

ADULT LEARNING FOR HEALTHY AGING: AN INVESTIGATION OF HEALTH  
LITERACY AND TECHNOLOGY USE IN OLDER ADULTS

by

Elizabeth Swann

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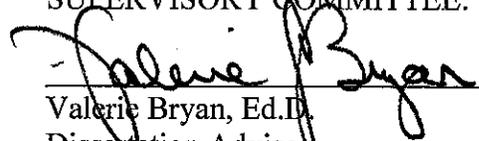
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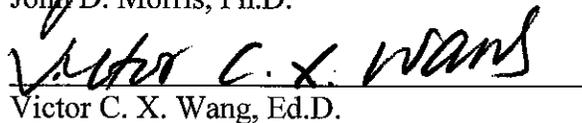
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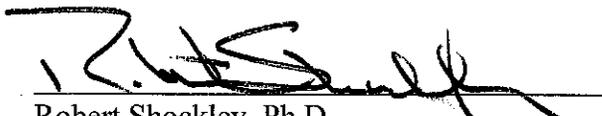
This dissertation was prepared under the direction of the candidate's dissertation advisor, Dr. Valerie Bryan, Department of Educational Leadership and Research Methodology, and has been approved by the members of her supervisory committee. It was submitted to the faculty of the College of Education and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

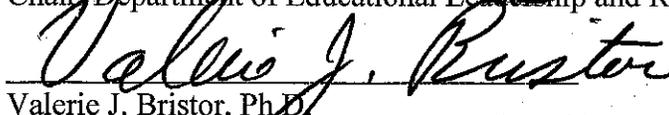
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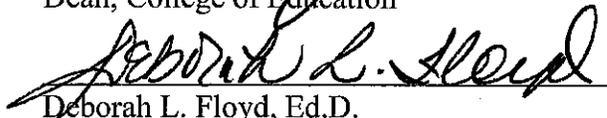
  
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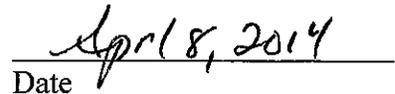
  
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In addition, I would like to acknowledge the staff at Florida Atlantic University's Healthy Aging Research Initiative (HARI) – especially Gabriella Engstrom and Dr. Ruth Tappen, Eminent Scholar and Professor, Christine E. Lynn College of Nursing, for being flexible, prompt, accommodating, and for allowing me the use of HARI data for this study.

## ABSTRACT

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This study explored the healthy aging process by: (a) examining the selected demographics of older adults in South Florida; (b) examining technology use of older adults in South Florida; (c) examining the health literacy levels of older adults in South Florida; (d) determining whether a relationship exists between older adults living in South Florida use of technology and their health literacy levels; and (e) evaluating the effects of health literacy as it relates to technology use in older adults in South Florida. Variables explored included health literacy, education, ethnicity, and technology use.

The sample study included 102 older adults (age > 60) living in South Florida that had completed profiles on the South Florida Quality Aging Registry, a part of the Healthy Aging Research Initiative (HARI). The sample size represented 22.3% of the total South Florida Quality Aging Registry population. The ethnicities of the participants among the South Florida Quality Aging Registry were African American (17%); Afro Caribbean (7.8%); Hispanic (10.7%); and European American (63.7%). The education

mean was 15, indicating that the majority of participants had an education level equivalent to completing high school. The mean health literacy score was 3.88, demonstrating that the majority of the participants had moderate levels of health literacy. The mean technology use score was 7.5 on a scale of one through ten, indicating that the majority of the participants had a moderate level of technology use.

Analysis of variance, correlation coefficients, and multiple regression analysis was used to explore the variables that may influence health literacy. There was a statistically significant difference among Afro Caribbean and African American, Afro Caribbean and European American, European American and Hispanic ethnicities related to their health literacy skill level ( $p < .01$ ). Additionally, there was a statistically significant difference among Afro Caribbean American and European American ethnicities and technology use ( $p < .01$ ).

## DEDICATION

I dedicate this dissertation to my parents, Betty and Bill. They have always believed in me and gave me the confidence to go out and pursue my dreams. It was their unconditional love, support, and encouragement that enabled me to persevere and achieve this goal and to make them proud. They were my inspiration to work hard and strive to be the very best I could be.

To my husband, Dustin, who was an enormous support throughout this entire process, who kept me focused and stood by my side throughout it all; thank you for your unwavering support, faith, and encouragement – I could not have done it without you. To my brother and sister, George and Catherine, your endless love, support, and encouragement have carried me through this spectacular journey.

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## 1. INTRODUCTION

It is estimated that 40 million Americans have limited literacy (Williams, Davis, Parker, & Weiss, 2002). Nearly half of all American adults, 90 million people have difficulty understanding and acting upon health information (Institute of Medicine, 2004). A great deal of health information comes from insurance forms, advertisement, patient education information, and complicated medical consent forms. These texts are considered to be complicated (Swann, 2012) and even people with strong literacy skills may have trouble obtaining, understanding and using health information. As a result, current medical information is inaccessible or untranslatable to millions of Americans; this may be an important barrier to receiving high quality care and managing one's own health.

Health literacy is 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” (Ratzan & Parker, 2006, p. 31). Studies show casual links between health literacy and several factors, including (a) poorer health outcomes; (b) higher medical costs; (c) health behaviors, personal health management and illness; and (d) access and use of health care. However, health literacy cannot be viewed from the individual's level alone. The Institute of Medicine denotes the emergence of health literacy occurs “when the expectations, preferences, and skills of the individuals seeking

health information and services meet the expectations, preferences, and skills of those providing [the] information and services” (Institute of Medicine, 2004, p. 2).

In the past, adults were restricted to a limited amount of medical information sources, with the majority of them targeted toward the medical professionals. In today’s society with ever advancing technology, including the Internet and mobile tools for internet access, individuals have a wide variety of health information available to them in multiple modes of access (U.S. Department of Health and Human Services, 2006). Being an informed patient of health care is becoming an increasing challenge, even for the individuals at the forefront of the latest trends in society.

### **Patient as Leader**

Changes in health, in particular illness, such as chronic disease associated with the aging process, can give adults opportunities for learning and self-leadership. Current health policies promote patient’s rights to access health information, which is viewed as “an important step in preventing disease and in improving health care and patient satisfaction” (Papen, 2012, p. 105). The Department of Health supports the idea of the informed patient for the purposes of fostering a participating “partnership” with health care providers (Papen, 2012). This view allows adults to self-lead; to choose how, when, where, and with whom they choose to receive health services, in essence allowing adults to be involved in health care management decisions, participatory decision-making.

Participating decision-making philosophy in health care has promoted an increase to access patient education material, for example the leaflets, info graphic posters in health care offices, educational videos, commercials, not to mention the plethora of online patient education material. Drawing on these resources and more, it is this material

that creates the expectation of patients being engaged in self-leadership and self-learning. It is in this context that it is reasonable to assume self-directed learning occurs. The act of “getting to know” the procedures and practices of the health care system or as Papen calls is the “socialization” of the health care system (Papen, 2012). Papen equates this learning context to the difficulties learners face when learning a language. The learning situation for adults dealing with chronic and ongoing health problems is literally like learning a new language. Papen’s 2012 study identified specific incidences of learning that were firmly embedded in the more generable process of becoming familiar with a disease and its treatment (pg. 107).

### **Adult Learning and Health**

This study views the relationship of adult learning and health self-management as an integral part of healthy aging. A central part of aging is the ability to care for one’s own health. Learning is essential to health (Hill & Ziegahn, 2010; Quigley, Coady, Gregoire, Folinsbee, & Kraglund-Gauthier, 2009). Adult learning allows individuals to cope with the changes in health, namely the decreased physical abilities, increased medical conditions, and the associated changes in lifestyle and social conditions (Hill & Ziegahn, 2010).

In a review of the literature on chronic illness and adult learning, Baumgartner (2011) found several themes. First, being diagnosed with an illness prompts various types of learning that occur in social contexts. Second, that learning is a social activity. Third, diagnosis of a disease and the subsequent learning involved with the health management was emotional. Lastly, adults used multiple resources to learn and that they experienced barriers to learning.

