to the problem of low literacy and providers' discomfort in discussing this important issue.

In a controlled, non-randomized study, Davis et al. (1998) tested an educational intervention consisting of a training video, coaching tool, written brochure, and verbal recommendations. This multi-modal approach significantly improved the rate of participation in mammography screening at six months, but not at 24 months, when compared with results from only verbal and written information. Murphy, Chesson, Walker, Arnold and Chesson (2000) tested a videotaped educational intervention against a written brochure at the same readability level in patients from a sleep disorders clinic. Subjects having lower health literacy showed a higher knowledge level with the video than the brochure for two of eleven survey questions. Recommendations by patients included a request for fewer polysyllabic words, more cultural representation in educational materials, and additional information on diagnosis and treatment of sleep disorders. Other studies suggest that the use of illustrations (Michielutte, Banson, Dignan, & Schroeder, 1992; Davis et al., 1996), pictographs (Houts et al., 1998; Houts, Witmer, Loscalzo, & Zabora, 2001) and photographs (Coleman et al., 2003) may increase the comprehension of health education materials in patients with low health literacy.

General recommendations for preparing health education materials for individuals with low health literacy include: use of non-medical terms and pictures, limiting non-essential information (Silver Wallace & Cohen, 2004; Safeer & Keenan, 2005), using active voice, including culturally sensitive content (Kerka, 2003; Murphy et al., 2000), allowing for white space in documents, and use of bulleted text (Silver Wallace & Cohen, 2004). Incorporation of the "show me" or "teach back" approach is suggested to validate patients' understanding of material presented (Safeer & Keenan, 2005).

Unfortunately, much of the improvement in comprehension found using these interventions appears to be short-lived. Large-scale, longitudinal studies and data on cost-benefit analyses of these interventions are needed to further evaluate these methods.

Baker et al. (2002) suggests that it may be helpful for health professionals to think about low health literacy as being analogous to a physical limitation. Just as a patient using a wheelchair wouldn't be expected to climb stairs to obtain health care services, it has been proposed that similar reasonable accommodations must be made for individuals with low health literacy. This example underscores the mismatch of the inappropriately high levels of health information in comparison to the low reading and comprehension abilities of those with this problem. The notion of "one size fits all" health information must be discarded in favor of more individualized approaches that encompass patients' unique abilities, backgrounds, and needs. Based on the information provided in the literature review, it is apparent that investigating the relationship among health literacy, social support, and patient activation is an important step in learning about factors which may impact on the problem of low health literacy and offer the potential to improve health outcomes. Examining which factors may be most predictive of patient activation (the skills, knowledge, beliefs, and motivation required to move individuals to better health and well-being) (Hibbard, Stockard, Mahoney, & Tusler, 2004), whether higher levels of social support are associated with higher levels of patient activation, and whether social support and health literacy are predictive of higher levels of patient activation, are critical to developing a greater understanding of ways to impact on the issue of low health literacy.

Shame and Stigma

Shame and stigma are frequently associated with the problem of low literacy. Persons with low literacy often try to hide their reading difficulties or may even avoid seeking health care to avoid embarrassment due to their literacy problems. In a study conducted with patients having low functional literacy, 19 percent of subjects had never disclosed their reading difficulties to anyone, 67.4 percent had never told a spouse, and 53.4 percent had never revealed this information to their children. Forty percent of those with low literacy felt shame about their reading problems (Parikh, Parker, Nurss, Baker, & Williams, 1996).

General Literacy

In an attempt to address the growing issue of literacy, the 1991 National Literacy Act was created. This Act required the U.S. government to evaluate the status and progress of English literacy in adults (National Center for Education Statistics [NCES]), 2006. The National Assessment of Adult Literacy (NAAL) was developed in 1992 in response to this mandate and represents the largest ongoing study of literacy in the United

States (U.S.). The 1992 NAAL survey included over 26,000 adults and revealed that approximately 21 to 23 percent had the lowest literacy skills in prose, document and quantitative reading and comprehension. Prose literacy is "...the knowledge and skills used to perform prose tasks (i.e., to search, comprehend, and use of information from continuous texts)" (National Center for Education Statistics [NCES], 2006, p.2). Document literacy includes searching, comprehending and using information from non-continuous texts while quantitative literacy refers to the ability to perform computations using numbers in printed materials (NCES, 2006). These subjects lacked the basic abilities required to read a thermometer to check for fever, understand a prescription medication label, or read a public transportation schedule needed to find their way to a health care appointment (Davis, Meldrum, Tippy, Weiss, & Williams, 1996). An additional 25 to 28 percent of subjects had slightly higher proficiency in these skills but were still significantly limited in their literacy abilities and their ability to participate in self- management of health.

Older Adults and Literacy

Of the older adults participants aged 60 and above in the NAALS 2003 survey group, 71 percent had limited prose skills and 68 percent of these older individuals had difficulty locating and comprehending printed quantitative information. Performance declined with age and older subjects tended to overestimate their literacy abilities when in actuality their performance was much lower. Older adults who were employed or retired and involved in volunteering had higher literacy skills than those who were unemployed or retired and not volunteering. Subjects with an annual household income of less than $10,000 were also much more likely to have limited literacy abilities (Kirsch et al., 1993). These studies provides important information useful for identifying and screening individuals at increased risk for low health literacy.

Gazmararian et al. (1999) studied 3260 Medicare enrollees in managed care organizations in four states to determine the prevalence of low health literacy among those 65 and older. The study found that 33.9 percent of English-speaking and 53.9 percent of Spanish speaking respondents had inadequate or marginal health literacy resulting in impaired ability to understand health messages and decreased ability to self-manage their health conditions. The authors concluded that elders were particularly at risk for low health literacy. Even older adults who are more affluent and have higher educational levels may also be at risk for low health literacy. In 2002, Gausman Benson and Forman conducted a study of 93 affluent residents from a geriatric retirement community with a mean age of approximately 70 years and found that 30 percent of the residents were unable to adequately understand written health information provided as measured by the Test of Functional Literacy in Adults [TOFHLA] (Nurss, Parker, & Baker, 2001). The subgroup which demonstrated poor comprehension had a mean of 13 years of formal education and a mean age of 85 years (Gausman Benson & Forman, 2002). This information supports the fact that older adults are at increased risk for low health literacy.

The 2003 NAAL follow-up survey measured three major literacy areas including prose, document and quantitative literacy (National Center for Education Statistics [NCES], 2006). The survey also included a new section on health literacy.

This represented the first large-scale, national study to include a measure of participants' ability to understand health-related information and materials such as health insurance forms, medication instructions, and wellness and disease prevention information. A nationally representative sample of approximately 19,000 adults aged 16 or older was surveyed. The study also included a sub-sample of approximately 1,200 inmates in federal and state correctional facilities.

Preliminary findings released thus far found that women scored higher than men in document and prose literacy while men had higher quantitative literacy scores. Older adults had lower levels of quantitative literacy compared to middle aged adults. [NCES], 2007).

Oldest adults had the lowest levels of literacy skills however, these scores were improved from the 1992 scores from the same age group (National Center for Education Statistics Further analyses of the 2003 NAAL survey are pending.

Social Support

Older adults born between 1946 and 1964 are considered to be part of the Baby Boomer generation (Maples & Abney, 2006). Boomers born in the late 1950s to early 1960s may experience differences in their retirement and standards of living such as higher Social Security payments and a reduction of up to 30% in these benefits for those who retire before the age of 67 (Caputo, 2005). Other major changes related to increasing lifespan includes the care of elderly parents by elderly children. The need to work longer while caring for aging parents has created new strains for boomers. Changing family structures have added to these strains. Many persons in the Baby

Boomer generation come from non-traditional family structures such as single-parent families, families who are childless, and blended families (Kutza, 2005). Due to a competitive job market, many families are separated in distant parts of the country thus making familial social support more difficult (Caputo, 2005).

The increased demands of a navigating a more complex and technological health system can be stressful. Social support may offer some benefit to individuals in dealing with this burden and may offer utility in identifying specific factors that can assist individuals in these tasks. Social support refers to "…any process through which social relationships might promote health and well-being" (Cohen, Underwood, & Gottlieb, 2000, p.4).

Other definitions stress a more reciprocal process viewing social support as "..a process through which help is provided to or exchanged with others in an attempt to facilitate one or more adaptational goals" (Dolbier & Steinhardt, 2000, p.1).

Social Support and Health

Positive health outcomes have been linked to high levels of social support (Cohen & Syme, 1985; Ornish, 1988; Cohen, 1988; Uchino, Cacioppo, Kiecolt-Glaser, 1996). Some of the beneficial health outcomes that have been linked to high levels of social support include increased psychological well-being; (Lambert, Lambert, Klipple, & Mewshaw, 1990) enhanced immune function, (Jemmott, Magliore, & Jennings, 1990), and lower rates of mortality (Berkman & Syme, 1979; Blazer, 1982; House, Robbins, & Metzner, 1982; Ruberman,Weinblatt, Goldberg, & Chaudhary, 1984). These findings have important implications for older adults.

Social relationships represent processes that can also influence health. An example of this process would include the exchange of specific resources such as emotional, informational or instrumental in response to perceptions that such support is needed by others. Perceived or actual availability of these types of social support resources has also been used to further categorize social support (Cohen, Underwood, & Gottlieb, 2000). In studies examining both the availability of perceived and actual social support, actual receipt of support was less predictive of health outcomes than perceived support (Cohen & Hoberman, 1983; Cohen & Wills, 1985; Wethington & Kessler, 1986; Helgeson, 1993). The associations between well-being and social support are made through cognitive mediation which may help explain why perception of support has a larger influence on well-being and health outcomes (Dolbier & Steinhardt, 2000). Interestingly, actual support received has been linked with negative outcomes in some studies (Hyman, 1971; Revenson, Wollman, & Felton, 1983; Helgeson, 1993).

Lee, Arozullah, and Cho (2004) describe individuals as "...social actors, residing in social environments that contain various degrees of support and resources" (p. 1312). The 1992 NALS survey revealed that approximately 25% of adults at the lowest literacy levels report receiving "lots of help from family members or friends" with reading printed information and completing complex forms, compared to only 12% of individuals with average reading ability (Kirsch & Jungeblat, 1993).

Social support has been theorized to include both a stress buffering effect and a a direct effect which could impact low health literacy. Direct effects would include the notion that support can improve health regardless of level of health literacy. Stress buffering effect is believed to moderate the impact that low literacy has on individuals (Lee, Arozullah, & Cho, 2004). Both effects have the potential to impact on overall health status and utilization of health care services. Beneficial effects of social support on individuals with low health literacy include an improved ability to access, understand and apply health information and needed resources. Positive social networks have the potential to improve health beliefs and behaviors of persons with low health literacy. However, conversely, it is possible that due to the increased vulnerability of those with low health literacy, poor social networks and support have the potential to negatively impact on health status and health behaviors through poor modeling and surrogate decision making.

Kim, Quadri, Lee, Lee, & Arozullah (2003) conducted a study examining the relationship of health literacy and social support on prescription filling behavior. Subjects were recruited from inpatients on general medical unit in a university affiliated, Veteran's Administration hospital over an eight month period in 2003. Seven hundred and ninety two prescriptions were reviewed from 239 subjects in the study. Results showed that neither health literacy or social support were significantly associated with prescription filling behavior.

In another study focused on determining the role of health literacy and social support in predicting preventable hospital admissions, Arozullah et al. (2005) interviewed 400 inpatients in a university affiliated, Veteran's Administration hospital. In non-binge-drinkers with lower social support for medical care, larger social networks were found to be predictive of preventability of hospitalization. In non-binge drinkers, higher support for medical care and lower rates of outpatient services utilization was found to be predictive of preventability of hospitalization. Study results showed that low health literacy was not predictive of preventability of hospitalization.

Lee, Gazmararian, and Arozullah (2006) studied the relationship of health literacy, social support and health status and health care use in older adults. Community dwelling Medicare beneficiaries who were HMO enrollees were included in the study which showed that those with low health literacy were more likely to be recipients of medical information support and health reminder support and less likely to receive tangible support for their health care needs compared with those with high health literacy. In both low and high health literacy groups, health reminder support and medical information support were association with lower physical and mental health status. A lower likelihood of hospitalization and a higher rate of doctor visits were associated with health reminder support in those with high health literacy. Higher physical and mental health status were associated with tangible support.

Social support offers many possibilities as a potential mediator of the negative effects of low health literacy. Further research offers opportunities for exploring ways in which social support may impact on the problem of low health literacy.

Chronic Illness

The U.S. has focused on an acute care model in an attempt to address the major health problems of the last century which were largely centered on communicable diseases (Lorig, 1996). This model served the public fairly well. The eradication of small pox, the almost complete elimination of polio, and the rapid growth of new life sustaining treatments and technologies represent some of the gains made during this time. One outcome of our ability to prolong life and deal with communicable disease is that people are living longer. Unfortunately, due to cellular senescence, organ function declines with aging. This decline, when coupled with genetics and negative behavioral influences often leads to the development of chronic illness (Weil, 2005).

Chronic illness has been defined as an illness lasting longer than three months that is not self-limiting. Chronic illness accounts for three quarters of all health care costs in the U.S. (Von Korff et al., 1997) and has been characterized as being currently the biggest threat to health status accounting for the most expenditures in health care (Lorig, 1999). The number of Americans living with chronic illness is expected to reach almost 150 million by the year 2030. These illnesses are associated with pain, suffering, decreased quality of life and major functional limitations and are experienced by one in every 10 people in the U.S. ("*Chronic disease overview*", 2005). A new era of health care is emerging but our health system is poorly prepared to deal with this using an acute care model. While there will always be a need to deal with acute health issues, more health care expertise is needed in chronicity. A chronic care paradigm must be adopted to meet changing societal needs.

Given current and future, predicted disease trends, self-management skills and participation in health decision-making have become essential components in controlling the progression of chronic illness and maintenance of health. Simply providing individuals with information about health risks and conditions is not enough to bring about a desired change in health behaviors. The increasing prevalence of chronic illness requires individuals to take a more active role in managing their own health.

Self-Management of Health

Corbin and Strauss (1988) posited that three specific types of work exist for those with chronic disease including: work necessitated by the disease such as visits to health professionals, taking prescribed medications, and following through on behavior modifications such as exercise; the maintenance of everyday life activities such as work and family responsibilities; and dealing with an altered view of the future. Within the chronic care model, patients must partner with their health professionals in order to develop the self-care management skills needed to effectively deal with chronic disease. This is a different model requiring the active involvement of patients compared to the acute care model which tends to put health professionals in an active role while patients remains more passive (Lorig, 1996).

These changing roles require different skill sets for both patients and health professionals and a willingness to partner with one another in the process of health care exchange. The self-management model is predicated on effective communication between these two parties. Health literacy is a key component in this communication process. If patients cannot read, understand, and apply information about their own care, this communication cannot effectively take place. Without appropriate intervention, low health literacy relegates the patient to being a passive recipient instead of an active, empowered, accountable partner in the health care process. Low health literacy has been associated with poor self-care in chronic illnesses (Kim, Love, Quistberg, & Shea, 2004). In patients with diabetes, low health literacy was associated with worse glycemic control and higher rates of microvascular complications such as retinopathy (Schillinger et al., 2002). Studies have shown that better health outcomes (Levinson, Kao, Kuby, & Thisted, 2005) result when patients are active participants in their own care, (Arora & McHorney 2000), are knowledgeable about their own health conditions (Rost, Flavin, Cole, & McGill, 1991), and are involved in health decision making (Deber, Kraetschmer, & Irvine, 1996).