Adults learn as a part of some everyday activity or concern without relying on instruction. This type of informal and self-directed learning matches contexts of health management as a part of aging. Self-directed learning is a key characteristic of what Knowles (1980) calls andragogy.

Self-directed learning is a central theme in disease management as a part of healthy aging. Self-directed learning is defined through three views, process, personal characteristics, and goal (Merriam, Caffarella & Baumgartner, 2007). The process of self-directed learning is defined by Knowles (1975) as a “process in which individuals take the initiative, with or without help of others, in diagnosing their learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes” (p. 18). The learning that occurs in the process of successfully navigating the health context of disease management is self-directed in nature (Baumgartner, 2011).

### **Statement of the Problem**

There is an expectation for adults to be informed and competent in managing their own health. Yet the challenges of navigating health information are especially great for the increasing population of older adults (U.S. Department of Health and Human Services, 2006). By 2050, there will be 112 million older adults (age 60+) almost three times the amount than recorded in 2000 (U.S. Administration on Aging, 2009). The U.S. Administration on Aging ranks Florida as the number one state for having the largest population of older adults (2009). Older adults are more likely to have chronic disease and therefore require more health care services than other segments of the population.

Older adults are faced with unique challenges that may make it difficult to navigate health information resulting in a gap in adequate self-management.

While there is an increasing number of older adults using technology for health or medical information (49% of older adults seek information online), the level of health literacy is not changing. Research studies demonstrate the importance of focusing on older adults and their health literacy challenges. A recent study indicates more than 33% of patients 65 and up have inadequate or marginal health literacy (Williams et al., 2002), and thus making this group the highest proportion of persons with poor health literacy. Given this difficulty, use of technology may be an added challenge. Understanding the level of health literacy in older adults, and their technology use, will lend researchers a platform for furthering the discussion on challenges older adults have in healthy aging. Investigating the possible interaction between health literacy and technology use in older adults will shed light on the complicated health contexts older adults are expected to successfully navigate.

### **Purpose of the Study**

The purpose of this study was to explore the healthy aging process by exploring the selected characteristics associated with health literacy.

### **Research Question**

One research question guided this study:

To what degree is health literacy associated with technology use, education and ethnicity?

## **Definitions**

*Health literacy*: health literacy in this study refers to, “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2006, p. 32). Health literacy will be measured by the Newest Vital Sign: a health literacy screening tool. *Older adults*: the term older adults in this study is characterized as individuals age 60 or older.

*Self-directed learning*: a “process in which individuals take the initiative, with or without help of others, in diagnosing their learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes” (Knowles, 1975, p. 18).

*South Florida*: is a region in U.S. state Florida. This location is bound by the following counties: Miami-Dade, Broward, and Palm Beach.

*Technology Use Skills*: the term technology use skills in this study is characterized by the habits and type of technology chosen for use in daily life. Technology use skills will be measured by *The Technology Use Questionnaire*: an instrument that was developed by the research staff at the Healthy Aging Research Institute (HARI) and was administered as a part of the *Demographic Questionnaire*. The purpose of this instrument was to evaluate the technology use among older adults.

## **Delimitations**

The sample is limited to older adults living in South East Florida registered in the Healthy Aging Research Institute.

## **Limitations**

Some of the data are based on self-reporting by older adults. The findings may be affected by a desire to provide an expected response or some other type of response bias. The questionnaire used to address some of the research questions has not been previously validated. There may be some issues of reliability and validity. The sample used may hold some limitations. The data from non-English speaking participants were collected by a bilingual research assistant; however, there was no account for variance in dialect. The level of education of the participant may affect participant responses.

## **Overview of the Chapters**

This chapter introduces the nature of the proposed study, the purpose of the research, and the research questions. The significance of the study is also defined within this chapter, along with the definitions, delimitations, and limitations. Chapter 2 provides an in-depth look in to the related literature that guided the research inquiry. Chapter 3 details the methodology for conducting the research. This chapter includes the description of the research setting and background of the study. The research design, sample, and procedures are included in this chapter. Chapter 4 includes descriptive information on the samples and the results of the analysis. Chapter 5 includes the conclusion and discussion drawn from the findings, implications from the findings, and suggestions for further research are also found in the chapter.

## II. REVIEW OF THE LITERATURE

This chapter begins with a broad review of the literature on health literacy, technology use in older adults, older adults in South Florida and the history of the Healthy Aging Research Institute.

### **Health Literacy**

**History of health literacy.** Research in the field of health literacy spans many different areas of investigation such as communication, education, behavioral psychology, medicine, anthropology, linguistics, and health promotion (Bessette, 2009). The term was first used in 1974 (Matzke, 2007). However, the first attempt to construct a complete profile of adult literacy in the United States came from the results from 2003 National Center for Education Statistics (NALS) (as cited in Matzke, 2007). The results from the Louisiana State Adult Literacy Survey part of NALS 1992 (Cormier, 2006; Matzke, 2007) prompted a state wide task force to address health literacy.

**Health literacy as its own field of study.** In recent years there has been a growth of the literature, specifically from 2001 to 2007.

Data analysis shows a clear upward growth in the numbers of articles published about health literacy from 1997-2007. In 2007 alone, 181 articles were published on this topic, almost 10 more than were published in 1997. This dramatic increase indicates a growing recognition of health literacy as a legitimate research topic

and denotes a better understanding of the subject as well as its implication for medical and educational practice. (Bankson, 2009, p. 150)

**Health literacy's conceptual model.** Many conceptual domains are present in the literature on health literacy. Two major underlying core concepts in health literacy are adult education (Merriam, 2004; Stein, 1998) and situated cognition perspective (Schechter & Lynch, 2010). Both theoretical frameworks are very similar to the participatory decision-making movement in medicine. In fact, Davis et al., (2001) found that when asked patients preferred “to-the point information focused on action and motivation and they wanted to emphasize the benefits of [health] screening...the recommendations follow adult learning theory” (p. 198).

Adult learning literature has focused for some time now on the context of health and related health literacy issues. Bankson (2009) results from her bibliometric analysis found that *Adult Learning* is the 6th leading “core” journal that published articles on health literacy between 1997-2007. This journal published 11 articles in the 10-year period. Bankson (2009) remarks that the presence of education related journals as “core journals” on the subject of health literacy, “denotes that health literacy is being explored in a variety of contexts, especially from an educational standpoint” (p. 149). Bankson's (2009) study shows that health literacy is a multidisciplinary topic, and it encourages more collaborative scholarship. She states, “both medical providers and adult literacy professionals can work in concert ... to combat low health literacy” (Bankson, 2009, p. 150).

**Contrasting definitions of health literacy.** Throughout the literature review multiple definitions of health literacy has arisen. “[W]e have allowed authors to define

health literacy as it relates to and forms the basis of their work” (Kars, Baker, & Wilson, 2008, p. xii). When reviewing the book *The Medical Library Association Guild to Health Literacy* McCord (2008):

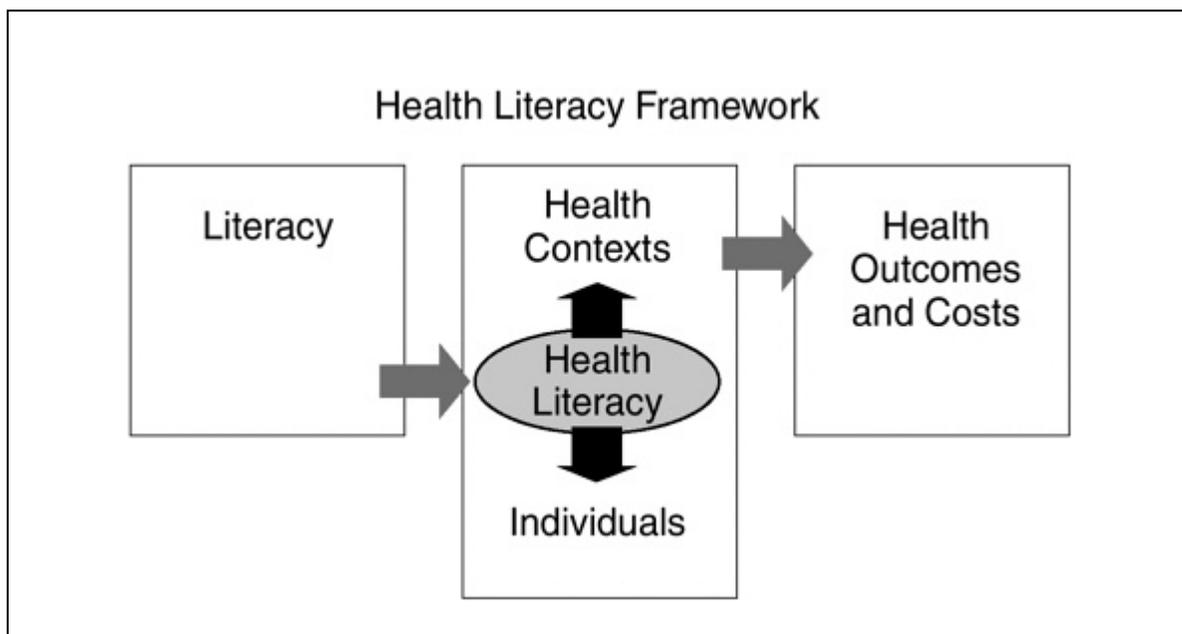
counted at least ten different definitions for the phrase ‘health literacy’ including those from the World Health Organization, the American Medical Association, the US Department of Health and Human Services, the National Institute on Deafness and Other Communication Disorders, and the Centre for Literacy in Quebec. (p. 155)

However, for the purpose of this paper, the author has chosen to define health literacy 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” (Ratzan & Parker, 2006, p. 32).

**Contrasting perspectives of health literacy.** In addition to contrasting definitions of health literacy, there is a difference in perspectives. Bessette (2009) views health literacy as a framework. Paasche-Orlow and Wolf (2007) choose to see causal pathways between low health literacy and health outcomes. Nutbeam (2008) viewed health literacy as an evolving concept. In that health literacy is seen as an asset (personal: educational, adult education, & health promotion roots) verses risk (clinical aspects). “In [the risk] context, poor literacy skills are seen as a potential risk factor that needs to be managed in the process of providing clinical care” (Nutbeam, 2008, p. 2,073). The risk model is more goal oriented and is restricted to clinical settings. “Health Literacy in [the asset factor] case is seen as a means to enabling individuals to exert greater control over their health and the range of personal, social and environmental determinants of health”

(Nutbeam, 2008, p. 2,074). The asset model focuses on enabling individuals to exert greater control over a broad range of factors that determine health. It can be applied to a broad range of settings.

For the purpose of this study, the framework for health literacy comes from a monograph published by the Institute of Medicine (Nielsen-Bohlman, Panzer, & Kindig, 2004). It places health literacy at the intersection between literacy, health context, and health outcomes. As illustrated by Figure 1, health literacy is the link between the individual and his/her health context.



*Figure 1.* Health Literacy Framework. Reprinted from *Health literacy: A prescription to end confusion* by L. Nielsen-Bohlman, A. M. Panzer, and D. A. Kindig, (Eds.). (2004). Washington, DC: The National Academic Press.

**Prevalence of low health literacy.** The extent of individuals that have low health literacy is astonishing. It is estimated that 40 million Americans have limited literacy (Williams, et al., 2002). This translates to approximately one-third of the population (36%) is estimated to have basic or below basic health literacy (Martin, et al, 2009). A

systematic review of U.S. studies show that in America the prevalence of low health literacy is 26% and 20% for marginal health literacy (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). Having marginal health literacy is still inadequate. When accounting for both low, and marginal health literacy, the Institute of Medicine found estimates that 90 million American adults may lack the necessary skills to effectively use the U.S. health care system (Institute of Medicine, 2004). Looking at select populations Williams, Davis, Parker, and Weiss (2002) found that more than 33% of patients 65 and up have inadequate or marginal health literacy, and 80% patients have inadequate or marginal health literacy in a hospital setting.

It is important to note that 66-75% of adults in the lowest level of literacy describe themselves as being able to read “well” or “very well” and that “official reports of the health literacy survey emphasized that the majority of adults (53%) had intermediate health literacy” (Ratzan & Parker, 2006, p. 713).

**Costs.** The prevalence of low health literacy is a very costly epidemic. Health literacy accounts for 3-5% of the nations’ total health care cost per year (Eichler, Wieser, & Brugger, 2009). Patients with low health literacy will see anywhere from \$143 to \$7,798 dollar increase in personal health related cost per person per year (Eichler et al., 2009).

**Individual factors associated with low health literacy.** Throughout the literature numerous studies show the factors associated with low health literacy. They are as listed:

- Efficacy (Parikh, Parker, Nurss, Backer, & Williams, 1996; Parker & Kreps, 2005)

- Age (Artinian, Lange, Templin, Stallwood, & Hermann, 2001; Beers et al., 2003; Gazmararian et al., 1999; Schechter & Lynch, 2010; Williams, Baker, Honig, Lee & Nowian, 1998; Williams et al., 2002; Wilson, Racine, Tekieli, & Williams, 2003)
- Cognitive ability (Baker, Gazmararian, Sudano, & Patterson, 2000; Baker et al., 2002; Matzke, 2007; Paasche-Orlow et al., 2005)
- Income (Matzke, 2007)
- Ethnicity (Artinian et al., 2001; Beers et al., 2003; Bennett et al., 1998; Foltz & Sullivan, 1996; Gazmararian et al., 1999)
- Geographic location (Al-Tayyib, Rogers, Gribble, Villarroel, & Turner, 2002; Artinian et al., 2001; Gazmararian et al., 1999)
- Education level (Gazmararian, 1999, Matzke, 2007; National Center for Education Statistics, 2006)
- Shame (Parikh et al., 1996; Parker & Kreps, 2005)
- Happiness (Angner, Miller, Ray, Saag, & Allison, 2010)
- Fear (Parikh et al., 1996; Parker & Kreps, 2005)
- Unwilling to admit low literacy (Kirch, Jungeblut, Jenkins, & Kolstad, 1993)
- Physical abilities; such as vision and hearing impairment (Porth, 2007; Saeed & Rasden, 1994)
- Social trust (Schechter & Lynch, 2010)
- Unwillingness to disclose information about personal health status to health professional (Schechter & Lynch, 2010)

**Health system factors associated with low health literacy.** There are several known health system factors associated with low health literacy. The first being compliance with complicated medication regimes (Matzke, 2007). “There are 11,000 types of medications available in the United States today than compared to several hundred available in the 1960s” (Schwartzberg et al. as cited in Matzke, 2007, p. 22). The second is time spent with patients; “Patients are experiencing shorter office visits and not having adequate time to communicate with their physicians” (Davidoff as cited in Matzke, 2007, p. 22). The third is the increases in expectations of self (Williams et al., 2002), and finally, the availability of multiple health care choices (Matzke, 2007).

**Health literacy and health outcomes.** Arguably, there is no stereotype for individuals with low health literacy (Williams et al., 2002). However, there are associated health outcomes (clinical verses public) of low health literacy. “Over the past 10 years, literature on the substantial and substantive impact of limited health literacy on individuals’ health and health care experiences has proliferated (e.g., Parker, 2000)” (Schechter & Lynch, 2010, p. 4). “The research evidence is now overwhelming” (Schechter & Lynch, 2010, p. 4).

**Public.** There is a proven link between low health literacy and higher medical costs (Cormier, 2006). “Weiss (2003) estimates that low literacy skills cost the United States \$50 to \$73 billion annually” (Cormier, 2006, p. 3). Individuals with low health literacy are at a greater risk for increased hospitalization (Baker, Parker, Williams, & Clark, 1998; Baker et al., 2002; Cormier, 2006; Matzke, 2007; Williams et al., 2002). Additionally research indicates higher emergency room visits (Baker et al., 2002) for individuals with low health literacy.

***Clinical.*** Individuals with low health literacy experience poorer health outcomes (Matzke, 2007). In a study by Weiss, Hart, McGee, and D'Estells (1992), they found a relationship between literacy and health status (as cited in Cormier, 2006). Poorer health knowledge (Matzke, 2007; Williams et al., 2002) is also associated with low health literacy. One study found that among individuals with high blood pressure and diabetes, those who had low health literacy were more likely to also have lower knowledge about their diseases (Williams et al, 1998). Ishikawa, Takeuchi, & Yano (2008) looked at patients who had type 2 diabetes and found that limited functional health literacy is related to poor knowledge of diabetes, congruent with previous research.