Active participation in self-management has been linked with improved health outcomes in older adults who participated in patient self-management programs for hypertension and diabetes (Chodosh et al., 2005). In a randomized clinical trial of hospitalized diabetic patients, control subjects participated in a comprehensive three day evaluation and educational program while those in the experimental group received a 45 minute patient activation intervention with a one hour self-administered “booster” in addition to the control program (Rost et al.,1991). Metabolic control as measured by glycated hemoglobin and functional status were tested at baseline and then again four months post-intervention. Patients in the experimental group asked significantly more questions at the time of discharge compared with those in the control group, and those in the experimental group reported significantly fewer limitations in activities of daily living at four month follow-up. Patients in the experimental group were also found to have a statistically significant improvement in glycated hemoglobin levels although this was not significantly lower than the control group’s levels at follow-up.

It is important to consider that not all patients prefer to be actively involved in their own care. In a population based survey of 2,765 English-speaking adults, Levinson, Kao, Kuby, and Thisted (2005) assessed individuals' preferences for decision making in a representative U.S. population sample. The study found that 96 percent of respondents preferred to be offered choices and asked their opinions. Fifty two percent of respondents preferred to have their physicians make final decisions on care and 44% preferred to not to seek medical knowledge for themselves but instead wanted to rely on their physician for this information. Subjects who were female, had more education, and who were healthier were more likely to have a preference for an active role in decision making. Hispanics and African-Americans were more likely to have a preference that their physicians make health decisions for them. Individuals' preferences for an active role in their health decision making increased up to 45 years of age but then declined.

While individuals' preferences must be taken into account, strains on the U.S. health care financing system make patient involvement a necessity. Clinicians must find ways to increase patients' involvement in their own care and to empower individuals to take a more active role in managing their own health.

Patient Activation

Patient confidence is central to activating persons to take a greater role in their own self-management. Better health has been linked to confidence. In a randomized, cross-sectional study of 302 veterans who participated in a postal survey, Rohrer, Young, Sicola, and Houston, (2007) used multiple regression analysis to test the hypothesis that health confidence is related to self-rated health. After controlling for obesity, cigarette smoking and participation in recreational activities, the results showed that confidence was associated with better health. However, confidence alone does not explain how to motivate or activate individuals to participate in self-care and health promoting activities. Activating or engaging patients in self-management has been discussed in several ways in the literature. Patient activation is needed to help move individuals to engage in more positive health behaviors. Hibbard, Stockard, Mahoney and Tusler (2004) noted that activation for health change has been conceptualized in a number for forms include health locus of control (Wallston, Stein, & Smith, 1994) self-efficacy (Lorig,1996), and readiness to change behaviors related to health (DiClemente et al., 1991; Prochaska, Redding & Evers, 1997). These theories focus on single health behaviors such as smoking cessation and weight loss. Hibbard et al. (2004) proposed the notion of patient activation to describe the factors required to move individuals to better health and well-being. The authors developed the Patient Activation Measure (PAM) which assesses individuals' self-reported levels of knowledge, skills, beliefs and confidence in their ability to self-manage health.

Greene, Hibbard, & Tusler (2005) studied the independent influence of health literacy and patient activation in specific behaviors (Medicare decision-making, health-care-related behaviors, healthy behaviors and chronic disease self-management behaviors) in which older adults must have skill or knowledge to manage their health and health care. The study included a convenience sample of 293 Medicare beneficiaries in Oregon. When compared with a national sample of Medicare beneficiaries, the individuals in the study sample had higher levels of education, were older and had better health. Health literacy and patient activation were found to be significantly and positively related to the specific behaviors mentioned above. While the study found that health literacy was predictive of health care related behaviors, health literacy was more strongly associated with Medicare decision making outcomes. Conversely, patient activation was more strongly associated with health related and self-care behaviors. n a large scale study of 1075 HMO enrollees with diabetes, Mosen, Hibbard, Sobel, and Remmers (2005) assessed participants' levels of patient activation, self-management behaviors, medication adherence, and emergency department visits for one year. After adjusting for age, gender, race/ethnicity, level of education, functional health status and geographic location, the authors used logistic regression to explore the independent association of patient activation on self-management behaviors, medication adherence, and emergency department utilization. The study found that higher patient activation was independently associated with higher performance of self-management behaviors, higher medication adherence, and reduced emergency department use. These findings have important implications for older adults' health.

Hibbard, Mahoney, Stock, and Tusler (2007) conducted a recent interventional study on patient activation. Four hundred and seventy nine participants were included in this randomized, controlled clinical trial. Subjects were recruited from a large medical group and inclusion criteria included having a least one of the following chronic conditions (diabetes, hypertension, heart disease, chronic obstructive pulmonary disease, or hyperlipidemia) and being between 50-70 years of age. The Chronic Disease Self-Management Program (CDSMP) was used to create change and variability in self-management in the study sample and served as the intervention. The CDSMP has been previously evaluated in the literature. The CDSMP is a community based, weekly workshop focused on the development of self-management skills for those with chronic illness. Participants who were randomized to the control group were given the option of participating in the CDSMP at the conclusion of the study. Data were collected at baseline, six weeks and six months from both the control and intervention groups. Findings of the study showed that positive change in activation was related to positive change in self-management behaviors, even when the behavior was not being performed at baseline. When the behavior was previously being performed, an increase in activation was related to maintaining relatively high level of the positive behavior over time. Interestingly, the intervention effect was less clear. As activation increased in the experimental group, this was matched by nearly equivalent increases in the control group. Overall, results suggested that a variety of improved behaviors will follow if patient activation is increased. Which specific interventions will improve activation remained unclear and should be examined in future intervention studies. This continues to be an important area of research.

Patient activation is an key factor in increasing self-management skills and behaviors and offers rich opportunities for further study. The relationship of patient activation to social support remains unclear. How social networks and other types of social support might interact in increasing patient activation has not been well studied. Since social networks (community groups, friends) and social support (information, tangible, emotional and affectionate) can potentially influence persons' knowledge, skills, beliefs and confidence in ability to self-manage health (patient activation), these relationships bear future investigation.

Theoretical Framework

Health literacy is believed to have a direct effect on health because it determines how well individuals can understand, process and apply health information to their own care. This, in turn, contributes to the individual's physical, mental, and social health outcomes. Patient activation which includes individuals' beliefs in their coping abilities, problem solving skills, knowledge and level of confidence in the ability to manage his or her own health, are important mediators in health care management. Collaboration with health providers and the ability to access needed care can also have a profound impact on health care outcomes as they represent processes by which individuals gain the requisite skills needed to be successful in meeting their own health care needs. Individuals with higher levels of patient activation are theorized to be better prepared or able to meet their own health care needs, to appropriately seek help and access resources from the health care system and tend to exert greater effort to accomplish their goals (Bandura & Schunk, 1991). This notion is supported by data in the literature which show that higher patient activation is positively associated with better self-management skills (Hibbard, Mahoney, Stock, & Tusler, 2007) and improved health outcomes (Mosen, Hibbard, Sobel, & Remmers, 2005; Greene, Hibbard, & Tusler (2005). Therefore, patient activation has the potential to have a direct effect on health care outcomes. A key assumption of this study is that patient activation leads to better self-management which in turn leads to improved health outcomes.

Social support, through meeting basic human needs for belonging, intimacy and reassurance of self worth, serves as a starting point in a connecting pathway toward health literacy. Social support can provide a direct effect on health as "...supportive ties may enhance well-being and health regardless of stress levels"(Israel & Heaney, 2002, p. 189). Social support also encompasses specific types of support such as instrumental support (eg. assistance with tasks of activities of daily living) and information support (providing information or accompanying someone to a doctor's appointment). These components are very important to individuals with low health literacy as they may assist in buffering some of the negative effects of this problem. The diagram in Figure 2 represents the SCT Model (Bandura, 1989).

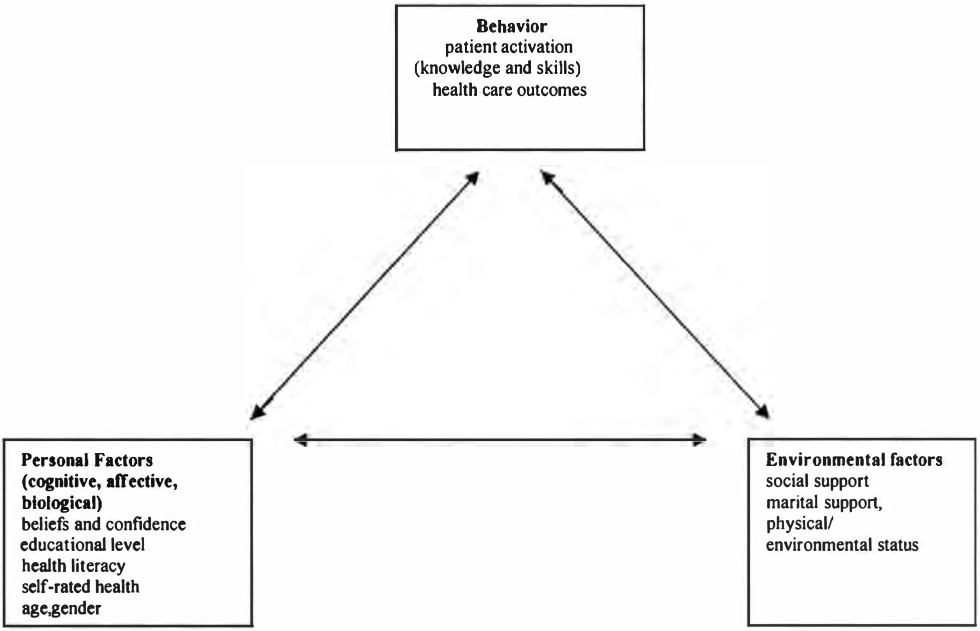

Figure 2. Triadic Model of Social Cognitive Theory (SCT)

CHAPTER 3: METHODOLOGY

Introduction

Approximately one-half of all adults in the United States have problems with low health literacy (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). This problem can make individuals prone to less knowledge of chronic disease (Gazmararian et al., 2003), poorer health outcomes and less preventative care (Bennett et al., 1998), lack of informed consent, difficulty completing medical forms, medication errors, missed medical appointments, and increased hospital admissions (Williams et al., 2002). Low health literacy has also been associated with inefficient use of health care services and increased health care costs (Baker et al., 2002; Williams, et al., 2002). Learning more about factors which may mediate the problem of low health literacy has the potential to offer new information that can be used to assist these individuals to better navigate the health care system and to have better access to resources and to develop better self-management skills. This could assist in the minimization of barriers which currently separate individuals from more effectively utilizing the health care system.

The purpose of this chapter is to offer specific information outlining the organization of this study involving community residing older adults with chronic illness. This information includes methodological evaluation, and details for future replication studies. Major sections to this chapter include participants (sampling and recruitment procedures, inclusion and exclusion criteria sample size and informed consent), design (description, equipment, independent and dependent variables and measurement tools), procedures (participant instructions and study contacts) and plan for analysis (descriptive and hypothesis testing).

Participants

Sampling and Recruitment Procedures

Sixty two years is the earliest age that older adults can retire with a partial Social Security benefit (Social Security Administration, Social Security Online, 2007). The population consisted of a convenience sample of older adults aged 62 and above with a chronic illness and who were community residing.

A letter and informational flyers were used to recruit older adult residents living in subsidized and unsubsidized elder high rise apartment housing in Luzerne County. Information meetings about the study were held at these senior housing sites.

Setting

Pennsylvania has the second highest state ranking for percentage of older adult residents aged 65 and older (PA Dept. of Aging, 2004). According to the U.S. Census Bureau (2005), Luzerne County has a total population of 299,279 with a population 65 years and above of 52, 651. The study setting included subsidized and unsubsidized elder housing complexes in a five city area in Luzerne County.

Inclusion Criteria

To be included in this study, participants needed to be community residing, aged

62 years or greater, with at least one chronic illness, and able to speak and read English. The Short Portable Mental Status Questionnaire (SPMSQ), a brief, 10-item, instrument was used to detect the presence of intellectual impairment and to determine the degree of such impairment (Pfieffer, 1975). The tool was designed specifically for older adults, and has been well tested, standardized and validated. There is a high level of agreement between the clinical diagnosis of organic brain syndrome and the SPMSQ scores that indicated moderate or severe organic impairment. A score of 0-2 errors was required for inclusion in this study.

Exclusion Criteria

Individuals with cognitive deficits, those with vision problems unable to be corrected by glasses or contact lenses were excluded from the study. Those without a chronic health condition were also excluded from the study. Individuals younger than 62 years or whom reside outside of Luzerne County did not participate in the research study.

Generalizability

The above exclusion criteria relating to non-English speakers or readers presents a concern for generalizability of the research findings. Since all materials were not available in other languages and only English speaking subjects were recruited, study findings cannot be generalized to certain racial or ethnic minorities, such as Hispanics who are not bilingual. Due to the shame and stigma associated with literacy problems, those with low health literacy may have self-selected not to participate in the study. Homebound and institutionalized older adults were excluded from the study which limits generalization to these groups. Since the sample was limited to community residing older adults in Luzerne County, generalization of study findings to the older adult population at large will be limited. Pennsylvania has a disproportionately higher percentage of older adult residents in comparison to other states which must be also be taken into account when considering generalizability of study results. The population of Luzerne County is a relatively heterogeneous group and is predominantly Caucasian. This will also limit generalizability of study findings to other racial and ethnic groups.

Number of Participants

Power analysis can be a useful tool in determining sample size. Using the largest sample size possible is encouraged, but is not an assurance of increased accuracy. Large sample sizes can be costly and may not be practical for all research projects. In order to decrease the risk of Type II errors (wrongly accepting a false null hypothesis), a power analysis should be done (Polit & Tatano Beck, 2004). To conduct such an analysis, the significance criterion (α), proposed sample size, the population effect size (γ) and power must be determined. Effect size refers to the magnitude or strength of the relationships between study variables. Effect size can be calculated based on findings from previous of similar scale and magnitude. However, when no relevant, similar prior studies exist, common rules are applied based on predicted effect size (small, medium or large). When this information is not available, a medium effect size is generally used. Using a standard table to determine sample size with alpha of α $p < 0.05$, and a power of 0.80, two predictor variables and an estimated effect size of f^2 .15, sample size would be 62 (Polit & Tatano Beck, 2004). Statistical software is readily available which allows the user to calculate sample power easily and accurately. An *a priori* test for sample size for multiple regression, sample power analysis was conducted using an online freeware statistical calculator (Soper, 2007). Using an alpha (α) of $p < 0.05$, and a power of 0.80, an f^2 of 0.15 which is considered a standard medium effect size for the behavioral sciences (Cohen, 1988), an N = 67 was calculated. This sample calculation confirms the value obtained from the standardized table, therefore, an N of 67 served as the sample size for this study. The researcher over-sampled to an N of 103 subjects to address the potential problem of missing data.

Informed Consent

The Virginia Commonwealth University (VCU) Institutional review Board (IRB) approval for an exempt review was obtained (IRB# HM10882). According to IRB policies, informed consent was not required however, an information sheet with contact information for the researcher and the VCU IRB Department was made available as per the approved protocol. As per VCU IRB policies, interested persons were able to ask the primary investigator questions prior to deciding whether or not to participate. Interested individuals were then enrolled in the study.

Design

The study of relationships between the variables of health literacy, social support and confidence in ability to self-manage health utilized a cross-sectional, descriptive, correlational design. Correlational studies are focused on examining the relationships that exist in a given situation (Burns & Grove, 2007). Correlational design allows the researcher to identify many interrelationships in a short period of time. No controls or interventions are used in correlational studies, however, variables must be clearly operationalized. An adaptation of the basic structural for the design was derived from Burns & Grove (2007, p. 248) and is depicted in Figure 3. The goals of this study were to examine the association between the predictor variables of health literacy, and level of social support, on the outcome variable, patient activation, in community residing older adults.