Additional evidence has found an association between low health literacy and poor awareness of health services available (Matzke, 2007). Those individuals are less likely to participate in health prevention activities (Matzke, 2007). For instance, they may be less likely to receive preventative services such as, vaccines (Scott, Gazmararian, Williams, & Baker, 2002), pap smears (Scott et al., 2002), mammograms (Baker et al., 2002; Scott et al., 2002), cancer screening for cervical cancer (Bennett et al., 1998; Davis et al., 2001; Lindau, Tomori, McCarville, & Bennett, 2001), routine health screenings (Lindau et al., 2001), and sexually transmitted disease (STD) screening (Fortemberry et al, 2001).

The lack of awareness for services, and the low likelihood for participation of routine health screenings, results in late entry into the health care system. This in turn causes advanced stages of disease in these individuals. Several studies outline the effects of late entry to the health care system due to low health literacy. Lindau et al. (2001) found an increase of cervical cancer. Davis et al. (2001) found an increase of colorectal

cancer, and Bennett et al. (1998) found an increase of prostate cancer (as cited in Cormier, 2006).

Issues with family planning are affected by the lack of awareness for services. Gazmararian, Parker, and Baker (1999) (as cited in Cormier, 2006), found that women with low health literacy are more likely to want more information on birth control and were more unaware of when they were more likely to become pregnant. Kaufman, Skipper, Small, Terry, and McGrew in 2001 (as cited in Cormier 2006) found that literacy levels were correlated to breastfeeding during the first two months postpartum and women with higher health literacy were more likely to breastfeed exclusively.

Arnold et al. (2001) (as cited in Cormier, 2006), found that women with low health literacy demonstrated less knowledge regarding health hazards related to smoking while pregnant.

Additionally, Fredrickson et al. (1995) found that individuals with low health literacy have difficulty seeking care for their children (as cited in Cormier, 2006).

**Access and use of health care.** How individuals access and use health care institutions are of interest to researchers in the field of health literacy. Research indicated that individuals with low health literacy may have difficulty with discharge instructions (Spandorfer, Karras, Hughes, & Caputo, 1995; Wilson & McLemore, 1997). McCray (2005) noted that individuals with low health literacy have poor recall and low comprehension of health care advice and instructions, as well as poor understanding of diseases, and poor problem-solving skills (as cited in Matzke, 2007). Williams et al. (1995) found that individuals with low health literacy have difficulty with follow up

appointments (as cited in Cormier, 2006). Lindau et al. study in 2001 found low rates of cervical cancer screening follow up appointments among women with low health literacy.

Issues of noncompliance with the plan of care (Gazmararian et al., 1999; Williams, Baker, Honig, Lee, & Nowlan, 1998; Williams Baker, Parker, & Nurss, 1998) are of concern among individuals with low health literacy, as well as, issues with medication adherence (Matzke, 2007; Williams et al., 1995). “There are 11,000 types of medications available in the United States today than compared to seven hundred available in the 1960s (Schwartzberg et al. as cited in Matzke, 2007, p. 22). Often patients are required to take multiple medications to manage their medical needs. These medications can be accompanied by a required time of day, specific diet, and whether or not to be taken with or without food. This relationship of medication and schedule, interceded by the idea of multiple medications, is complex even for the educated and highly organized individual.

**Management of health and illness.** Self-efficacy plays a major role in management of health and illness. Issues of motivation (Schechter & Lynch, 2010) have been found among individuals with low health literacy. Researchers have found difficulties with chronic disease management with individuals with low health literacy (Gazmararian, Williams, Peel, & Baker, 2003; Matzke, 2007). Chronic disease management difficulties are found among such diseases as: diabetes (Schillinger et al., 2002; Reid et al., 1995), heart disease (Williams, Baker, Parker, & Nurss, 1998), Depression (Gazmararian, Baker, Parker & Blazer, 2000), prostate cancer (Bennett et al., 1998), cervical cancer (Lindau et al., 2001), and asthma (Williams, Baker, Honing, Lee, & Nowlan, 1998). Kalichman, Romachandran, and Catz (1999) found that individuals

with HIV and low health literacy had compliance issues with drug therapy; they were four times more likely to report skipped dosage. Li et al. (2000) (as cited in Cormier, 2006) found that patients with lower health literacy who had breast cancer were significantly correlated with lower medication compliance.

### **Low Health Literacy Among Older Adults**

One population significantly affected by low health literacy skills is older adults (Beers et al., 2003; Benson & Forman, 2002, Gazmararian et al., 1999; Schillinger et al., 2002, Williams et al., 1995, 1998). Issues such as vision, hearing, and cognitions are common in the elderly population and are often additional obstacles to overcome. Hearing loss occurs with age and affects 23% of individuals between the age of 65 and 75 and 40% older than 75 years of age (Saeed & Rasden, 1994). “Approximately 13 million individuals have cataracts which cause visual problems and they occur in 50% of individuals between 64 and 74 years of age and 70% in those over 75 years (Solomon & Donnenfeld, 2003)” (Matzke, 2007, p. 20). Often these issues go unreported (Friedman et al., 1999).

Older adults generally carry the largest burden of both chronic disease management and higher health care costs (Berk & Monheit, 2001). Older adults demand the most health care needs, “limited health literacy in older adults may contribute to a situation in which those most in need of healthcare may be those least able to access and benefit from the care” (Institute of Medicine, 2004, p. 80). A major component of this study was to investigate the impact of technology has on older adult’s health literacy.

## **Technology Use and Health Literacy in Older Adults**

**Internet challengers for older adults.** In an expert panel review in 2009, the U.S. Department of Health and Human Services identified eight challenges older adults have in regards to internet usage (Centers for Disease Control and Prevention, 2009). They are as listed: (a) many web sites use technical jargon and scientific terms that are not familiar to the lay audiences; (b) many search engines do a poor job of identifying appropriate and accurate information; (c) consumers often have trouble knowing which information is accurate; (d) few computers have innovative features that would make it easier for older adults to use; (e) older adults have limited access to the internet; (f) computer functions may be physically difficult for older adults to use; (g) screen flicker inherent to many computer screens makes online information difficult for older adults to read.

## **South Florida's Aging Population**

According to the 2010 Census, South Florida's population demographics are made up of 70.3% white, 21% African American, 41.6% Hispanic, 0.3% Native American, 2.3% Asian, 3.5% other races, and 2.5% two or more races (U.S. Census Bureau, 2010). South Florida has the highest percentage of senior residents in the country, with 17.3% older than age 65 in 2010 (Bureau of Economic and Business Research, 2011). The U.S. Census figures show Palm Beach County has Florida's largest number of people who are 85 and older (49,205). Ten years ago, Miami-Dade County held the highest. Palm Beach County's 85-plus population grew 40.7% between 2000 and 2010 totaling 99,849 people who are 80 and older. Older adults make up 21.6% of Palm Beach County's population (Bureau of Economic and Business Research, 2011).

## **Healthy Aging Research Institute**

The Healthy Aging Research Institute (HARI) at Florida Atlantic University was created by Dr. Joseph G. Ouslander and Dr. Ruth Tappen (See Appendix C). The goal of the three-year project was to first recruit a diverse sample of community dwelling adults from four ethnic groups to participate in the Healthy Aging Research Registry. This population will serve as the initial population for future longitudinal studies and a series of intervention studies. The HARI also provided faculty and students from multiple colleges' opportunities to collaborate on interdisciplinary studies that utilized data collected from the registry. An additional goal of HARI was to build a self-sustaining institute or center on healthy aging.

### III. METHODOLOGY

This chapter describes the research study and design. The research design included a description of the sample in this study and delineated the procedures for collecting data. The methods for data analysis are outlined. In addition, this chapter reviews the relevant information regarding the Healthy Aging Research Institute and the data stored in the participant registry.

The data that were used in this study was archival, being that it had already been collected and stored in accordance with institutional standards. Only selected criteria were chosen for the purposes of this study as it related to the research questions.

#### **Purpose of the Study**

The purpose of this study was to explore the healthy aging process by: (a) examining the selected demographics of older adults in South Florida; (b) examining technology use of older adult in South Florida; (c) examining the health literacy levels of older adults in South Florida; (d) determining whether a relationship exists between technology use and health literacy levels among a group of older adults living in South Florida; and (e) evaluating the effects of health literacy as it related to technology use in older adults in South Florida. One research question and hypothesis guided this study. It is listed in chapter one and in the procedures section of this chapter.

#### **Research Setting**

This study will present data from an ongoing project involving older adults residing in southern Florida. The aging population in this region is uniquely diverse (U.S. Census Bureau, 2010), with a substantial population consisting of African American, Afro Caribbean, Hispanic, and European-American individuals.

### **Research Design**

This study employed a non-experimental research design. This study included data gathered from The South Florida Quality Aging Registry as a part of Florida Atlantic University's Healthy Aging Research Initiative (HARI). Results of this research study should enhance and continue the discussion on the factors associated with healthy aging in South Florida.

This research study first examined data from selected demographics of older adults, their health literacy levels, and their patterns of technology use. Then an investigation was made to determine whether a relationship existed between older adults' use of technology and their health literacy levels. This research study used previously collected data from the South Florida Quality Aging Registry as a part of Florida Atlantic University's Healthy Aging Research Initiative (HARI).

**HARI's study population.** HARI recruited a diverse and heterogeneous sample of participants for the South Florida Quality Aging Registry. HARI used the following criteria for inclusion:

- Minimum age of 60
- Speak English or Spanish
- Capable of ambulating with minimal assistance and/or an assistive device such as a cane or walker

- Be a member of the ethnic groups under the study (African American, Afro Caribbean, Hispanic, and European-American)
- Pass the assessment of decisional capacity: an adjusted (age and education) Mini-Mental State Examination (MMSE) score minimum for eligibility/pass (score greater than 23).

The sample used in this study was collected during an initial three-year project (2010-2013). The goal of the Registry was to enroll 200 participants age 60 or older from each of the four different ethnic groups (African American, Afro Caribbean, Hispanic, and European-American). Currently, the Registry holds a population of 456 total participants.

**HARI's recruitment and consent process.** The Healthy Aging Research Institute (HARI) used a multifaceted recruitment strategy to recruit among the study's selected ethnic groups. HARI's research assistants who primarily collected the data from the participants represented the diverse ethnic backgrounds involved in the study population. HARI's research assistants were trained in the following research recruitment strategies:

- Worked with the leadership of senior centers, senior living communities, churches, and synagogues to gain their support in developing effective strategies to recruit in their populations;
- Conducted educational programs at these sites to discuss healthy aging and generate interest in the population;
- Made a wide distribution of attractive, easy to read flyers (see Appendix A) through mailings and postings;

- Ensured easy access to recruiters by phone;
- Conducted in-person assessments at local sites, or participant's homes if they so desired to avoid transportation challenges;
- Provided reimbursement for transportation when needed; and
- Provided various incentives to enroll and continue participating, including periodic newsletters and free educational events.

The above mentioned recruitment strategies were used both to recruit and to enhance participant retention over time. The HARI's goal was to retain 85% of participants over the course of the first three years for additional studies.

Informed consent was obtained from participants in the Healthy Aging Research Institute, and the Florida Atlantic University institutional review board approved the study. Participants were informed of the purpose of the study, its research methods, and the risk/benefit. The voluntary and confidential aspects of this study were emphasized. All questions were answered before consent was signed. Participants were given a copy of signed documents. A bilingual research assistant conducted the consent process when a participant preferred to speak in Spanish. The trained research assistants conducted the assessments in person. Participants were given the option of completing assessments at home or at one of the collaborating institutions. Participants were informed that they were free to decline to answer any questions that they did not wish to answer or to stop participating at any time.

## **Instrumentation**

The instruments used for this research included: (a) the HARI Demographic Questionnaire; (b) the *Newest Vital Sign*; and (c) the HARI Technology Use Questionnaire.

**The Demographic Questionnaire.** Research personnel from the Healthy Aging Research Institute (HARI) collaboratively developed the *Demographic Questionnaire*. The purpose of this instrument was to evaluate various demographic characteristics of older adults living in South Florida.

The *Demographic Questionnaire* consists of 124 questions. For the purposes of this study, only two questions from the *Demographic Questionnaire* were used:

Question one: Which racial and ethnic group do you most identify with? African American, Afro Caribbean, Hispanic, and European-American.

Question two: Education in number of years.

**The Newest Vital Sign.** The *Newest Vital Sign (NVS)* was an instrument designed by a panel of health literacy experts, actual patients, interviewers, and data analysts, using a variety of scenarios. Over 1000 patients were given health-related information and then the patients demonstrated their ability to use the information by answering questions about the various scenarios. The Spanish version of this test was developed by translation and back-translation of the English version.

The health literacy level was measured using the *Newest Vital Sign (NVT)* (see Appendix D), “a nutrition label that is accompanied by 6 questions and requires 3 minutes to administer” (Weiss et al., 2005, p. 1). The instrument yields a total score ranging from 0 to 6. Responses with more than four correct are unlikely to have low

health literacy, whereas fewer than 4 correct responses indicates a possibility for limited health literacy (Weiss et al., 2005). According to Weiss et al. (2005) the *Newest Vital Sign* is reliable; “The Internal consistency of the Newest Vital Sign was good (Cronbach’s  $\alpha = 0.76$  in English) as was the criterion validity ( $r = 0.59$ ,  $p < .001$ )” (p. 517). It has been used among a variety of populations and is one of the two industry standards for health literacy measurement.

**Technology Use Questionnaire.** The *Technology Use Questionnaire* is an instrument that was developed by the research staff at the Healthy Aging Research Institute (HARI) and was administered as a part of the *Demographic Questionnaire*. The purpose of this instrument was to evaluate technology use among older adults.

The *Technology Use Questionnaire* consists of 24 questions. For the purpose of this study, only 10 of the questions from the *Technology Use Questionnaire* were used. The selected 10 questions are “yes/no” type questions that are summed to give a score between 0-10. An overall score was derived for responses from each participant. Responses ranging 10-8 are considered high technology use, responses that range among 7-5 are considered moderate technology use, and responses ranging from 4-0 are considered low technology use.

### **Validity and Reliability**

To test for internal consistency a single construct item analyses was conducted on the 10 item from the *Technology Use Questionnaire* assumed to assess technology use. Cronbach’s alpha for the *HARI Technology Use Questionnaire* 10 items, were .83 respectively. Friedman’s test,  $\chi^2(9, N=102) = 314.8$  was found significant at the .000 level and the Kendall coefficient of concordance of .26 indicating fairly strong difference

among the items. Resulting in the use of the initial scale, *HARI Technology Use Questionnaire* 10 items used, to assess technology use in this study.

## **Procedures**

**Data Collection.** All archival data collected from the Healthy Aging Research Institute (HARI) was compiled into a data registry called the South Florida Quality Aging Registry. Participant's data were entered into Excel spreadsheets and then uploaded into SPSS for quantitative analysis.

The data registry was handled with strict attention to maintaining confidentiality. All data collected were kept under lock and key in the research assistant's office located on the main campus of Florida Atlantic University. Electronic files of the HARI participant registry were password protected and access was given to project personnel only. All project personnel have completed the Human Subject Training established by the University Division of Research, Office of Research Integrity and the Florida Atlantic University Institutional Review Board.

For the purposes of this study, the researcher used selected measures from the HARI testing protocol (see Appendix E). These selected measures were collected on day one of HARI's testing protocol. Two categories were looked at: the Socio-demographic Measure (as measured by the *Demographic questionnaire* and the *Technology Use Questionnaire*) and the Functional Status Measures (as measured by the *Newest Vital Sign*). In particular selected Socio-demographic Measures were looked at including the Use of Technology (Figure 2) and the newest vital sign (a measure for health literacy).