Potential Threats to Reliability and Validity

Because a convenience sample was used, selection bias resulting from preexisting differences between groups must be considered (Polit & Tatano Beck, 2004). Differences in mobility, health concerns and socio-economic status may have contributed to selection bias.

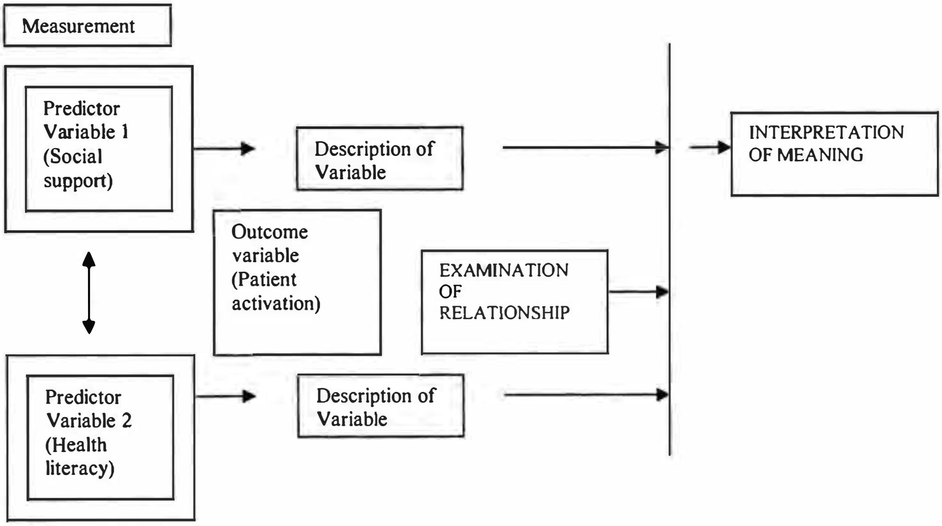

Figure 3. Descriptive correlational design

The data obtained through the survey tool was self-reported so recall bias and low reliability may have affected validity of the study findings. These factors must be considered when analyzing study data for reliability and validity. Due to the cross-sectional correlational design, causality between variables cannot be examined and the study did not provide information related to the longitudinal relationships between health literacy, social support and patient activation.

Independent Variable Measurement

The Short Form of the Test of Functional Literacy in Adults (S-TOFHLA) is designed to assess level of functional health literacy and takes approximately seven to twelve minutes to administer. It is available in 14-point font typeface, eliminating the need for visual acuity screening (Parker, Baker, Williams & Nurss, 1995). The S-TOFHLA is a 36 item test of reading comprehension using the modified Cloze procedure. This procedure omits every fifth to seventh word in a passage of writing and readers must choose one of four multiple choice options to correctly complete the passage. The writing passage is taken from instructions for preparation for a gastrointestinal (GI) series x-ray test at a fourth grade reading level and the patient rights and responsibilities portion of a Medicaid insurance form. Gunning Fog Index (Gunning, 1952) readability levels of the S-TOFHLA are grades 4.3 (GI series instructions) and 10.4 (Medicaid insurance information). The passages are organized by increasing difficulty (Parker et al., 1995).

Medicare Part-D was created to provide senior citizens with increased access to prescription medication with less out of pocket costs. Although the intention of this program was to make medications more affordable for the older adults, many seniors remain frustrated and baffled by the complexity of this insurance coverage and are experiencing catastrophic costs due to poorly explained benefits, confusing terminology and difficulty challenging or correcting errors in enrollment and benefits (Center for Medicare Advocacy, 2006). In order to explore and understand new and important health benefits, a portion of Medicare Part-D benefit information written at a 10th grade reading level was substituted for the Medicaid information on Part B of the S-TOFHLA.

Construct validity of the S-TOFHLA was ensured by use of actual hospital medical texts and insurance information. Concurrent validity was tested by administering two other assessments of literacy, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) and the Wide Range Achievement Test Revised WRAT-R (Wilkinson, 1984) reading subtest. The S-TOFHLA showed good correlation with the REALM and WRAT-R with correlation coefficients of r 0.74 and r 0.84, respectively. The measure showed good reliability (internal consistency) and correlations with the REALM at 0.80. Sub-scores of the Numeracy and Cloze sections were correlated with the REALM at 0.61 and 0.81 respectively. All correlations were significant at $p < 0.001$. Psychometric test data offers support to the validity and reliability of the S-TOFHLA measure. The S-TOFHLA has been widely used in studies on health literacy (Chew, Bradley, & Boyko, 2004; Silver Wallace & Lennon, 2004) and with older adults (Greene, Hibbard, & Tusler, 2005; Baker, et al., 2002; Baker, Parker, Williams, & Clark, 1998; Baker et al., 1997). Krause and Markides cited three major confounding issues that can make accurate measurement and definition of social support challenging: confounding potential vs actual support received, variation in individual support needs, and identification of the type of or dimensions of social support (1990). Measures can quantify the amount or evaluate the quality of social support. These tools can assist in the assessment of a specific social support structure such as family or friends, and functions, such as emotional or informational support (Dolbier & Steinhardt, 2000). In some studies perceived report was found to be more predictive of health outcomes than actual support (Cohen & Hoberman, 1983; Cohen & Wills, 1985; Wethington & Kessler, 1986; Helgeson, 1993).

Social support was measured by the Medical Outcomes Survey (MOS) Social Support Survey Instrument (Sherbourne & Stewart, 1991). This is a 20 item multi-dimensional, self-administered, questionnaire which measures both perceived functional and actual structural support. The first MOS Social Support Survey question addresses the notion of quantified support by asking the individual to give the number close friends and relatives they have that they can talk to, "About how many close friends and relatives to you have (people you feel at ease with and can talk to about what is on your mind)?" (Sherbourne & Stewart, 1991, p. 713). The tool was designed specifically for use with adults having chronic medical problems and has been used as a measure in several studies involving older adults (Greaves & Farbus, 2006; Kornblith et al., 2006; Lee, Gazmararian, & Arozollah, 2006; Michael, Allen, & Macko, 2006). A study validating the instrument was conducted based on data collected from 2987 subjects ages 18 and older. Multi-trait scaling analyses, a technique which test convergent validity, was conducted on questionnaire items on a hypothesized scale. This technique also tests discriminant validity of items in relation to other *a priori* scales. Confirmatory factor analysis was also used. Discriminant validity of social support subscales was tested by inspection of correlations between factors. Multi-trait correlation findings showed overlap between emotional support and informational support items so these were combined into a single scale labeled emotional/ informational support. One positive interaction item was a poor discriminator so it was deleted from the tool. All items showed a high correlation on the social support subscales ($\geq$0.72) which exceeded the convergent validity criterion (where correlations should be than $r = .30$). Discriminant validity criteria were met as these items were correlated by two standard errors on their own scale compared to any other social support scale. Results from confirmatory factor analysis showed similar results with a high correlation between emotional and information support (0.99). Internal-consistency reliability estimates exceeded for all support measures exceeded a 0.50 standard (Sherbourne & Stewart, 1991).

A large scale, cross-sectional study by Lee, Gazmararian and Arozullah (2006) examined health literacy, social support and their relations to health status and health care use in 3,260 elderly Medicare enrollees in a national managed care organization. The S-TOFHLA and the MOS Social Support Survey tools were used to measure the health literacy and social support constructs. As part of their methods of analysis, the authors tested whether the degree of social support was related to health literacy level using a Spearman's rho correlation (Chen & Popovich, 2002) and found no statistically significant interactions, which provides supportive evidence of the discriminant validity of the STOFHLA and the MOS Social Support Survey tools (Lee, Gazmararian, & Arozullah, 2006). These analyses show support for the psychometric soundness of the measurement tools selected.

Dependent Variable Measurement

In order to assess participants' self-reported knowledge, skill and confidence in health self-management, the Patient Activation Measure (PAM) Short-Form, a 13 item survey will be used (Hibbard et al., 2005). The original 22 item measure was tested for psychometric soundness in a study of 1515 adults via a telephone survey. The results of this survey showed a high reliability and validity. The PAM "...is a uni-dimensional, probabilistic, Guttman-like scale that reflects a developmental model of activation across four stages: (1) believing that the patient role is important; (2) having the necessary confidence and knowledge to take care; (3) taking action to maintain and improve health; and (4) staying the course even under stress" (Greene, Hibbard, & Tusler, 2005; p. 2). This scale was further refined in a recent article by the authors as follows: "Stage 1-does not yet understand an active role is important (score $\leq$ 47.0); Stage 2-lacks knowledge and confidence to take action (score $\geq$ 47.1 and $\leq$ 55.1); Stage 3- beginning to take action (score $\geq$ 55.2 and $\leq$ 67.0); and Stage 4- maintaining behaviors over time (score $\geq$67.1)" (Mosen, Schmittdiel, Hibbard, Sobel, Bellows; 2007, p. 23). The cut-points for these stages were developed using the SPSS program, Answer Tree, which employs an empirical technique to predict outcome variables using a continuous scale (M. Tusler, personal communication, July 10, 2007). In order to evaluate construct and criterion validity, the 22 conceptually related variables on the long form of the PAM were examined with the measured variables of activation to look for relationships. The authors hypothesized that higher levels of patient activation would be correlated with increased likelihood of engagement in specific self-care and preventative behaviors. In those with a specific chronic disease, the authors hypothesized that those individuals would be more likely to engage in self-care behaviors consistent with their specific condition. These hypotheses were supported by the results of the analyses. Individuals with higher activation scores were significantly more likely to exercise regularly, refrain from smoking, and consume more fruits and vegetables. The authors also found that in those with a specific chronic illness, measured activation levels were significantly associated with specific self-management behaviors.

The authors used these data again in testing development and testing of a short-form of the PAM. Iterative use of Rasch analysis was employed to identify items that could be deleted to shorten the tool. Rasch analysis uses a model in which "..the total score summarizes a person's standing on a variable. Thus the Rasch model is taken as a criterion for the structure of the responses which should be satisfied, rather than a mere statistical description of the responses". This model "..gives a range of details checking whether or not adding the scores is justified in the data which is called test of fit between the data and the model" (RUMM Laboratory, Rasch analysis, 2007, p.1). These items were deleted one at a time to ensure preservation of the precision and reliability of the measure. Following each deletion, item scale locations were recalibrated to assess for loss of measurement precision. Item fit values were within accepted range between 0.5 and 1.5. Construct validity was assessed and showed preventative behaviors, disease-specific self-management behaviors, and the consumeristic behaviors were all were strongly linked with activation scores with little difference in relationships regardless of whether the short form or the long form PAM was used. These analyses provide evidence that the 13 item short-form PAM is a reliable and valid measure of patient activation with a high degree of construct and criterion validity and it has also been tested with older adults (Greene, Hibbard, & Tusler, 2005; Hibbard, Mahoney, Stockard, & Tusler, 2005; Hibbard, Greene, & Tusler, 2005; Hibbard, Stockard, Mahoney, & Tusler, 2004).

Greene, Hibbard, and Tusler (2005) examined the relationship between health literacy and patient activation and the influence of each on the various areas that older adults have skill or knowledge to manage their health or health care. Using the original 22-item PAM and the STOFHLA, patient activation showed a slightly stronger relationship to health-care-related health and self-management behaviors than health literacy. The study also found an association between health literacy and patient activation with subjects who had adequate health literacy scoring an average of 3.5 points higher than those with barely adequate PAM scores and 7 points higher that those with inadequate and marginal health literacy levels. Secondary analyses were conducted to look for interactions between patient activation and health literacy to determine whether a combination of the two resulted in additional impact on the dependent variables, however the authors found no significant interaction terms.

Other Variables and Measures

Subjects then completed a demographic questionnaire. Included in this questionnaire were questions about age, educational level, gender, race/ethnicity, annual income, marital status, employment status, whether or not subjects are accompanied by someone at doctor's appointments, and participation in volunteer activities. In a study of health education preferences of older adults with low health literacy, Spears (2003) found that individuals with low health literacy preferred to have health information provided to them in the presence of a caregiver or presented directly to a caregiver. Kirsch et al., (1993) found that older adults who were active as volunteers had higher literacy skills compared with those who were unemployed or retired and not volunteering. Based on this information, questions relating to volunteerism and bringing a caregiver or significant other to doctor's appointments will be included in the demographic survey.

A question on self-rated health from the Short Form Health Survey (SF-36) was also used (Ware, Snow, Kosinski, & Gandek, 1997). The SF-36 is composed of 36 questions and measures individuals' self-reported perceptions about their physical and mental health. The tool is further subdivided into an eight-scale functional health profile. This tool was developed in response to a need for shorter surveys to avoid losing subjects to follow-up in health survey research. Several of the SF-36 survey questions have been used as scales or as individual questions in many studies for over 20 years. In a study on self-rated health and patient confidence, Rohrer et al. (2007) measured self-rated health by a single question and found that this proved to be significantly related to behavioral risk factors of subjects, which supported its use as an outcome indicator. One question, from the SF-36, "In general, would you say your health is: excellent, very good, good, fair or poor, was used to measure self-rated health. The

SF-36 has been frequently used in studies with older adults (Das, Wilcoxson, Corrado, & West, 2007; Parker, Bechinger-English, Jagger, Spiers, Lindesay, 2006; Kuo, Raji, Peek, & Goodwin, 2004; Hayes, Morris, Wolfe, & Morgan, 1995).

Subject Fatigue

Subject fatigue can occur with lengthy surveys and limiting survey time is suggested as an important strategy to consider when surveying older adults (O'Brien King & Pettigrew, 2004). The attention span of the older adult is between 20-40 minutes (Mauk, 2006). Length of time to complete the tool was tested with a small pilot group and on average was 30-35 minutes. The combined length of the health literacy test and survey tool is within accepted time ranges for older adults.

Strategies for Elder Friendly Survey Design

In order to accommodate for common age-related changes in vision, certain simple modifications can make written materials easier to read for older adults. These modifications include use of sans serif type such as Arial and Helvetica, and use of 12 or 14 point font type size for body text (Hartley, 1999; Echt, 2002). Body text should be presented in upper and lower case letters using capital letters and italics in headlines only. All body space should be double spaced and left justified. Use of active voice and simple text are helpful. Dark typeface on a white background and avoiding yellow and blue and green in close proximity are also recommended. Inclusion of elder friendly design principles into survey development is essential to research with older adults. These recommendations were incorporated in the development of the survey tool to enhance readability and usability for study participants.

Procedures

All data will be maintained by the principal investigator in a double locked file cabinet. No other individuals will be permitted to have access to the research data other besides the dissertation chair and committee members.

One research assistant was used to assist in data collection. The research assistant received training on human subjects' protection, confidentiality, and proper procedures to avoid bias in data collection as per the VCU Course in the Protection of Human Research Subjects (CITI). The research assistant was observed while collecting data on a pilot sample of three subjects to test for intra-rater consistency.
During each trial, the assistant asked the SPMSQ inclusion criteria questions of her pilot subjects and was then observed while she conducted the S-TOFHLA test. These observations helped to ensure intra-rater consistency in the data collection process.

Participant Instructions and Timing

After obtaining participants' consent to participate in the study and determining that subjects met the outlined inclusion criteria, subjects completed the S-TOFHLA. Subjects were then given the survey tool. Subjects were encouraged to answer all questions however, they were told that they could skip any question(s) that they wished. A trained research assistant was available to answer questions that subjects may have during the survey. The survey took approximately 30 minutes to complete. Upon completion of the survey subjects were given a ten dollar gift card to a local grocery store which served as a nominal incentive for participation. This incentive was well received by participants.

Participant Contacts

The principal investigator served as the participant contact for the study. Contact information was provided to study participants so that they could speak with the researcher's advisor regarding any questions or concerns about the study as per Virginia Commonwealth University's Institutional Review Board policies.