1)	Do you use the World Wide Web, or the internet?	Yes	No
	If yes, do you regularly use the World Wide Web, or the internet for:		
1.	Sending and receiving email?	Yes	No
2.	Making purchases?	Yes	No
3.	Searching for information?	Yes	No
4.	Making reservations (i.e. travel)?	Yes	No
2)	Do you use health related apps?	Yes	No
3)	Do you use the internet to find information related to health?	Yes	No
4)	Are you familiar with social media networks (Facebook, Twitter, YouTube, Blogs, etc.)?	Yes	No
5)	Do you use social media networks (Facebook, Twitter, YouTube, Blogs, etc.) to find information about health and wellness?	Yes	No
6)	Do you own a cell phone?	Yes	No

Figure 2. Selected questions from the HARI Technology Use Questionnaire.

**Data Analysis.** This study explored the selected demographic and technological characteristics associated with health literacy. Data was analyzed using the computer software package, IBS SPSS version 21. An alpha level of .05 was used to assess statistical significance.

**Research question.** To what degree is health literacy associated with technology use, education and ethnicity?

Archival data on the population made up of 456 older adults among HARI's participant registry on measures: (a) *Demographic Questionnaire*; (b) *Use of Technology Questionnaire*; and (c) *Newest Vital Sign* was used to test the research question 1.

To determine if there were any statistically significant differences among ethnic groups and their associated health literacy level, a one-way ANOVA was performed. To determine if there were any statistically significant differences among Ethnic groups and their technology use, a one-way ANOVA was performed. A correlation coefficient was performed to assess the degree that health literacy and education level are related. A correlation coefficient was performed to assess the degree that health literacy and technology use are related. Multiple regression analysis was used to evaluate how well the variables of education, ethnicity, and technology predicted health literacy score.

Only data from participants who successfully completed all measures were included: (a) *Demographic Questionnaire*; (b) *Use of Technology Questionnaire*; and (c) *Newest Vital Sign* was used to test the research question.

### **Chapter Summary**

This chapter outlined the proposed research study and design. The research design included a description of the sample in this study and delineated the procedures for collecting data. The methods for data analysis were outlined. This chapter reviewed the relevant information regarding the Healthy Aging Research Institute and the data stored in the participant registry. Chapter 4 discusses the results and the findings from the statistical procedures reviewed in this chapter.

## IV. RESULTS

The purpose of this research was to explore the healthy aging process by exploring the selected characteristics associated with health literacy. The research further investigated the relationship between health literacy and technology use among older adults. Additionally, this study examined the variables that predict health literacy. The criterion variables explored in this study included: education, ethnicity, and technology use.

### **Research Question**

One research question guided this study:

To what degree is health literacy associated with technology use, education and ethnicity?

### **Descriptive Information**

For this study, the sample of 102 (22.3%) of the 456 participants from the South Florida Quality Aging Registry were selected for analysis. This was a sample of 102 participants who successfully completed: (a) the *HARI Technology Use Questionnaire*; (b) *Newest Vital Sign (NVS)* health literacy measures; and (c) answered all of the *Demographic Questionnaire*. The sample of participants met the following criteria established by Healthy Aging Research Initiative (HARI) for inclusion in the South Florida Quality Aging Registry: (a) were a minimum age of 60; (b) spoke English or Spanish; (c) were capable of walking without assistance; (d) identified themselves as a

member of the ethnic groups under the study (e.g., African American, Afro Caribbean, Hispanic, and European-American); and (e) were able to pass the Mibi-Mental State Examination (MMSE).

### **Missing Data**

As outlined in Chapter 3 the South Florida Quality Aging Registry holds archival data for a total of 456 participants. Of that, the researcher found only 206 participants that had records of successfully completing the health literacy measure. Amongst the 206 participants who completed the health literacy measure, only 104 participants completed the selected questions of the *HARI Technology Use Questionnaire*.

The researcher elected to eliminate two additional participants from the study. The first participant eliminated failed to answer the sub-question on question one of the technology questionnaire. The second participant eliminated answered contradictory responses in one of the questions in the technology questionnaire. The resulting data set used for this study had a total of 102 participants.

### **Descriptive Statistics**

The total number of participants ( $n = 102$ ) represented diverse demographics; there was a disproportionate amount of European American among the sample. Ethnicity percentages are as listed: 18 (17%) of African American, 8 (7.8%) Afro Caribbean, 11 (10.7) Hispanic, and 65 (63.7%) European-American was represented. Demographic data are listed in Table 1.

Table 1

*Demographic Characteristics for Older Adults in South Florida*

Sample from South Florida Quality Aging Registry		
Ethnicity	n	%
African American	18	17.6
Afro Caribbean	8	7.8
Hispanic	11	10.7
European American	65	63.7
Total	102	100
Education	15.00	
Mean score (in years)	(n = 102)	
Health literacy	3.88	
Mean Scores	(n = 102)	
Technology Use	7.5	
Mean Scores	(n = 102)	

**Data Collection Methods**

Health literacy was determined from the *Newest Vital Sign* total score.

Technology use was determined from the *Technology Use Questionnaire* total score.

Both education and ethnicity were determined from the *Demographic Questionnaire*.

Participants' scores from the South Florida Quality Aging Registry were verified through the Healthy Aging Research Institute (HARI).

**Results of Hypothesis Testing**

One research question, converted to null hypothesis for statistical analysis, was used to guide this study. The findings for each are presented.

**Research Question.** To what degree is health literacy associated with technology use, education and ethnicity? H<sub>0</sub>1: Health literacy is not associated with technology use, education and ethnicity.

Archival data on the sample made up of 102 older adults among HARI's participant registry on measures: (a) *Demographic Questionnaire*; (b) *Use of Technology Questionnaire*; and (c) *Newest Vital Sign* was used to test the research question 1. To determine if there were statistically significant differences between ethnic groups and their associated health literacy level a one-way ANOVA was performed.

A one-way analysis of variance was conducted to evaluate the relationship between ethnicity and health literacy. The independent variable, ethnicity, included four groups: African American, Afro Caribbean, Hispanic, and European-American. The dependent variable was the total health literacy score. The ANOVA was significant,  $F(3,98) = 9.568$ ,  $p < .001$ , observed power = 0.95. The strength of the relationship between ethnicity and health literacy, as assessed by  $\eta^2$ , was strong, with ethnicity accounting for 23% of the variance of health literacy ( $\eta^2 = .227$ ). The null hypothesis that there are no differences among the groups was rejected.

Follow up tests were conducted to evaluate pairwise differences among the means. Because the standard deviations among the four ethnicities ranged from 1.18 to 1.87, the researcher choose to assume variances among ethnicities were homogeneous and conducted post hoc comparisons with the use of Tukey HSD. Results indicated were significant differences in means. The African American ethnic group's mean scored was higher than those among the Afro Caribbean ethnic group ( $p < .05$ ). The European American ethnic group mean scored was higher than the Hispanic ( $p < .05$ ) and Afro

Caribbean ( $p < .001$ ) ethnic groups. The Hispanic ethnic group mean scored was lower than the African American ( $p < .05$ ) and European American ( $p < .05$ ) ethnic groups. The Afro Caribbean ethnic group mean scored was lower than the European American ethnic group ( $p < .05$ ). The 95% confidence intervals for the pairwise differences, as well as the means and standard deviations for each ethnic group, are reported in Table 2.

Table 2

*Health Literacy 95% Confidence Intervals of Pairwise Differences in Mean Between Ethnic Groups*

	M	SD	European American	Hispanic	Afro Caribbean	African American
African American (n=18)	3.56	1.79	-2.04 to .29	-1.12 to 2.23	.32 to 4.04*	
European American (n=65)	4.43	1.72		.01 to 2.86*	1.42 to 4.69**	-2.23 to 1.12
Hispanic (n=11)	3.00	1.18	-2.86 to -.01*		-.41 to 3.66	-4.04 to -.32*
Afro Caribbean (n=8)	1.38	1.50	-4.69 to -1.42*	-3.66 to .41		

*Note.* An asterisk indicates that the mean difference is significant at the 0.05 level using Tukey HSD procedure. A double asterisk indicates that the mean difference is significant at the 0.01 level using Tukey HSD procedure.

Correlation coefficients were computed between education level and health literacy. The correlation between education and health literacy was not significant,  $r(100) = .103$ ,  $p < .4$ . The results of the correlational analysis were not statistically significant.

Correlation coefficients were computed among health literacy and technology use. The correlation of health literacy and technology use was significant,  $r(100) = .32$ ,  $p <$

.001. The results suggest that low scores on health literacy tend to be associated with low scores on technology use, and high scores on health literacy tend to be associated with high scores on technology use. However, it is important to note that this is a relatively small effect. The variance in health literacy score that can be predicted from technology use is 10%.

Multiple regression analysis was used to evaluate how well the variables of education, ethnicity, and technology predicted health literacy score. The four ethnicities were dummy coded into three binary predictor variables. The total model accounted for a moderate to small (26.1%) amount of the health literacy variability,  $R^2 = .261$ , adjusted  $R^2 = .222$ ,  $F(5,96) = 6.773$ ,  $p < .001$ . Multicollinearity was not an issue; all VIFs were less than 2.

### **Chapter Summary**

Based on the results of this analysis, there was a relationship between health literacy, technology use, ethnicity and education. Ethnicity plays a significant role in health literacy levels.

The African American ethnic group's mean score was higher than those of the Afro Caribbean ethnic group ( $p < .05$ ). The European American ethnic group mean score was higher than the Hispanic ( $p < .05$ ) and Afro Caribbean ( $p < .01$ ) ethnic groups. The Hispanic ethnic group mean score was lower than the African American ( $p < .05$ ) and European American ( $p < .05$ ) ethnic groups. The Afro Caribbean ethnic group mean score was lower than the European ethnic group ( $p < .05$ ).

There was no statistical support that indicated that educational level contributed to health literacy level. Participant's ethnicity group, education and technology usage predicted his/her health literacy level.

Chapter 5 will summarize the findings of this study. The findings are discussed along with an interpretation of the findings relative to the research literature for health literacy. Conclusions and recommendations for future research are also included in Chapter 5.

## V. DISCUSSION

Health literacy, an individual's ability to successfully navigate the health care system, has been linked to poorer health status (Cormier, 2006; Matzke, 2007; Williams et al., 2002), lower use of preventative services (Scott et al., 2002), and higher health care costs (Eichler, Wieser, & Brugger, 2009). Higher rates of limited health literacy are found in individuals who are non-European American (Artinian et al., 2001; Bennett et al., 1998; Beers et al., 2003; Foltz & Sullivan, 1996; Gazmararian et al., 1999; Poureslami, Rootman, Doyle-Waters, Nimmon, & FitzGerald, 2011) and have lower education levels (Gazmararian et al., 1999; , Baker et al., 1999). Older adults are a venerable population and are subject to the financial and structural access to health care. They may also be burdened by the many individual or personal barriers to health care. There may not be "universal access" to health care because of potential personal barriers to receiving or obtaining health care.

Technology holds the promise of enriching lives and improving health care. But for millions of older adults, technology and the Internet are sources for anxiety and confusion, barriers rather than resources. Technology use has created new opportunities for access to health care but it has also magnified persistent problems. Technology use is unequally distributed, as underserved groups may be less likely to have access or possess the skills to use technology efficiently. Similarly, health literacy is affected by demographic characteristics.

Long-term potential for technology use for improved health literacy rests in part on the ability of researchers to identify the relationship between the two. The results of this study provide the findings and summary of health literacy and technology use among a group of older adults in South Florida.

The purpose of this study was to explore the healthy aging process by: (a) examining the selected demographics of older adults in South Florida; (b) examining technology use of older adult in South Florida; (c) examining the health literacy levels of older adults in South Florida; (d) determine whether a relationship exists between older adults living in South Florida use of technology and their health literacy levels; and (e) evaluate the effects of health literacy as it relates to technology use in older adults in South Florida.

One research question guided this study:

To what degree is health literacy associated with technology use, education and ethnicity?

The sample studies included 102 older adults (age > 60) living in South Florida who had completed profiles on South Florida Quality Aging Registry, as part of the Health Aging Research Initiative (HARI). The sample size represented 22.3% of the total South Florida Quality Aging Registry population. The ethnicities of the participants among the South Florida Quality Aging Registry were African American (17%); Afro Caribbean (7.8); Hispanic (10.7%); European American (63.7%). The education mean was 15, indicating that the majority of participants have education equivalent to have completed high school. The mean health literacy scores were 3.88, demonstrating that the majority of the participants have moderate levels of health literacy. The mean technology

use score was 7.5, indicating that the majority of the participants have a moderate level of technology use.

The primary interest of this study was to explore the characteristics associated with health literacy in older adults and the relationship amongst them. The variables of health literacy, technology use, education, and ethnicity were analyzed for the sample of older adults living in South Florida and a part of South Florida Quality Aging Registry.

There have been several studies examining the associated characteristics with health literacy: efficacy (Parikh et al., 1996; Parker & Kreps, 2005), age (Artinian et al., 2001; Beers et al., 2003; Gazmararian et al., 1999; Schechter & Lynch, 2010; Williams, Baker, Honig, Lee, & Nowian, 1998; Williams et al., 2002; Wilson et al., 2003), cognitive ability (Baker et al., 2000; Baker et al., 2002; Matzke, 2007; Paasche-Orlow et al., 2005), income (Matzke, 2007), ethnicity (Artinian et al., 2001; Beers et al., 2003; Bennett et al., 1998; Foltz & Sullivan, 1996; Gazmararian et al., 1999), geographic location (Al-Tayyib et al., 2002; Artinian et al., 2001; Gazmararian et al., 1999), education level (Gazmararian et al., 1999, Matzke, 2007; National Center for Education Statistics, 2006), shame (Parikh et al., 1996; Parker & Kreps, 2005), happiness (Angner et al., 2010), fear (Parikh et al., 1996; Parker & Kreps, 2005), unwilling to admit low literacy (Kirsch et al., 1993), physical abilities; such as vision and hearing impairment (Porth, 2007; Saeed & Rasden, 1994), social trust (Schechter & Lynch, 2010), and unwillingness to disclose information about personal health status to health professional (Schechter & Lynch, 2010).

Predictor variables such as education and ethnicity have been explored in conjunction with health literacy; however, the variable of technology use is unique to this study. Archival data from participants among the South Florida Quality Aging Registry, a

part of the Healthy Aging Research Initiative (HARI) was used. The instruments used for this research included: (a) *Demographic Questionnaire*; (b) the *Newest Vital Sign*; and (c) the *Technology Use Questionnaire*.

The conclusions and discussion are presented in three areas of research: ethnicity and health literacy, education and health literacy, and the relationship of health literacy and technology use.

## **Conclusions**

**Interpretation.** After exploring the healthy aging process by examining the selected demographics of older adults in South Florida, their technology use and health literacy levels, and the relationship between their health literacy skills and technology use, this study shows that in older adults the demographic factor, ethnicity impacts health literacy level and technology use is related to health literacy. There was one hypothesis presented in this study, it was supported.

***Ethnicity and health literacy.*** The first conclusion resulting from these findings is that a difference does exist among health literacy scores when comparing ethnic groups of older adults. The study examined the relationship between four ethnic groups (African American, Afro Caribbean, Hispanic, and European American) and health literacy scores as measured by the results of the *Newest Vital Sign*. To explore the differences among ethnic group, results of a demographic questionnaire and a health literacy measure were collected from older adults living in South Florida who were members of South Florida Quality Aging Registry.

A one-way analysis of variance was conducted to evaluate the relationship between health literacy and ethnicity. Results from the analysis indicated that older adults

among the African American ethnic group's mean score was higher than those of the Afro Caribbean ethnic group ( $p < .05$ ). The European American ethnic group mean score was higher than the Hispanic ( $p < .05$ ) and Afro Caribbean ( $p < .01$ ) ethnic groups. The Hispanic ethnic group mean score was lower than the African American ( $p < .05$ ) and European American ( $p < .05$ ) ethnic groups. The Afro Caribbean ethnic group mean score was lower than the European ethnic group ( $p < .05$ ). The differences in score between the four ethnic groups was statistically significant  $F(3,98) = 9.568, p < .01$ , and was the strongest relationship found among this study.