Debriefing

All subjects were informed that they may request a copy of the final summarized data and conclusions. No individual debriefings took place.

Analysis

Upon completion of data collection, data was statistically analyzed using descriptive and multivariate statistical methods. The outcome variable was patient activation, and the predictor variables were social support and health literacy. Results of these analyses are outlined in Chapter Four.

Data Cleaning and Screening

The Statistical Package for Social Sciences (SPSS) version 15.0 was used as the program for data analysis. Data were entered and cleaned by running frequency tables to look for any data that were misclassified or improperly coded. Missing data can be a frequent problem in research (Horton & Kleinman, 2007). This may occur due to subjects' declining to provide some values or removal of information due to privacy concerns. The more data that are missing, the greater the likelihood that the issue of incomplete cases will need to be addressed. Several options exist for handling missing data and these approaches are selected based on several factors including the size of the data set being analyzed and the statistical technique being used (Horton & Kleinman, 2007). Mean substitution is a commonly accepted method for handling missing data. In this method, a variable's mean is calculated based on available cases and is used to fill in the values of the missing cases which should avoid skewing the data. Mean substitution was used to address the issue of missing data in the PAM and MOS-SS components of the survey. Specifically, missing cases where mean substitution was used were as follows: PAM question four (three cases), question eight (one case), question ten (one case), question 11 (one case), question 13 (three cases); MOS-SS question two (one case), question four (one case), question five (two cases), question six (one case), question seven (one case), question 8 (one case), question nine (two cases), question 11 (three cases), question 12 (one case), question 13 (one case), question 14 (two cases), question 15 (four cases), and question 16 (three cases). If more than one third of the data for a given case are missing for a particular research item, the item may need to be deleted from the data analysis. Next inter-rater reliabilities were conducted on all data.

Descriptive Analysis

Descriptive statistics provided information about age, educational level, gender, race/ethnicity, self-rated health, income, marital status, retirement status, volunteerism, and whether or not individuals have someone accompany them and stay with them at health care appointments. These data provided information about the characteristics of the sample.

Hypothesis Testing

Correlational statistical techniques are used to examine relationships between variables. They can be used to determine whether relationships exist and to test hypotheses (Munro & Page, 1993). Correlations can also be used to judge the strength of relationships but cannot show causality since other factors may be affecting the variables under consideration. In order to calculate *r*, certain assumptions must be made and these include that the study must have a minimum of two measures on each subject, usually at the interval level, the sample should be representative of the population to which the inference will be made and each of the variables being correlated must be normally distributed and should have homoscedasticity (equal variability) (Hair, Anderson, Tatham, & Black, 1998). The relationship between the two variables must be linear (i.e., when viewed on a scatter plot). Frequency distributions were done to verify whether or not these assumptions have been met. If any of the assumptions are violated, data transformations, such as square root or logarithmic transformations may be required to achieve normality, homoscedasticity, or linearity.

Pearson's Product Moment correlation coefficient (*r)* was used to test for correlation between the variables of social support and patient activation, and health literacy and patient activation (Hypotheses One and Two). Social support was measured by the MOS Social Support Survey which measure perceived social support using a 20 item, interval scale. Health literacy was measured by the S-TOFHLA which measures degree of health literacy using a 36 item summated interval scale. Patient activation was measured by the PAM, a 13 item interval scale measuring knowledge, skill, and confidence in ability to self-manage health which meet the metric requirement for Pearson's Product Moment correlation coefficient.

Multiple linear regression is a statistical technique by which a regression equation is developed and used to predict the values of a dependent variable for a specific population or to explain causal relationships among variables (Mertler & Vannatta, 2002). It is particularly appropriate when a measurable multiple correlation between a group of predictor variables and one dependent variable exists (Munro & Page, 1993).Independent variables are selected and used one after the other based on their ability to account for the greatest variance in the dependent variable. Independent variables can vary in level of measurement (nominal to ratio), however, outcome variables should be measured at interval or ratio level. The outcome variable, patient activation is an interval level scale which meets the metric requirement for linear regression. When the outcome variable is entered into the regression equation, the relationships between the predictor variables and the outcome variables are evaluated. The regression model is complete after all the relationships of interest are tested. Multivariate linear regression analyses was used to analyze the variable of health literacy and whether or not this variable account for a significant part of the variance in older adults' level of patient activation (Hypothesis Three).

Secondary analyses were conducted to determine which of the two predictor variables (health literacy and social support) accounts for the greatest proportion of the variance or is the strongest predictor of variance. This was done using beta *(b)* weight which is the standardized regression coefficient (Munro & Page, 1993). "Beta reflects of the actual measure with its associated mean and standard deviation" (p.203). Beta is considered to be a measure of the relationship between and predictor and outcome variable with the influence of the other independent variable held constant (partial correlation coefficient).

Error (Residual) Score Assumptions

Error or residual scores assumptions are the difference between the actual observed score of a subject on a particular criterion and the predicted regression equation score (Licht, 1995). It is preferred that these error scores "...(a) have a mean of zero; (b) are homoscedastic (i.e., have equal variances at all values of the predictors); (c) are uncorrelated with each other and with the predictors; and 9d) are normally distributed" (p. 49). Moderate violations of these characteristics tend not to be problematic.

Summary

The research question for this dissertation (as presented in chapter one) is: what are the relationships among health literacy, social support and patient activation in community residing older adults? Results of this question offer the opportunity to learn more about factors that may mediate the impact of low health literacy (Lee et al., 2004). In addition, new information about the relationships among health literacy, social support and patient activation has the potential to decrease health care costs associated with the problems of low health literacy and chronic illness, which are so prevalent in our society (Williams et al., 2002; Howard et al., 2005). The study methodology required the use of data from community residing, older adults with chronic health problems. In order to participate in the study, subjects had to be aged 62 years or above, able to read English, with adequate cognition (as measured by the SPMSQ).

The predictor variables of interest were health literacy and social support and the outcome variable is patient activation. The descriptive, correlational design allowed analysis of variables of health literacy and social support and whether or not these variables accounted for a significant part of the variance in older adults' patient activation. Table 1 provides a list of the independent and dependent variables and Table 2 offers a summary of the data analysis plan.

Table 1

Variables for study of health literacy, social support, and patient activation

Predictor variables	**Operationalization for Measurement**	**Scale**
Health literacy	S-TOFHLA	Interval
Social support	Medical Outcomes Study (MOS), Social Support Survey Instrument	Interval
Control variables	**Operationalization for Measurement**	**Scale**
Age	Demographic tool	Interval
Gender	Demographic tool	Dichotomous
Marital Status	Demographic tool	Categorical
Education	Demographic tool	Categorical
Self-rated health	Demographic tool	Interval
Outcome Variable	**Operationalization for Measurement**	**Scale**
Patient activation	Patient Activation Measure (PAM) Short Form	Interval

Table 2

Data Analysis Plan

Statistical test	**Variable tested**
General data procedures	Clean and screen data by running frequency tables, test for inter-rater reliabilities
Descriptive statistics	Demographic variables
Pearson's Product Moment correlation coefficient (*r*)	To test whether social support and health literacy are related to patient activation and if so, what is the strength of these relationships
Multiple linear regression	To analyze factors accounting for a significant part of the variance in subjects' patient activation level
Beta weight	To analyze which of the two independent variables (social support or health literacy) account for the greatest proportion of the variance

Justification for the study is found in Bandura's Social Cognitive Theory (SCT) (Bandura, 1997). As outlined in chapter two, SCT demonstrates the triadic, reciprocal nature of the factors of health literacy (personal), social support (environmental) and patient activation (behavioral).

CHAPTER 4: RESULTS

Sample Characteristics

The settings for the study were subsidized, elder apartment housing in a five-city area in Luzerne County, Pennsylvania. One hundred and twelve individuals consented to participate in the study. Two persons were excluded because of severe visual impairment and seven persons were excluded due to having greater than two errors on the Short Portable Mental Status Questionnaire scoring indicating mild to moderate cognitive impairment. One hundred and three individuals met the inclusion criteria and were enrolled as subjects in this study. Of these, thirteen subjects were eliminated from analysis due to large amounts of missing data (one or more pages of survey tool questions missing). Missing data were analyzed for patterning but none emerged. The group ranged from 62 to 91 years of age with a mean age of 77 years. Due to a few cases with missing demographic variables, the N changes slightly in the analyses conducted. Eighty subjects were female, 10 were male and all were of Caucasian origin. Subjects reported level of education as follows: 18.4% less than high school, 48.5% high school diploma, 17.5% some college or vocational school, and 2.9% college graduate or higher. The majority of subjects, (67%), reported an annual income of <$15,000 per year, 16.5% reported $15,000 -$24,999, while 1.0% reported an annual income of $35,000 or greater. Demographic information showed that 10.7% of subjects were never married, 16.5%

were divorced, 1.9% were separated, 51.5% were widowed, and only 5.8% were married.

Table 3

Demographics for Study Sample

Factor	(n=90)	%
Age: (years; Mean ± SD)	77.17 ± 7.2	
SPSMQ: (Mean ± SD)	.76 ± .75	
Gender	80 females; 10 males	
Race/Ethnicity	90 Caucasian	
Marital status (N = 89)		
Never married	11	10.7
Divorced	17	16.5
Separated	2	1.9
Widowed	53	51.5
Married	6	5.8
Level of Education		
Less than high school	19	18.4
High school grad	50	48.5
Some college/vocational school	18	17.5
College graduate or more	3	2.9
Annual Income		
< $15,000	69	67.0
$15,000- 24,999	17	17.0
≥$25,000	1	1.0
Retired(N = 89)		
Yes	86	83.5
If not retired, employed? (N= 89)		
Part-time	2	1.9
Full-time	1	1.0
Volunteer		
Yes	39	37.9

About half of the sample reported going to doctor's visits alone (49.5%), while 29.1% went with a family member, 6.8% with a friend, and 1.1% reported being accompanied by a paid caregiver. Of those who reported being accompanied to the doctor's office for visits, 21.4% reported that these individuals stayed in the waiting room, while 17.5% reported that they were accompanied into the examination room for doctor's visits. These results are shown in Table 4.

Table 4

Additional Demographic Information Table

Factor	Frequency	Percent	N
Do you go to doctor's visits:			89
Alone	51	57.3	
With family member	30	33.7	
With a friend	7	7.9	
With paid Caregiver	1	1.1	
If someone accompanies you, do they:			90
Stay in waiting room	22	21.4	
Go with you into exam room	18	17.5	

Results Related to Hypothesis One:

Social support is positively related to patient activation.

Chronbach's alpha was conducted to assess internal consistency and reliability for the social support index and four subscales. Results indicated that these measures had a high level of internal consistency and reliability (social support index , alpha (α) .961; emotional/informational, alpha (α) = .931; tangible, alpha (α) = .883; positive interaction, alpha (α) = .830; and affection, alpha (α) = .900) shown in Table 5 with descriptive data.

Table 5

Descriptive Statistics for Social Support Measure; N = 90

Measure	Number of items	Mean	Standard Deviation	N	Alpha (α)
Emotional /info support (+)	8	78.93	29.43	90	.931
Tangible support (+)	4	58.48	33.09	90	.883
Positive interaction (+)	3	76.42	29.43	90	.830
Affection (+)	3	81.77	27.34	90	.900
Overall support index (+)	19	71.00	17.85	90	.961

Alpha (α) = Chronbach's internal-consistency reliability coefficient; (+) A high score indicates more support.

The sample reported moderate levels of social support on the overall social support index with a mean of 71.00 (± 17.85). The group also reported a mean number of five close friends and five close relatives that they felt they could "talk to about what was on their minds" as shown on Table 6.

The Chronbach's alpha coefficient was also computed for the Patient Activation Measure (PAM) which demonstrated a high level of internal consistency and reliability (alpha .924) and is found in Table 7 with descriptive statistics for this computation.

A frequency distribution indicated the sample reported low levels of patient activation. Seventy-two subjects were at Stage 1 of activation (does not yet understand an active role is important) and 18 subjects were at the Stage 2 level of activation (lacks knowledge and confidence to take action).

Table 6

Descriptive statistics for study sample for MOS Social Support Measure Questions 1a and 1b; N =90

Factor	Mean (S.D.)	Range
1a) About how many close friends do you have (people you feel at ease with and can talk to about what is on your mind?)	5.30 (4.60)	0-20
1b) About how many close relatives do you have (people you feel at ease with and can talk to about what is on your mind?)	5.26 (4.83)	0-30

Table 7

Descriptives statistics for Patient Activation Measure; N = 90

Measure	Number of items	Mean	Standard Deviation	Observed Range	Alpha
Patient Activation	13	64.23	15.66	33-52	.924

Alpha = Chronbach's internal-consistency reliability coefficient; A high score indicates more activation.

None of the subjects were found to be at Stage 3 (beginning to take action) or Stage 4 (maintaining behaviors over time) of activation. This frequency distribution is shown in Table 8.

The Pearson correlation coefficient is used to determine the strength of the linear relationship between two variables (Cronk, 2004) and was used to test Hypothesis

Table 8

Frequency table for Stages of Activation; N = 90

Stage of Activation	Frequency	Percent
Stage 1	72	80
Stage 2	18	20
Stage 3	0	0
Stage 4	0	0
Total	90	100

One. As shown in Table 9, the correlation was not statistically significant ($r = .128, p > 0.01$), indicating that there was no linear relationship between the two variables.

Table 9

Intercorrelations Between Measures for Community-dwelling Older Adults; N = 90

Measure	1	2	3	4	5
Patient activation	-	.128	*.246	**-.289	**-.286
Social support		-	.107	-.014	*-.215
Health literacy			-	-.129	*-.208
Age				-	.132
Self-rated health					-

1 = patient activation, 2 = social support, 3 = health literacy, 4 = age, 5 = self-rated health; ** Correlation is significant at the 0.01 level (1-tailed); * Correlation is significant at the 0.05 level (1-tailed).

Social support subscales and patient activation were also examined in a one-tailed, Pearson correlation coefficient matrix. No correlation was found (emotional/info support ($r = .180$, $p > 0.01$); tangible support ($r = .143$, p 0.01); affection support ($r = .091$, $p > 0.01$); positive social interaction support ($r = .161$, $p > 0.01$) indicating that no linear relationship was shown between any the four social support subscales and patient activation as shown in Table 10.

Table 10

Intercorrelations Between Social Support Subscales and Patient Activation Measures for Community-Dwelling Older Adults; N = 90

Measure	1	2	3	4	5	6	7
Patient activation	-	.180	.143	.091	.161	.123	.128
Emot/ Information Support		-	**.357	**.558	**.545	**.470	**.749
Tangible Support			-	**.564	**.534	**.439	**.702
Affec/ Support				-	**.652	**.450	**.739
Positive Soc/ Interaction Support					-	**.574	**.751
Additional Item Support						-	**.773
Social Support Overall Index							-

1 = patient activation, 2 = emotional/information support, 3 = tangible support, 4 = affectionate support, 5 = positive social interaction support, 6 = additional item; 7 = overall index of social support ; ** Correlation is significant at the 0.01 level (1-tailed); * Correlation is significant at the 0.05 level (1-tailed).

All Social Support subscales were significantly correlated with each other and with the overall Social Support Index. Although Hypothesis One was not supported, level of education was significantly and positively correlated to social support ($r = .206$, $p < 0.05$), and interestingly, social support was significantly and negatively correlated with self-rated health ($r = -.215$, $p < 0.05$)..

Results Related to Hypothesis Two:

Health literacy is positively related to patient activation.

Descriptive statistics indicate the sample had a high level of health literacy overall. One percent of the sample population had inadequate health literacy, 4% had marginal health literacy, and 83% were found to have adequate health literacy. These findings are outlined in Table 11.

Table 11

Descriptive Statistics for Health Literacy; N = 90

Level of Literacy	Frequency	Percentages
Inadequate	1	1.1
Marginal	4	4.4
Adequate	85	94.4
Total	90	100.0

One-tailed Pearson correlation coefficient was calculated to examine the correlation between health literacy and patient activation. Health literacy was significantly and positively correlated to patient activation ($r = .246$, $p < 0.01$) (see Table 9). The Chronbach's alpha coefficient was also computed to assess internal consistency and reliability of the Short form of the Test of Functional Health Literacy (STOFHLA) and its subtests, Part A, and Part B. Results support the high level of internal consistency and reliability of these measures (STOFHLA, alpha .872; STOFHLA Part A, alpha .739; STOFHLA Part B, alpha .854) and are found in Table 12.

One-tailed Pearson correlation coefficient was calculated to examine the correlation between patient activation and health literacy subscales (S-TOFHLA Part A & B). Health literacy was significantly and positively correlated to patient activation (r = .246, $p < 0.01$) and the S-TOFHLA subscale Part A (r = .813, $p < 0.01$) and Part B (r = .923, $p < 0.01$)were highly correlated to the S-TOFHLA overall measure (see Table 12).

Table 12

Chronbach's internal-consistency reliability coefficient table for the S-TOFHLA and its sub-tests A and B

Measure	Alpha
Health Literacy (STOFHLA)	.872
STOFHLA Part A	.739
STOFHLA Part B	.854

Alpha = Chronbach's internal-consistency reliability coefficient

The S-TOFHLA subscale Part A (r = .145, $p < 0.01$) was not correlated with patient activation, but the Part B (r = .270, $p < 0.01$) showed a significant correlation with patient activation (see Table 13).

Results Related to Hypothesis Three:

Health literacy will account for the greater amount of variance in patient activation.

When independent variables are strongly correlated with dependent variables in a regression equation, multicollinearity is said to exist. This can be problematic as multicollinearity decreases the power of significance tests by increasing sampling error of coefficients, and cause the signs of coefficients to be incorrect. Large changes can occur in calculation of coefficients with the removal of a single observation (Burns & Grove, 1993). Multicollinearity is considered to exist if bivariate correlation exceeds .65 while other sources suggest that a correlation of .80 or greater is viewed as an marker of multicollinearity (Schroeder, 1990).

Table13

Intercorrelations Between Patient Activation Measures and S-TOFHLA Part A and Part B Subscales for Community-dwelling Older Adults; N = 90

Measure	1	2	3	4
Patient Activation	-	**.246	.145	**.270
S-TOFHLA Overall Score		-	*.813	**.923
S-TOFHLA Part A			-	**.528
S-TOFHLA Part B				

1 = patient activation, 2 = ,S-TOHFLA Overall Score, 3 = S-TOFHLA Part A, 4 = S-TOFHLA Part B; ** Correlation is significant at the 0.01 level (1-tailed).

Since the Pearson correlation coefficients were < .30, no further analysis to assess for multicollinearity was required.

A multiple linear regression analysis was performed to assess whether health literacy or social support accounted for the greater part of the variance in the analysis. The dependent variable for the regression was patient activation and the independent variables age, level of education, gender, marital status, and self-rated health were then entered in as a block in model one. Then the S-TOHFLA (health literacy) variable was added to the regression to create model two, and finally, the MOS-SS (social support) variable was added to create model three. Model one showed a significant regression equation (F (5, 83) = 4.07, $p < .002$), with an R^2 of .197 and this model explained 20% of the variance. Of the blocked descriptive coefficients, age ($\beta = -.297$, $p < .006$), gender ($\beta = .207$, $p < .051$), and self-rated health ($\beta = -.250$, $p < .021$), were significant as shown in Table 14.

Table 14

Summary of Model 1 Blocked Descriptive Coefficients

	Standardized Coefficients Beta	t	Sig
(Constant)	_	3.717	.000
Age	*-.297	-2.807	.006
Level of Education	-.041	0.380	.705
Gender	*.207	1.979	.051
Self-rated health	*-.250	-2.346	.021
Current marital status	.049	0.475	.636

The histogram in Figure 3 illustrating the distribution of the Model 1 regression shows a relatively normal distribution with a slight positive skew. Based on these findings, further error (residual) score analysis were performed. Model two (F (1,

82) = 1.83, $p > .01$), and model three (F (1, 81) = 0.19, $p > .01$), were not significant. The total regression equation in model three explained 22% ($R^2 = .216$) of the variance. A comparison of beta weights showed that health literacy explained a greater proportion of the variance in patient activation ($\beta = .145$) when compared with social support as seen in model three ($\beta = .044$) but these models were not statistically significant so therefore, the null hypothesis cannot be rejected. A regression matrix is shown in Table 15.

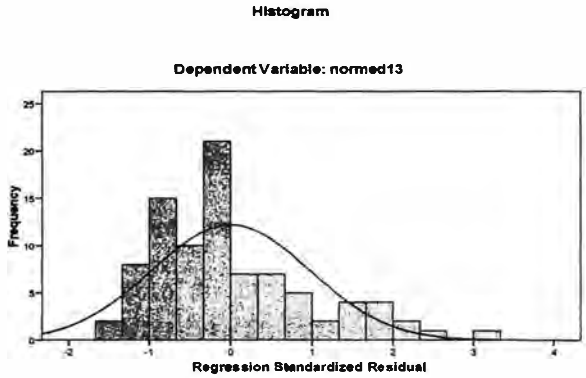

Figure 3. Frequency Histogram of Distribution Model 1

Table 15

Summary of Hierarchical Regression Analysis; N = 88

Model	R	R Sq	R Sq Change	F Change	df1	df2	Sig. F Change	β	Sig.
1	.444	.197	.197	4.071	5	83	.002	-	-
2	.463	.214	.018	1.830	1	82	.180	.145	.180
3	.465	.216	.002	0.190	1	81	.664	.044	.674

CHAPTER 5: DISCUSSION AND LIMITATIONS

Low health literacy affects approximately half of all adults in the U.S. Previous research has been focused on identifying the scope and breadth of the problem of low health literacy but little information exists regarding factors which may ameliorate the negative effects of this problem. The purpose of this study was to examine the relationships among health literacy, social support and patient activation in community residing older adults and to determine which of the two predictor variables, health literacy or social support account for the greatest proportion of the variance in the outcome variable patient activation.

Social Support

In the current study, on average subjects reported moderate to high levels of social support. An interesting finding of the study was that self-rated health was significantly and negatively correlated to social support. One explanation for this finding may be that individuals who receive higher levels of social support have a greater awareness of the problems associated with their health status. Another explanation to consider is that as an individual's health status worsens, the demands placed on the social support network increase which could overwhelm those providing the support and support could therefore drop off or be lost altogether. Lee, Gazmararian, and Arozullah examined health literacy, social support, and their relation to health status and health care usage among older adults. As with this study, the authors' sample group was skewed with a larger proportion of subjects having high health literacy. These results have some congruency with the findings of this current study. In another recent study examining the role of low literacy and social support in predicting preventability of hospital admissions, Arozullah et al. (2005) found that although social support is thought to have a positive influence on health care utilization, their study found an increased likelihood of preventable hospitalizations in individuals who interacted with 12 or more people weekly. The authors posited that individual may rely on support or counsel from larger social networks instead of established health care settings. The authors concluded that future studies should not only evaluate the presence or absence of social support, but should also evaluating various ways that social support is utilized by individuals.

Social support includes a structural component (participation in community groups, maintaining social contacts, engagement in social networks) as well as functional support (eg. information and emotional support). While it has been theorized that these forms of support could provide some mediation for the effects of low health literacy by causing persons to adopt positive health norms and standards of a social group, Lee, Arozullah, and Cho (2004) note that it is important to consider, conversely, association with certain social groups could potentially reinforce negative health attitudes or behaviors such as tobacco use or excessive alcohol use. Being part of a low-education social network could reinforce low literacy or poor health practices and perceptions which may offer another explanation for the negative correlation between social support and self-rated health however this seems unlikely given that study findings showed that level of education was significantly and positively correlated with social support and participants had higher levels of education.

Half of the sample reported going to doctor's visits alone. Of those who were accompanied to doctor's visits 21% reported having the person accompanying them stay in the waiting room while 18% reported having someone accompany them into the exam room for the doctor's visit. For individuals with low health literacy, this support could be invaluable. Having another person with a higher health literacy level present to reinforce key information and instructions from the doctor's visit could potentially help avoid negative outcomes such as medication and treatment errors which are associated with low health literacy and should be considered in future intervention studies.

Social support was not significantly correlated to patient activation indicating that according to this study, social support is not a strong factor in patient activation. Therefore the study must fail to reject the null hypothesis for Hypothesis One. In this study, social support was not linked to patient activation, nor was it linked to health literacy.

Health Literacy

Overall, the study showed that the participants in the study had adequate levels of health literacy. This is surprising given the age, level of education and income levels of participants since the literature indicates that older age, low levels of education and low income are major risk factors for low health literacy (Kirsch et al.,1993; Williams, et al., 1998; Gazmararian et al., 1999; Beers et al., 2003). One issue to consider when interpreting these results is that the Part B of the STOFHLA (Short form of the Test of Functional Health Literacy) was altered to include information on Medicare Part-D benefits. The Chronbach's Alpha (internal consistency) for the original, nationally normed, Part B of this instrument was 0.97.The modified version used for this study had a Chronbach's Alpha (internal consistency) of .854. Given these values, it seems unlikely that use of the modified instrument contributed to this scoring pattern.

Level of education was significantly and positively correlated to health literacy. While level of formal education attained does not serve as an accurate proxy for health literacy, lower levels of education tend to be associated with low health literacy (Gazmararian et al.,1999).

Volunteerism has been associated with higher levels of health literacy (Kirsch et al., 1993) and 38% of participants in this study reported volunteering which is consistent with the literature. As with social support, self-rated health was significantly and negatively correlated with health literacy. Poorer self-rated health has been independently associated with low health literacy (Weiss, Hart, McGee, & D'Estelle, 1992). Given the high level of health literacy of the sample overall, this finding is puzzling. It is conceivable that increased knowledge and health awareness may have had a negative effect on participants' self-perceptions of health through a more realistic appraisal of health status. An alternate explanation could be that as health declines, individuals have more encounters within the health care system and with health care providers. Additional education and teaching received during or as a result of these encounters could potentially increase levels of health literacy.

Health literacy was positively and significantly correlated with patient activation. Therefore, Hypothesis Two is supported and the null hypothesis must be rejected. This finding is consistent with previous studies in the literature (Greene, Hibbard, Tusler, 2005) and future studies should further examine the relationship between these two variables.

Patient Activation

In this study, subjects had low levels of patient activation overall. Results showed that the majority of subjects (70%) were at Stage 1 of activation (does not yet understand an active role is important) and 20% were at Stage 2 of activation (lacks knowledge and confidence to take action). As with social support and health literacy; self-rated health was also significantly and negatively correlated with patient activation. Age and patient activation were significantly and negatively correlated. As age increased, patient activation level decreased. Given that many older adults come from a different paradigm where they have been more passive recipients of care as opposed to active actors in health care exchange, this study's findings seem consistent (Lorig, 1996) and supportive of previous findings in the literature which showed that age was negatively correlated with patient activation (Greene, Hibbard & Tusler, 2005). Since patient activation is predictive of health care outcomes such as preventative health behaviors, this has negative implications for older adults.

Model One in which the outcome variable patient activation, was blocked with the independent variables age, gender, current marital status, level of education, and self-rated health was significant (F (5, 83) = 4.07, p <.002), with an R^2 of .197 and explained 20% of the total variance. The predictor variable health literacy was added in Model Two (F (1, 82) = 1.83, p > .01), and then the predictor variable social support added in Model Three (F (1, 81) = 0.19, p > .01). Neither Model Two nor Model Three were significant. The regression in Model Three included all the variables listed above explained 22% (R^2 = .216) of the total variance.

A comparison of beta weights was done to determine whether health literacy was a better predictor of patient activation compared with social support. This comparison showed that health literacy explained a slightly greater proportion of the variance in patient activation (β = .145) when compared with social support as seen in Model Three (β = .044) however, since Models Two and Three were not statistically significant, the null hypothesis cannot be rejected. These findings suggest that future research should include variables of age, gender, self-rated health in predictive modeling. Social support may not be related to patient activation.

The regression equation was only able to explain 20% of the total variance in patient activation. Since only a small proportion of the variance was explained, further studies should be done to validate these results before designing intervention level studies. It is possible that changing the Part B of the S-TOFHLA test was a confounding factor in these results. Future studies with side by side comparisons of the current and modified S-TOFHLA and other literacy instruments would be helpful. Interestingly, the modified Part B of this tool showed a statistically significant correlation with patient activation while the Part A did not. This would suggest that further piloting and refining the Part B tool should be done. This may offer more sensitive measures of older adults' health literacy and patient activation in future studies.

Another aspect to consider is that this study utilized the Medical Outcomes Survey Measure of Social Support. Although the literature indicates that in some studies, perceived support was more predictive of health outcomes than actual support (Cohen & Hoberman, 1983; Cohen & Wills, 1985; Wethington & Kessler, 1986; Helgeson, 1993), the MOS-SS instrument was chosen due to the fact that it is a broad measure which includes both tangible and perceived support. It is possible that the measure didn't adequately capture data related to this variable since it was a global measure of support. It would be helpful to compare the MOS-SS with a tool measuring perceived support only in future studies to evaluate any differences in study outcomes.

Relationship to Social Cognitive Theory

Social Cognitive Theory (SCT) was proposed in Chapter Two as a means of conceptualizing the relationships among health literacy, social support and patient activation, and how these relationships might impact on self-management of health. Data produced from this study suggests that the notion of reciprocal determinism ("...the continuing interaction among the characteristics of a person, the behavior of that person, and the environment within which the behavior is performed..", Baranowski, Perry, Parcel, 2002, p. 168) has merit. When one of these components change, the other components will be altered as well. Therefore, when health literacy changes, social support and patient activation, and their sub-components will change too. What is less clear is why perceptions of health decreased as health literacy, social support and patient activation increased. While these relationships are dynamic and supportive of SCT, the direction of the change remains puzzling. Use of the SCT framework in larger scale future studies might offer more insight into these findings and the directionality of the relationship changes.

Limitations

This study had several limitations which must be considered when evaluating these results. Shame and stigma are frequently associated with the problem of low literacy. Previous studies indicate that almost half of those with low literacy feel a sense of shame about their reading difficulties (Parikh, Parker, Nurss, Baker, & Williams, 1996). Those with low health literacy may have self-selected not to participate in the study due to the shame and stigma of this problem. This suggests that new strategies should be developed to improve recruitment of this at risk population. Further, not only should various methods of testing low health literacy be trialed to determine which are most sensitive and specific in identifying low health literacy in elders, but also, which are most acceptable and least threatening to individuals with this problem.

Only community dwelling older adults were included in the study. Pennsylvania has a disproportionately higher percentage of older adult residents in comparison to other states. A convenience sample was used and non-English speaking individuals were excluded. These factors, in addition to differences in socio-economic status, mobility and health will limit generalizability of study findings.

Since data were obtained through self-report, recall bias and low reliability may have affected the validity of these study findings. Causality between variables cannot be examined since a cross-sectional correlational design was used so the study did not provide longitudinal information about relationships among health literacy, social support and confidence and patient activation.

The data revealed that participants in the sample were a relatively homogenous group. The group had fairly high levels of health literacy when compared to national data. Also, all participants in the study identified their racial/ethnic group as "Caucasian" so minority elders were not part of the sample. Additional questions to consider include how does the nature of social support change once persons become ill or engaged in the health care system?

Conclusions and Directions for Future Research

Additional information regarding the relationships among health literacy, social support and patient activation were provided by this study. Although contradictory to some findings in the literature, the results of this study do not support the use of social support and health literacy as predictors of patient activation and raises new questions about whether health literacy and social support affect patient activation. Additional questions to consider include how does the nature of social support change once persons become ill or engaged in the health care system? Future research should include measurement of levels of stress and coping. Self-efficacy should be explored as a main variable for future studied as this may offer a better linkage to patient activation compared to social support.

The results also suggest that examination of psychological or disease factors should be considered in future research studies. It would be important to consider adding psychological or disease factors (SF-12 or 36) and objective health status measures (HgA1C) into future regression formulas to better isolate health status. Including measures of health service utilization (inpatient vs outpatient; number of prescriptions filled) may also provide useful information.

Additional multi-site, larger scale studies over a more comprehensive area are recommended and this would assist in the recruitment of subjects with greater diversity in all areas including level of education and literacy, socioeconomic status, race and ethnicity which could then inform future intervention studies.

Although health outcomes were beyond the scope of this study, stage-specific interventions focused on increasing patient activation (Hibbard & Tusler, 2007) with information graded to appropriate health literacy level should be included in future studies. It would be helpful to consider more generalized interventions as opposed to disease specific interventions since many individuals have multiple co-morbid conditions which may not be adequately addressed in single disease focused models. The Chronic Disease Self-Management Program (CDSMP) (Lorig, Sobel, Ritter, Laurent & Hobbs, 2001) offers some promise for these types of interventions. The program has some limitations in that improved health behaviors have not been universal among participants in the course but further development of the program could be done to further address these limitations (Hibbard, Mahoney, Stock, & Tusler, 2006). This approach would assist in working toward the goal of improvement of health outcomes for older adults with low health literacy. An incremental change approach focused on small gains is also recommended. By designing customized approaches to individuals with low health literacy, the deleterious effects and negative outcomes of this problem may be comprehensively addressed.

REFERENCES

Arnold, R., Ranchor, A.V., DeJongste, M.J., Koeter, G.H., Ten Hacken, N.H., Aalbers, R., Sanderman, R. (2005). The relationship between self-efficacy and self-reported physical functioning in chronic obstructive pulmonary disease and chronic heart failure. *Behavioral Medicine, Fall, 31* (3), 107-115.

Arora, N., McHorney, C. (2000). Patient preferences for medical decision-making: Who really wants to participate? *Medical Care, 38,* 325-341.

Arozullah, A.M., Lee, S.D., Kahn, T., Kurup, S., Ryan, J., Bonner, M., Soltysik, R. (2005). The roles of low literacy and social support in predicting the preventability of hospital admission. *Journal of General Internal Medicine, 21*, 140-145.

Artinian, N.T., Lange, M.P., Templin, T.N., Stallwood, L.G., Hermann, C.E. (2002). Functional health literacy in an urban primary care clinic. *Internet Journal of Advanced Nursing Practice, 5* (2), 24-37.

Ashcroft, J., Leinster, S., Slade, P. (1986). Mastectomy vs breast conservation: Psychological effects of patient choice of treatment. In: Watson, M., Creer, E. (Eds). *Psychological issues in malignant diseases.* Oxford, U.K.: Pergamon Press, 55-71.

Baker, D.W. (1999). Literacy and screening for breast and cervical cancer among Medicare managed care enrollees. Presentation at *the second annual cancer care Symposium,* Chicago, November 12.

Baker, D.W., Parker, R.M., Williams, M.V., Clark W.S., (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine. 13,* 791-798.

Baker, D.W., Gazmararian, J.A.., Williams, M.V., Scott, T., Parker, R.M ,Green, D., Ren, J., Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health, 92* (8), 1278-1283.

Baker, D.W., Parker, R.M., Williams, M.V., Clark W.S., Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health, 87,* 1027-1030.

Baker, D.W., Parker, R.M., Williams, M.V., Pitkin, K., Parikh, N.S., Coates, W., Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine, 5* (6), 329-334.

Bandura, A. (1986). *Social foundations of thought and action.* Englewood Cliffs, NJ: Prentice Hall.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York, NY: W.H. Freeman and Company.

Bandura, A., Schunk, D.H. (1981). Cultivating competence, self-efficacy, and intrinsic interest through proximal self-motivation. *Journal of Personality and Social Psychology, 41,* p. 586-598.

Baranowski, K., Rimer, B.K., Lewis, F.M. (2002). How individuals, environments, and health behavior interact: Social cognitive theory. In: Karen Glanz, Barbara K. Rimer, Frances Marcus Lewis (Eds.). *Health behavior and health education: Theory, research, and practice.* (2002) (3rd ed). San Francisco, CA: Jossey Bass.

Beers, B.B., McDonald, V.J., Quistberg, D.A., Ravenall, K.L., Asch, D.A., Shea, J.A. (2003). Disparities in health literacy between African American and non-African American primary care patients. Abstract. *Journal of General Internal Medicine, 18* (Supplement 1), 169.

Bennett, C.L., Ferreira, M.R., Davis, T.C. , Kaplan, J., Weinberger, M., Seday, M.A., Sartor, O. (1998). Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *Journal of Clinical Oncology, 16,* 3101-3104.

Berkman, N.D., DeWalt, D.A., Pignone, M.P., Sheridan, S.L., Lohr, K.N., Lux, L., Sutton, S.F., Swinson, T., Bonito, A.J. (2004). *Literacy and health outcomes.* Evidence Report/Technology Assessment, Number 87 (Prepared by RTI International-University of North Carolina Evidence-based Practice Center under Contract no. 290-02-0016). AHRQ Publication No. 04-E007-2. Rockville, MD: Agency for Health Research and Quality. January 2004.

Berkman, L.F., Glass, T., Brissette, I., Seeman, T.E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science and Medicine, 51,* 843-857.

Berkman, L.F., Syme, L. (1979). Social networks, host resistance, and mortality: A nine year follow-up study of Alameda county residents. *American Journal of Epidemiology, 109,* 186-204.

Berland, G., Elliot M., Morales, L. (2005). Health information on the Internet: Accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association, 285,* 2612-2621.

Blazer, D.G. (1982). Social support and mortality in an elderly community population. *American Journal of Epidemiology, 115,* 684-694.

Berland, G.K., Elliot, M.N., Morales, L.S., Alganzy, J.I., Kravitz, R.L., Broder, M.S., Kanouse, D.E., Munoz, J.A., Puyol, J.A., Lara, M., Watkins, K.E., Yang, H., McGlynn, E.A. (2005). Health information on the Internet: Accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association, 285* (20), 2612-2621.

Brody, D. (1980). The patient's role in clinical decision-making. *Annals of Internal Medicine, 93,* 718-722.

Brown, S.C., Park, D.C. (2002). Roles of age and familiarity in learning health information. *Educational Gerontology, 28* (8), 695-710.

Brown, H., Prisuta, R., Jacobs, B., Campbell, A. (1992). *Executive summary of literacy of older adults in America.* Washington, D.C.: Department of Education.

Burns, N., Grove, S.K. (1993). *The practice of nursing research: Conduct, critique,& utilization.* (2nd Ed.). W.B. Saunders Company: Philadelphia, PA

Burns, N., Grove, S.K. (2007). *Understanding nursing research: Building an evidence based approach.* (4th Ed.). W.B. Saunders Company: Philadelphia, PA

Caputo. R.K. (Ed). *Challenges of aging on U.S. families: Policy and practice implications.* (2005). Binghamton. NY.: Haworth Press, Inc.

Center for Health Care Strategies, Inc. *Health literacy and understanding medical information fact sheet. (1997).* Available online: Retrieved on July 13, 2006 from http://www.chcs.org/resources/hl.html

Center for Medicare Advocacy, Inc. (2006). *Medicare Part D progress report: Six months later headaches persist.* Available online: Retrieved on February 12, 2007 from *http://www.fairmedicare.org/Resources/PartDReport72006.pdf*

Chen, P.Y., Popovich, P.M. (2002). *Correlation: Parametric and nonparametric measures.* Thousand Oaks, CA: Sage Publications.

Chew, L.D., Bradley, K.A., Boyko, E.J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine, 36* (8), 588-594.

Chodosh, J., Morton, S.C., Mojica, W., Maglione, M., Suttorp, M.J., Hilton, L., Rhodes, S., Shekelle, P. (2005). Meta-analysis: Chronic disease self-management programs for older adults. *Annals of Internal Medicine, 143* (6), 427-438.

Clark, N.M., Dodge, J.A. (1999). Exploring self-efficacy as a predictor of disease management. *Health Education and Behavior, 26*, 72-89.

Coleman, E.A., Coon, S., Mohrmann, C., Hardin, S., Stewart, B., Gibson, R.S., Cantrell, M., Lord, J., Heard, J. (2003). Developing and testing lay literature about breast cancer screening for African American women. *Clinical Journal of Oncology Nursing, 7* (1), 66-71.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, N.J.: Lawrence Erlbaum Associates.

Cohen, S., Hoberman, H. (1993) Positive events and social support as buffers of life change stress. *Applied Psychology, 13,* 99-125.

Cohen, S., Underwood, L., Gottlieb, B.H. (2000). *Social support measurement and intervention.* New York: Oxford University Press.

Cohen, S., Syme, S.L. (1985). *Social support and health.* Orlando, FL: Academic Press.

Cohen, S. (1988). Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychology, 7,* 269-297.

Cohen, S., Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98,* 310-357.

Cohen-Cole, S.A. (1991). *Why three functions?* In the Medical Interview: The three-function approach; Cohen-Cole, S.A. (Ed.) Mosby: St. Louis, MO.

Corbin, J., Strauss, A. (1988). Carers working together. *Nursing Times, 84* (15), 48-49

Cronk, B.C. (2004). *How to use SPSS* (3rd ed.). Glendale, CA: Pyrczak Publishing

Davis, T.C. Berkel, H.J., Arnold, C.L., Nandy, I., Jackson, R.H., Murphy, P.W. (1998). Intervention to increase mammography utilization in a public hospital. *Journal of General Internal Medicine, 13* (4), 230-233.

Das, A.K., Wilcoxson, P.D., Corrado, O.J., West, R.M. (2007). The impact of long-term warfarin on the quality of life of elderly people with atrial fibrillation. *Age and Ageing, Jan. 1, 36* (1), 95-97.

Davis, T.C., Bocchini, J.A., Fredrickson, D., Arnold, C., Mayeaux, E.J., Murphy, P.W. et al. (1996). Parent comprehension of polio vaccine information pamphlets. *Pediatrics, 97* 6 (Pt 1), 804-810.

Davis, T.C., Long, S.W., Jackson, R.H., Mayeaux, E.J., George, R.B., Murphy, P.W., Crouch, M.A. (1993). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine, 25* (6), 391-395.

Davis, T.C., Meldrum, H., Tippy, P.K.P., Weiss, B.D., Williams, M.V. (1996). How poor literacy leads to poor health care. *Patient Care, 30* (16), 94-116.

Davis, T.C., Wolf, M.S. (2004). Health literacy: Implications for family medicine. *Family Medicine, 36* (8), 595-598.

Deber, R., Kraetschmer, N., Irvine, J. (1996). What role do patients wish to play in treatment decision-making? *Archives of Internal Medicine, 156,* 1414-1420.

Department of Health and Human Services, (2004) The State of Aging and Health In America 2004. Center for Disease Control, Vol. 3., Available online: retrieved July 15, 2006 from http://www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf

DiClemente, C.C., Prochaska, J.O., Fairhurst, S.K., Velicer, W.F., Valsquez, M.M., Rossi, J.S. (1991). The process of smoking cessation: An analysis of precontemplation, contemplation, and preparation stages of change. *Journal of*

Consulting and Clinical Psychology, 59 (2), 295-304.

Dolbier, C.L., Steinhardt, M.A. (2000). Development and validation of the Sense of Support Scale. *Behavioral Medicine, Winter, 25* (4), 169-179.

Echt, K.V. (2002). Designing web-based health information for older adults: Visual considerations and design directives. In R.W. Morrell, ed. *Older adults, health information, and the World Wide Web.* 61-88. Mahwah, N.J.: Lawrence Erlbaum Associates.

Educational Attainment in the United States. *US Census.* 2003. Available online, retrieved on April 20, 2006 from http://www.census.gov

Ende, J., Kazis, L., Ash, A., Moskowitz, M. (1989). Measuring patient's desire for autonomy: Decision-making and information-seeking preferences among medical patients. *Journal of General Internal Medicine, 4,* 23-30.

Fallowfield, L., Hall, A., Maguire, P., Baum, M., A'Hern, R. (1994). Psychological effects of being offered choice of surgery for breast cancer. *British Medical Journal, 309,* 448.

Feld, S., Dunkle, R.E., Schroepfer, T. (2005). When do couples expand their ADL caregiver network beyond the marital dyad? In: Caputo. R.K. (Ed). *Challenges of aging on U.S. families: Policy and practice implications.* (2005), pp. 27-43. Binghamton. NY. Haworth Press, Inc.

Finn Maples, M., Abney, P.C. (2006). Baby boomers mature and gerontological counseling comes of age. *Journal of Counseling & Development, 84*, 3-9.

Flesch, R. (1948). *A new readability yardstick*, Journal of Applied Psychology, Vol. 32, pp. 221-233, Fortenberry J.D., McFarlane M.M., Hennessy M., Bull S.S., Grimley D.M., Lawrence J.St, Stoner B.P., VanDevanter N. (2001). Relation of health literacy to gonorrhea related care. *Sexually Transmitted Infections, 77* (3): 206-11.

Freebody, P., Freiberg, J. (1997). *Adult literacy and health.* Melbourne Australia: National Languages and Literacy Institute (ED 430 088).

Friedland, R. (1998). New estimates of the high cost of inadequate health literacy. In: *Proceedings of Pfizer Conference "Promoting Health Literacy: A Call to Action." October 7-8, 1998, Washington, DC.:* Pfizer, Inc. Pp. 6-10.

Gausman Benson, J., Forman, W.B. (2002). Comprehension of written health care information in an affluent geriatric retirement community; Use of the Test of Functional Literacy. *Gerontology*, 48, 93-97.

Gazmararian, J.A., Baker, D.W., Williams, M.W., Parker, R.M., Scott, T.L., Green, D.C., Fehrenbach,S.N., Ren, J., Koplan, J.P. (1999). Health literacy among Medicare enrollees in a managed care organization. *Journal of the American Medical Association 281,* (6), 545-551.

Gazmararian, J.A., Williams, M.V., Peel, J., Baker, D.W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling, 51,* 267-275.

Greaves, C.J., Farbus, L. (2006). Effects of creative and social activity on the health and well-being of socially isolated older people: outcomes from a multi-method observational study. *Journal of the Royal Society of Health, May;126* (3), 134-42.

Greenberg, D. (2001). *A critical look at health literacy.* Adult Basic Education, 11 (2), (Summer 2001), 67-69.

Greene, J., Hibbard, J., Tusler, M. (1995). How much to health literacy and patient activation contribute to older adults' ability to manage their health? American Association for Retired Persons (AARP), #2005-5, p.1-24,

Greenfield, S., Kaplan, S.H., Ware, J.E. (1985). Expanding patient involvement in care: Effects on patient outcomes. *Annals of Internal Medicine, 102,* 520-528.

Greenfield, S., Kaplan, S.H., Ware, J.E., Yano, E.M., Frank, H.J. (1988). Patient's participation in medical care: Effects on blood sugar control and quality of life in diabetes. *Journal of General Internal Medicine, 3,* 448-457.

Guadagnoli, E., Ward, P. (1998). Patient participation in decision-making. *Social Science Medicine, 47* (3), 329-339.

Hair, J.F., Anderson, R.E., Tatham, R.L., Black, W.C. (1998). *Multivariate data analysis.* (5th ed.). Prentice Hall: Upper Saddle River, New Jersey.

Hartley, J. (1999). What does it say? Text design, medical information and older Readers. In D.C. Park, R.W. Morrell, and K. Shifren, eds. *Processing medical information in aging patients.* Mahwah, N.J.: Lawrence Erlbaum Associates.

Hayes, V., Morris, J., Wolfe, C., Morgan, M. (1995). The SF-36 Health Survey Questionnaire: Is it suitable for use with older adults? *Age and Ageing, 24* (2), 120-125.

Heaney, C.A., Israel, B.A. (2002). In: Glanz, K., Rimer, B.K., Marcus Lewis, F. (Eds). In: *Health behavior and health education: Theory, research, and practice.* (3rd ed., pp.185-209). San Franciso, CA: Jossey Bass.

Helgeson, V.S. (1993). Two important distinctions in social support: Kind of support and perceived versus received. *Journal of Applied Social Psychology, 23,* 825-846.

Hibbard JH, New Roles for Patients and Consumers in Assuring High Quality Care (2004). *Virtual Mentor, American Medical Association.* Available online: Retrieved on June 20, 2006 from http://www.ama-assn.org/ama/pub/category/12490.html

Hibbard, J., Greene, J., Tusler, M. (2005). Identifying Medicare beneficiaries with poor health literacy skills: Is a short screening index feasible? *American Association of Retired Persons Public Policy Institute,* Report #2005-01.

Hibbard, J.H., Mahoney, E.R., Stock, R., Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research, 42*(4), 1443-1463.

Hibbard, J.H., Mahoney, E.R., Stockard, J., Tusler, M. (2005). Development and testing of a short form of the Patient Activation Measure. *Health Research and Educational Trust, 40* (6), Part I (December 2005).

Hibbard, J.H., Stockard, J., Mahoney, E.R., Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services research, 39*, 1005-1026.

Hibbard, J.H., Tusler, M. (2007). Assessing activation stage and employing a 'next steps' approach to supporting patient self-management. *Journal of Ambulatory*

Care Management, 30 (1), 2-8.

Hoffman, C., Rice, D., Sung, H-Y. (1996). Persons with chronic conditions: Their prevalence and costs. *Journal of the American Medical Association, 276,* 1473-1479.

Horton, N.J., Kleinman, K.P. (2007). Much ado about nothing: A comparison of missing data methods and software to fit incomplete data regression models. *The American Statistician, 61* (1), 79-90.

House, J.S., Robbins, C., Metzner, H.L. (1982). The association of social relationships and activities with mortality: Prospective evidence from the Tecumseh Community Health Study. *American Journal of Epidemiology, 116,* 123-140.

Houts, P.S., Bacharach, R., Witmer, J.T., Tringali, C.A., Bucher, J.A., Localio, R.A. (1998). Using pictographs to enhance recall of spoken medical instructions. *Patient Education Counseling, 35* (2), 83-88.

Houts, P.S., Witmer, J.T., Egeth, H.E., Loscalzo, M.J., Zabora, J.R. (2001). Using pictographs to recall of medical instruction II. *Patient Education Counseling, 43* (3), 231-242.

Howard, D.H., Gazmararian, J., Parker, R.M. (2005). The impact of low health literacy on medical costs of Medicare Managed Care enrollees. *The American Journal of Medicine, 118,* 371-377

Hyman, M.D. (1971). Disability and patients' perceptions of preferential treatment: Some preliminary findings. *Journal of Chronic Diseases, 24,* 329-342.

Jemmott, J.B., Magloire, K. (1988). Academic stress, social support, and secretory immunoglobulin A. *Journal of Personality and Social Psychology, 55*(5), 803-810.

Kalichman, S.C., Ramanchandran, B., Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine, 14* (5), 315-317.

Kalichman, S.C., Rompa, D. (2000). Functional health literacy is associated with health status and health related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndrome, 25,* 337-344.

Kaplan, S.H., Greenfield, S., Ware, J.E. (1989). Assessing the effects of physician-patent interactions on outcomes of chronic disease. *Medical Care, 27* (supplement 3), S110-S127.

Katz, S.J., Kabeto, M., Langa, K.M. (2000). Gender disparities in the receipt of home care for elderly people with disability in the United States. *Journal of the American Medical Association, 284* (23). 3022-3027.

Kellerman, R., Weiss, B.D. (1999). “Health literacy and the JAMA patient page”. Letter to the editor, *Journal of the American Medical Association, 282* (6), 525.

Kerka, S. (2003). Health literacy beyond basic skills. *ERIC Digest,* Educational Resources Information Center, Publication No. EDO-CE-03-245.

Kim, S., Love, F., Quistberg, D.A., Shea, J.A. (2004). Association of health literacy with self-management behavior in patients with diabetes. *Diabetes Care, 27* (12), 2980-2982.

Kim, J., Quadri, S.M., Lee, T., Lee, S., Arozullah, A.M. (2003). Is health literacy or social support associated with prescription filling behavior? *Abstract 236, Social of General Internal Medicine.*

Kirsch, I., Jungeblut, A., Jenkins, L., Kolstad, A. (1993). *Adult literacy in America: A first look at the results of the national adult literacy survey.* Washington, D.C.: Department of Education.

Kornblith, A.B., Dowell, J.M., Herndon, J.E. 2nd, Engleman, B.J., Bauer-Wu, S., Small, E.J., Morrison, V.A., Atkins, J., Cohen, H.J., Holland, J.C. (2006). *Cancer, Dec.1; 107* (11), 2706-2714.

Krause, N., Markides, K. (1990). Measuring social support among older adults. *International Journal for Aging and Human Development, 30* (1), 37-53.

Kuo. Y.F., Raji, M.A., Peek, M.K., Goodwin, J.S. (2004). Health-related social disengagement in elderly diabetic patients: Association with subsequent disability and survival. *Diabetes Care, July 1, 27* (7), 1630-1637.

Kutza, E.A. (2005). The intersection of economics and family status in late life: Implications for the future. In: Caputo. R.K. (Ed). *Challenges of aging on U.S. families: Policy and practice implications.* (2005), pp. 9-26. Binghamton. NY.: Haworth Press, Inc.

Lambert, V.A., Lambert, C.E., Klipple, G.L., Mewshaw, E.A. (1990). Relationships among hardiness, social support, severity of illness, and psychological well-being in women with rheumatoid arthritis. *Health Care for Women International, 11* (2), 159-173.

Lee, S.D., Arozullah, A.M., Cho, Y.I. (2004). Health literacy, social support, and health: A research agenda. (2004). *Social Science and Medicine, 58,* 1309-1321.

Lee, S.D., Gazmararian, J.A., Arozullah, A.M. (2006). Health literacy and social support among elderly Medicare enrollees in a managed care plan. *The Journal of Applied Gerontology, 25* (4), 324-337.

Levinson, W., Kao, A., Kuby, A., Thisted, R.A. (2005). Not all patients want to participate in decision making: A national study of public preferences. *Journal of General Internal Medicine, 20*, p. 531-535.

Licht, M. (1995) Multiple regression and correlation. In: L.G. Grim & P.R. Yarnold (Eds). *Reading and understanding multivariate statistics*. American Psychological Association: Washington, D.C.

Lorig, K. (1996). Chronic disease self-management: A model for tertiary prevention. (Perspectives on chronic illness: treating patients and delivering care). *American Behavioral Scientist 39* (6), 676-684.

Lorig, K., Ritter, P.L., Stewart, A.L., Sobel, D.S, Brown, B.W., Bandura, A., Gonzalez, V.M., Laurent, D., Homan, H.L. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care, 39* (11), p. 1217-1223.

Lorig, K., Sobel, D.S., Stewart, A., Brown, B.W., Bandura, A., Ritter, P., Gonzales, V.M., Laurent, D., Holman, H.R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care, 37* (10), p. 5-14.

Martire, L.M., Schultz, R., Mittlemark, M.B., Newsom, J.T. (1999). Stability and change in older adults' social contact and social support: The cardiovascular health study. *Journal of Gerontology: Social Sciences, 54B* (5), S302-311.

Mauk, K.L. (Ed.) (2006). *Gerontological nursing: Competencies for care.* Jones and Bartlett Publishers: Sudbury, Massachusetts.

McCormack Brown, K. (1999). *Social cognitive theory.* Available online: Retrieved February 11, 2006 from http://hsc.usf.edu/~kmbrown/Social_Cognitive_Theory_Overview.htm

McLaughlin, G.H. (1969). SMOG grading: A new readability formula. *Journal of Reading, May,* 639-646.

Mendonca, P., Brehm, S. (1983). Effects of behavioral treatment of overweight children. *Journal of Social Clinical Psychology, 1,* 343-358.

Mertler, C.A.& Vannatta, R.A. (2002). *Advanced multivariate statistical methods: Practical application and interpretation.* Los Angeles, CA: Pyrczak Publishing.

Michael, K.M., Allen, J.K., Macko, R.F. (2006). Fatigue after stroke: Relationship to mobility, fitness, ambulatory activity, social support, and falls efficacy. *Rehabilitation Nursing, Sept.-Oct; 31* (5), 210-217.

Michielutte, R., Bahnson, J., Dignan, M.B., Schroeder, E.M. (1992). The use of illustrations and narrative text style to improve readability of a health education brochure. *Journal of Cancer Education, 7* (3), 251-260.

Mosen, D.H., Hibbard, J., Sobel, D., Remmers, C. (2005). *Is patient activation associated* *with better health outcomes for adults with diabetes?* Presentation at American Public Health Association 133rd Meeting and Exposition, Dec. 2005.

Mosen, D.H., Schmittdiel, J., Hibbard, J., Sobel, D., Remmers, C., Bellows, J. (2007). Is patient activation associated with outcomes of care for adults with chronic conditions? *Journal of Ambulatory Care Management, 30* (1), 21-29.

Munro, B.H., Page, E.B. (Ed.), (1993). *Statistical methods for health care research.* (2nd ed.). J.B. Lippincott Company: Philadelphia

Murphy, P.W., Chesson, A.L., Walker, L., Arnold, C.L., Chesson, L.M. (2000). Comparing the effectiveness of video and written material for improving knowledge among sleep disorders clinic patients with limited literacy skills, *Southern Medical Journal, 93* (3), 297-304.

National Academy on an Aging Society. (1999). *Fact sheet: Low health literacy skills increase annual health care expenditures by $73 billion.* Available online: Retrieved April 05, 2006, from http://www.agingsociety.org/agingsociety/publications/fact/fact_low.html

National Center for Education Statistics, (2006). *Key concepts and features of the 2003 national assessment of adult literacy* . U.S. Department of Education, publication # NCES 2006-471.

National Center for Education Statistics, (2006). *National assessment of adult literacy (NAAL): a first look at the literacy of America's adults in the 21st century.* U.S. Department of Education, publication # NCES 2006-470.

Neilson-Bohlman, L., Panzer, A.M., Hamlin, B., Kindig, D.A. (Eds.) (2004). *In: Institute of Medicine Report:.* Committee on Health Literacy, Board on Neuroscience and Behavioral Health.

Nurss, Parker, Baker, (2001). *TOFHLA: Test of functional health literacy in adults.* Peppercorn Books and Press, Inc.: Snow Camp, North Carolina.

O'Brien King, M., Pettigrew, A.C. (2004). Complementary and alternative therapy use by older adults in three ethnically diverse populations: A pilot study. *Geriatric Nursing, 25* (1), 30-37.

Ornish, D. (1988). Love and survival: *The scientific basis for the healing power of intimacy.* New York: Harper Collins.

Owen, W.F. (2004). Inequality in quality: Are patient health activation and CQI corrective approaches? *Journal of the American Society of Nephrology, 15,* 2951-2952.

Parikh, N.S., Parker, R.M., Nurss, J.R., Baker D.W.,Williams, M.V. (1996) Shame and health literacy: The unspoken connection. *Patient Education and Counseling, 27,* 33-39.

Parker, R.M., Baker, D.W., Williams, M.V., Nurss, J.R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine, 10,* 537-541.

Parker, R.M., Ratzan, S.C., Lurie, N. (2003). Health literacy: A policy challenge for advancing high-quality health care. *Health Affairs, 22* (4), 147-153.

Pennsylvania Department of Aging (2004). Governor Rendell proclaims May older

Pennsylvanians month. Available online, Retrieved November 12, 2005 from http://www.state.pa.us/papower/cwp/view.asp?A=11&Q=436859

Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatric Society, 23* (10), 433-441.

Pintrich, P.R., Schunk, D.H. (1996). *Motivation in education: Theory, research, and applications.* Englewood Cliffs, N.J.: Prentice Hall.

Polit, D.F., Tatano Beck, C. (2004). *Nursing research: Principles and methods.* (7th ed.). Philadelphia: Lippincott, Williams, & Wilkins.

Revenson, T.A., Wollman, CA, Felton, B.J. (1983). Social support as stress buffers for adult cancer patients. *Psychosomatic Medicine, 45,* 321-331.

Rohrer, J.E., Young, R., Sicola, V., Houston, M. (2007). Overall self-rated health: A new quality indicator for primary care. *Journal of Evaluation for Clinical Practice, 13,* 150-153.

Rosenthal, M.S., Werner, M.J., Dubin, N.H. (2004). The effect of a literacy training program on family medicine residents. *Family Medicine, 36* (8), 582-587.

Rost, K., Flavin, K., Cole, K. (1991). Change in metabolic control and function status after hospitalization: Impact of patient activation intervention in diabetic patients. *Diabetes Care, 14,* 881-889.

Ruberman, W., Weinblatt, E., Goldberg, J.D., Chaudhary, B.S. (1984). Psychosocial influences on mortality and myocardial infarction. *New England Journal of Medicine, 311,* 552-559.

Rudd, R., Moeykens, B.A., Colton, T.C. (2000). Health and literacy: A review of medical and public health literature. In: Comings, J., Garners, B., Smith, C. (Eds). In: *Annual review of adult learning and literacy.* New York: Jossey-Bass.

RUMM Laboratories, (2007) *Rasch Analysis.* Retrieved July 19, 2007. Available online at: http://64.233.169.104/search?q=cache:_2u_VeLolcQJ:www.rasch-analysis.com/rasch- analysis.htm+Rasch+analysis+AND+%22test+of+fit+between+the+data+and+the+model%22&hl=en&ct=clnk&cd=1&gl=us

Safeer, R.S., Keenan, J.K. (2005). Health literacy: The gap between physicians and patients. *American Family Physician, 72* (3), 463-468.

Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Dahner, C., Palacious, J., Diaz Sullivan, G., Bindman, A.B. (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association, 288* (4), 475-482.

Schloman, B.F. (2004). Health literacy: A key ingredient for managing personal health. *Online Journal of Nursing Issues, February 2004,* p.9. Available online: Retrieved on January 15, 2006 from http://www.nursingworld.org/ojin/infocol/info_13.htm

Scott, T.L., Gazmararian, J.A., Williams, M.V., Baker, D.W. (2002). Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care, 40* (5), 395-404.

Selden, C.R., Zorn, M., Ratzan, S.C., Parker, R.M. (2000). *Health literacy* (Current Bibliographies in Medicine 2000-1). Available online: Retrieved April 05, 2006, from http://www.nlm.nih.gov/pubs/cbm/hliteracy.html

Sherbourne, C.D. & Stewart, A.L. (1991). The MOS Social Support Survey. *Social Science and Medicine, 32,* 704-714.

Schroeder. M.A. (1990). Diagnosing and dealing with multicollinearity, *Western Journal of Nursing research, 12* (2), 175-187.

Silver Wallace, L., Lennon, E.S. (2004). American Academy of Family Physicians patient education materials: Can patients read them? *Family Medicine, 36,* (8), 571-574.

Simonds, S. (1974). *Health education as social policy.* Health Education Monograph 2 (Baltimore: Johns Hopkins University, 1974), 1-25.

Social Security Administration (2007). *Social Security Online.* Available online: Retrieved February 11, 2007 from http://www.ssa.gov/retirechartred.htm

Soper, D. (2007). *A-priori sample size calculator.* Available online: Retrieved February 12, 2007 from http://www.danielsoper.com/statcalc/calc01_do.aspx

Spears, K.N. (2003). Examination of health education preferences of older adults with inadequate health literacy. *Dissertation Abstracts International, 64 (11A).*

Uchino, B.N., Cacioppo, J.T., Kiecolt-Glaser, J.K. (1996). The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. *Psychology Bulletin, 199,* 488-511.

University of Texas, Information Technology Services (2004). Research consulting; General FAQ #25: Handling missing or incomplete data. Available online:

Retrieved February 21, 2007from http://www.utexas.edu/its/rc/answers/general/gen25.html

U.S. Census Bureau (2005). *American Fact Finder.* Available online, Retrieved February 15, 2007 from http://factfinder.census.gov/home/saff/main.html?_lang=en

U.S. Department of Health and Human Services, Center for Disease Control, *"Chronic Disease Overview"*, available online, retrieved February 25, 2005 from http://www.cdc.gov/nccdphp/overview.htm.

U.S. Department of Health and Human Services, Center for Disease Control. (2004). *The state of aging and health in American* Washington, D.C.

U.S. Department of Health and Human Services. (2000) *Healthy People 2010*: Understanding and Improving Health. (2nd ed.) Washington, DC: U.S. Department of Health and Human Services, November 2000.

Von Korff, M., Gruman, J., Schaefer, J., Curry, S.J., Wagner, E.H. (1997). Collaborative management of chronic illness. *Annals of Internal Medicine, 127* (12), 1097-1102.

Wallston, K.A., Stein, M.J., Smith, C.A. (1994). Form C of the MHLC scales: A condition specific measure of locus of control. *Journal of Personality Assessment, 63* (3), 534-553.

Ware, J.E., Snow, K.K., Kosinski, M., Gandek, B. (1997). *SF-36 Health Survey: Manual and interpretation guide.* Boston, Massachusetts: The Health Institute, New England Medical Center.

Weil, A. (2005). *Health aging: A lifelong guide to your physical and spiritual well-being.* New York: Alfred Knopf.

Weiss, B.D., Hart, G., McGee, D.L., D'Estelle, S. (1992). Health status of illiterate adults: Relation between literacy and health status among persons with low literacy skills. *Journal of the American Board of Family Practice, 5* (3), 257-264.

Wethington, E., Kessler, R.C. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behavior, 27,* 78-79.

Wilkinson, G.S. (1984). *Wide Range Achievement Test- Revised 3.* Wilmington, DE: Jastak Associates.

Williams, M.V., Baker, D.W., Parker, R.M., Nurss, J.R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease: A study of hypertensions and diabetes. *Archives of Internal Medicine, 158,* 166-172.

Williams M.V., Davis, T., Parker R.M. & Weiss, B.D. (2002). The role of health literacy in patient-physician communication. *Family Medicine, 34* (5), 383-389.

Williams, M.V., Parker, R.M., Baker, D.W., Parikh, N.S., Pitkin, K., Coates, W.C., Nurss, J.R. (1995). Inadequate functional literacy among patients at two public hospitals. *Journal of the American Medical Association, 274* (21), 1677-1682.

Wongwiwatthananukit, S. (2002). Development and validation of an instrument to assess the self-confidence of students enrolled in the advanced pharmacy practice experience. *American Journal of Pharmaceutical Education, Spring,* p. 1-16

Appendix A: Subject Recruitment Flyer

Research Study

IRB #: HM0882

If you:

- Are 62 or older
- Reside in Luzerne County
- Have one or more chronic health problem(s)

You are invited you to take part in this research study. The study will help us learn more about how older adults' take care of their health problems and the kinds of friends and support older adults have in their lives. You will be asked to read some information, answer a few questions and then complete a brief written survey. This should take about 30 minutes.

Those who complete the study will receive a $10.00 Grocery Gift Card. There is no cost for the study.

Information sessions will be held in the community room followed by the study on:

Tuesday June 19 1:30 PM - 4:00 PM

Wednesday June 20 10:00 AM - 12:00 PM and 1:00 - 4:00PM

Friday June 22 1:30PM - 4:00 PM

Thank you for your interest in this research study.

Appendix B: Research Subject Information Form

RESEARCH SUBJECT INFORMATION FORM

IRB #: HM10882

Title: "An exploration of the relationship among health literacy, social support and patient activation in community residing older adults".

This form may have words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home a copy of this form to think about or discuss with your family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this study is to learn more about how older adults' learn about and take care of their health problems and the kinds of friends and support older adults have in their lives. You are being asked to participate in this study because you are an older adult living in the community.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT'

If you decide to be in this research study you will be asked to complete a survey and answer some questions after you have had all your questions answered and understand what you will be asked to do.

In this study you will be asked to read some health information and part of a Medicare insurance application form and then you will be asked about your understanding of this information and how clear this information is to you. You will then be asked to complete a written survey about how you feel about your ability to take care of your health and the kind of friends and support you have in your life. This should take about 30-45 minutes.

RISKS AND DISCOMFORTS

There are no risks to participating in this study.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but the information we learn from people in this study may help us design better ways to help older adults manage their health.

COSTS

There are no costs for participating in this study other than the time you will spend answering questions and completing the survey.

PAYMENT FOR PARTICIPATION

You will receive a $10.00 gift card after completing the survey.

CONFIDENTIALITY

We will not tell anyone the answers that you give us. Information is being collected only for research purposes. No identifying information will be asked. Paper forms will be stored in a locked research area and kept in a locked file cabinet and will be kept until all data is entered into electronic files. Electronic data will be kept until the research study is complete. Access to all data will be limited to study personnel. What we find in this study may be presented in meetings or published in papers, but no individual information will be used in these presentation or papers.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped any time by the study staff without your consent. The reasons might include:

- The study staff thinks it necessary for your health or safety;
- You have not followed study instructions;
- Administrative reasons require your withdrawal

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact: Dr. James Cotter, [redacted]

If you have any questions about your rights as a participant in this study, you may contact:

[redacted]

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at http://www.research.vcu.edu/irb/volunteers.htm

Your completion of the survey says that you consent to participate in this study. You will receive a copy of this information form. You are encouraged to share this information with family or friends to help you decide whether or not to participate.

Appendix C: Short Portable Mental Status Questionnaire (SPMSQ)

Short Portable Mental Status Questionnaire (SPMSQ)

Circle One: Sex: M F Race: White Black Other

Yrs of Education: Grade School High School Beyond High School

Instructions: Ask questions 1 to 10 on this list and record all answers. (Ask Question 4a only if the subject does not have a telephone.) Record the total number of errors based on the answers to the 10 questions.

+	-	Questions	Instructions
		1. What is the date today?	Correct only when the month, data and year are all correct.
		2. What day of the week is it?	Correct only when the day is correct.
		3. What is the name of this place?	Correct if any of the description of the location is given. "My home", the correct city/town or the correct name of the hospital /institution is acceptable.
		4. What is your telephone number?	Correct when the number can be verified or the subject can repeat the same number at a later time in the interview.
		4a. What is your street address?	Ask only if the subject does not have a telephone.
		5. How old are you?	Correct when the stated age corresponds to the date of birth
		6. When were you born?	Correct only when the month, data, and year are correct.
		7. Who is the president of the United States?	Requires only the correct last name.
		8. Who was the president just before him?	Requires only the correct last name.
		9. What was your mother's maiden name?	Needs no verification; it only requires a female first name plus a last name other than the subject's.
		10. Subtract 3 from 20 and keep subtracting 3 from each new number all the way down.	Any error in the series- or an unwillingness to attempt the series- is scored as incorrect.

_____ Total Number or Errors

0-2 errors = Intact Intellectual Function 5-7 errors= Moderate Intellectual Dysfunc.
3-4 errors= Mild Intellectual Dysfunc. 8-10 errors= Severe Intellectual Dysfun

Appendix D: Patient Activation Measure Short-Form For Chronic Disease

Patient Activation Measure Short-Form For Chronic Disease

PAM					
Please check the box that best describes your feelings about each question. (Disagree, Disagree Strongly, Agree or Agree Strongly)					
	Disagree Strongly	**Disagree**	**Agree**	**Agree Strongly**	**Not Applicable**
1. When all is said and done, I am the person who is responsible for managing my health condition(s).					
2. Taking an active role in my own health care is the most important factor determining my health and ability to function.					

3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition(s).					
4. I know what each of my prescribed medications does.					
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.					
6. I am confident I can tell a doctor concerns I have even when he or she does not ask.					

7. I am confident that I can follow through on medical treatments I need to do at home.					
8. I understand the nature and causes of my health condition(s).					
9. I know the different medical treatment options available for my health condition(s).					
10. I have been able to maintain the lifestyle changes for my health condition(s) that I have made.					
11. I know how to prevent further problems with my health condition(s).					

12. I am confident I can figure out solutions when new situations or problems arise with my health condition.					
13. I am confident that I an maintain lifestyle changes, like diet and exercise, even during times of stress.					

Appendix E: Medical Outcomes Survey of Social Support

Medical Outcomes Survey of Social Support

NEXT ARE SOME QUESTIONS ABOUT THE SUPPORT THAT IS AVAILABLE TO YOU.

1a. About how many close friends do you have (people you feel at ease with and can talk to about what is on your mind)?

1b. About how many close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? (Please circle the number in the appropriate box)

	None of the Time	**A Little of the Time**	**Some of the Time**	**Most of the Time**	**All of the Time**
2. Someone to help you if you were confined to bed..........	1	2	3	4	5
3. Someone you can count on to listen to you when you need to talk............	1	2	3	4	5
4. Someone to give you good advice about a crisis........	1	2	3	4	5

5. Someone to take you to the doctor if you needed it........	1	2	3	4	5
6. Someone who shows you love and affection......	1	2	3	4	5
7. Someone to have a good time with.........	1	2	3	4	5
8. Someone to give you information to help you understand a situation........	1	2	3	4	5
9. Someone to confide in or talk to about yourself or your problems.......	1	2	3	4	5
10. Someone who hugs you.......	1	2	3	4	5
11. Someone to get together with for relaxation....	1	2	3	4	5
12. Someone to prepare your meals if you were unable to do it yourself.....	1	2	3	4	5
13. Someone whose advice you really	1	2	3	4	5

want…..					
14. Someone to do things with to help you get your mind off things…………	1	2	3	4	5
15. Someone to help with daily chores if you were sick…….	1	2	3	4	5
16. Someone to share your most private worries and fears with………..	1	2	3	4	5
17. Someone to turn to for suggestions about how to deal with a personal problem………	1	2	3	4	5
18. Someone to do something enjoyable with…..	1	2	3	4	5
19. Someone who understands your problems….	1	2	3	4	5
20. Someone to love and make you feel wanted…	1	2	3	4	5

Appendix F: Short Form of the Test of Functional Health Literacy in Adults

(S-TOFHLA)

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

PASSAGE A

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

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

You must have an _____________ stomach when you come for ______.

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

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

The X-ray will ____________ from 1 to 3 ___________ to do.

a. take
b. view
c. talk
d. look

a. beds
b. brains
c. hours
d. diets

THE DAY BEFORE THE X-RAY.

For supper have only a _____________snack of fruit, ________and jelly,

a. little
b. broth
c. attack
d. nausea

a. toes
b. throat
c. toast
d. thigh

with coffee or tea.

After ___________, you must not __________ or drink

a. minute
b. midnight
c. during
d. before

a. easy
b. ate
c. drank
d. eat

anything at ___________ until after you have __________the X-ray.

a. ill

a. are

b. all
c. each
d. before

b. has
c. drank
d. eat

THE DAY OF THE X-RAY.

Do not eat ____________________.

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

Do not eat ____________________, even______________.

a. drive,
b. drink,
c. dress,
d. dose,

a. heart
b. breath
c. water
d. cancer

If you have any ____________, call the X-Ray ____________ at 616-4500.

a. answers
b. exercises
c. tracts,
d. questions

a. Department
b. Sprain
c. Pharmacy
d. Toothache

PASSAGE B

Medicare drug plans will cover ________ and brand-name drugs.

a. generic
b. good
c. average
d. safe

Plans may have _________about what drugs are _________in different drug

a. risk
b. medicine
c. discharge
d. rules

a. covered
b. medical
c. dental
d. healthy

categories to be sure people with different health __________can get the

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

treatment they need. Most plans will have a list of drugs ___________by

a. generic
b. duplicate
c. singular
d. covered

the plan. This____ must meet Medicare's____________, but it can change

a. pencil
b. list
c. refuse
d. mend

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

when plans get new_________.

a. information
b. centimeter
c. prove
d. discharge

Your plan must let you know at least ___ (60) days before a drug you use is

a. three
b. six
c. sixty
d. five

_________from the list or if the ______are changing.

a. remarkable
b. reason
c. removed
d. duplicate

a. reasonable
b. section
c. risk
d. costs

If your _______thinks you need a drug that isn't on the list,

a. doctor
b. abdomen
c. vision
d. single

or if _____of your drugs is being removed from the list, you or ____doctor

a. send
b. gain
c. one
d. thirsty

a. your
b. mine
c. certain
d. you

can apply for an _________or appeal the___________.

a. denounce
b. capture
c. discuss
d. exception

a. potential
b. decision
c. decide
d. denture

If you have limited _________ you may qualify for extra _______.

a. resources
b. participate
c. tension
d. stressed

a. principles
b. central
c. help
d. mileage

The amount of _______help depends on your income and____________.

a. exercises
b. muscle
c. ligament
d. extra

a. residence
b. resources
c. argument
d. lenses

Appendix G: Demographic survey

Demographic survey

AGE:		
What is your age?	☐	
EDUCATION:		(Please check the appropriate box)
Less than High School	☐	
High School Diploma	☐	
Some College/Vocational School	☐	
College Graduate or More	☐	
GENDER:		
Male	☐	
Female	☐	
RACE/ETHNICITY THAT YOU PRIMARILY IDENTIFY YOURSELF AS:		
African-American	☐	
Asian	☐	
Caucasian	☐	
Hispanic	☐	
Native American	☐	
Pacific Islander	☐	
HOW WOULD YOU RATE YOUR HEALTH? WOULD YOU SAY IT'S:		
Excellent	☐	
Very Good	☐	
Good	☐	
Fair	☐	

Poor	
INCOME PER YEAR:	
Less than $15,000	
$15,000 - $24,999	
$25,000 - 34,999	
$35,000 or more	

CURRENT MARITAL STATUS:	
Never married	
Divorced	
Separated	
Widowed	
Married	
ARE YOU RETIRED?	
Yes	
No	
IF YOU ARE NOT RETIRED, ARE YOU EMPLOYED?	
Part-time	
Full-time	
DO YOU PARTICIPATE IN VOLUNTEER/SERVICE PROJECTS OR ACTIVITIES?	
Yes	

No	

DO YOU USUALLY GO TO DOCTOR'S VISITS OR OTHER HEALTH CARE APPOINTMENTS:

Alone	
With a Spouse	
With a Family Member	
With a Friend	
With a Paid Caregiver	

IF SOMEONE ACCOMPANIES YOU TO YOUR DOCTOR'S VISITS OR OTHER HEALTH CARE APPOINTMENTS DO THEY USUALLY:

Stay in the waiting room	
Go with you into the examination room	

VITA

[redacted]