These findings are consistent with prior research. Several quantitative research studies have reported health literacy is associated with ethnicity (Artinian et al., 2001; Bennett et al., 1998; Beers et al., 2003; Foltz & Sullivan, 1996; Gazmararian et al., 1999; Heinrich, 2012; Poureslami, Rootman, Doyle-Waters, Nimmon, & FitzGerald, 2011). Howard, Sentell, and Gazmarian (2006) found significant differences in health literacy among community dwelling adults when ethnicity backgrounds were considered.

***Health literacy and education.*** This study examined whether other demographic factors besides ethnicity would contribute to health literacy level. To explore differences among education level, results of a demographic questionnaire and a health literacy measure were collected from older adults living in South Florida who were members of South Florida Quality Aging Registry. Correlation coefficients were calculated among education level and health literacy. The results of the correlational analysis did not show a statistically significant relationship. These findings are inconsistent with prior research.

Research in the field of health literacy has demonstrated that education is an associated factor of health literacy. However, a distinction should be made between

education level, efficacy, and literacy level. Education level does not always dictate an individual's abilities. The seminal study by Paasche-Orlow et al. (2005) reviewed 85 quantitative research studies in the United States. Their analyses revealed that over 25% of subjects had low literacy and 20% had marginal health literacy. This review summarized the "prevalence of health literacy skills in American adults as depicted by reports in the medical literature" and revealed that education, ethnicity, along with age, are associated with low health literacy (Paasche-Orlow et al. 2005, p. 182). Additional quantitative studies reported that health literacy was associated with education level and age (Artinian et al., 2001; Beers et al., 2003; Gazmararian et al., 1999; Williams, Baker, Honig et al., 1998; Wilson et al., 2003). Results from the 2003 National Assessment of Adult Literacy confirm these findings related to education (National Center for Education Statistics, 2006). According to these numerous studies, age, ethnicity, and education level are associated factors of health literacy.

***Predictor variables of health literacy.*** This study examined the variables that predict health literacy. The predictor variables explored were: education, ethnicity, and technology use. Multiple regression analysis was used to evaluate how well the variables of education, ethnicity, and technology predicted health literacy score. Results from this analysis indicated that the total model accounted for a moderate to small (26.1%) amount of the health literacy variability,  $R^2 = .261$ , adjusted  $R^2 = .222$ ,  $F(5,96) = 6.773$ ,  $p < .001$ .

Consistent with prior research, education is among the variables identified as key predictors of technology use, others being gender and age (Fox, 2008, 2011; Kaiser Family Foundation, 2005). Selected studies have confirmed that higher educated

individuals were more likely to go online for health information (Jensen, King, Davis, & Guntzviller, 2010).

The results of this study are congruent to the findings of Jensen et al. (2010). Their study found that among a group of low-income adults, those individuals with higher health literacy skills were more likely to use technology. Furthermore, Jensen et al. (2010) found that health literacy mediated the relationship between age and technology use for health information, similar to previous studies (Fox, 2008).

### **Limitations**

The current study had several limitations. The sample was derived from archival data on older adults (age 60 or older) from South Florida, and therefore, may not be representative of older adults of the rest of the United States. The use of archival data are a limitation of this study. The potential disadvantages of using archival data include, but are not limited to: appropriateness of data, completeness of documentation, identifying errors, and quality of data (Shultz, Hoffman, & Reiter-Palmon, 2001). Thus, the study's sample size was a result of limited or missing archival data. This was mitigated by the researcher's choice of study design and statistical analysis appropriateness for the sample size. This was typical of the field. Additional limitations include the measurement of technology use. The instrument used in this study has not been validated outside this population. The data from non-English speaking participants were collected by a bilingual, Spanish-English speaking research assistant; however, there was no account for variance in dialect or language. Each of these limitations could affect the interpretation of the findings.

## **Recommendations**

Based on the findings from this study, the recommendations for further study are to:

- Further investigate the relationship of health literacy and technology use among a population of older adults. This research should clearly differentiate between use, access, and type of use. Research on the use of technology often takes into account location of use, this should be considered as well. Several researchers have suggested additional research on the rigorous assessment of health literacy, including a focus on the cognitive demands associated with the use of this assessment tool.
- Replicate this study in a larger population to determine if the findings of this study are consistent. This research should include an equally diversified population across individual's characteristics, such as ethnicity. It should also include clearly defined terminology as it pertains to technology use measurement.
- Further investigate the role of ethnicity in health literacy, more specifically the ethnicity of Afro Caribbean.
- Further evaluate the role ethnicity plays in technology use through qualitative assessment.
- Explore the relationship between education level and health literacy among older adults. This research should investigate, cognitive abilities, efficacy as it relates to education level, and health literacy. Previous studies suggest further investigation into the role education level plays on health literacy level, as it is often debated whether education level dictates literacy level.

- Utilize mixed method approach to understanding the relationship of health literacy and technology use among a population of older adults.
- Explore other variables associated with health literacy such as age, gender, overall wellness.
- Further explore the relationship between health literacy and technology use by evaluating the demographic variables that may moderate the relationship.

### **Closing Remarks**

Some of these findings are important for researchers, educators, and practitioners. These findings further confirm what is already known in the field about individual factors associated with health literacy. These findings suggest that the role of technology, and technology use is an important factor in an individual's health literacy. Healthy aging is a multifactorial process that is impacted by not only individual characteristics, but is also the divergence between the individuals' health literacy skills, technology use and the complicated demands of the health care system. Exploring the relationship between health literacy and technology use should continue. This understanding is essential to alleviating health disparities among older adults.

## APPENDIXES

### Appendix A. HARI Research Recruitment Flyer



**FAU** Institutional Review Board  
Approved on: 3/9/2012  
Expires on: 3/8/2013

# We Need Your Help to Improve the Health of Older Americans!

*Participants (Men and Women) Must Be Age 60 or Older*

**Participation will involve:**

- Two sessions to assess your health and well-being, including tests of memory, mood, and physical function
- Taking your vital signs, including blood pressure and pulse
- Providing a small blood sample (optional)
- Regular brief follow-up calls or visits to assess changes in your health

**Participants will receive:**

- Results of assessments
- Opportunities to participate in education on healthy aging
- A gift certificate to a local store at each session
- A certificate of appreciation at the end of the year
- Opportunities to participate in other studies if interested

*Participation in any aspect of this project is completely voluntary and all information will be kept confidential*

**FAU PROGRAM ON HEALTHY AGING**

**Project Co-Directors:**  
Dr. Joseph Ouslander, MD, Associate Dean and Professor,  
Charles E. Schmidt College of Medicine  
Dr. Ruth Tappen, EdD, RN, Eminent Scholar and Professor,  
Christine E. Lynn College of Nursing

**If you are interested, contact:  
Dr. Sanya Diaz: 561-297-4323**

**FAU**  
FLORIDA ATLANTIC  
UNIVERSITY

## Appendix B. HARI Research Study Executive Summary

### Healthy Aging: Interdisciplinary Research to Improve the Quality of Life and Quality of Care for Aging Americans

PI: Joseph G. Ouslander, MD  
Professor and Associate Dean for Geriatric Programs  
College of Biomedical Science  
Professor (Courtesy), College of Nursing  
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Co-PI: Ruth Tappen, EdD, RN, FAAN  
Eminent Scholar and Professor  
College of Nursing  
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#### Executive Summary

This is a proposal to build the infrastructure for a nationally recognized interdisciplinary research program on healthy aging. The rationale underlying this proposal is compelling. Our country faces a demographic imperative - the aging of our population. Aging is inevitable, and all of us hope to age in a healthy manner with a good quality of life. At FAU we sit in the epicenter of the aging phenomenon, and we have a tremendous opportunity to contribute to research that will make this hope become a reality.

The Healthy Aging research initiative will result in new interdisciplinary collaborations among FAU faculty and students that would not otherwise occur, provide opportunities for a broad range of research (including health services, clinical, translational, and basic), and result in innovative research proposals for federal, state, foundation, and other sources of funding. It involves eight colleges, two FAU community programs (the Memory and Wellness Center and the Life Long Learning Society), and five external collaborators (three academic institutions and two community agencies), and encompasses three additional research themes submitted as FAU pre-proposals (Health Disparities, Health Technology, and Caring).

The goals of the proposed 3-year project are to: 1) recruit a diverse sample of community dwelling adults from four ethnic groups to participate in a “Healthy Aging Research Registry”, which will serve as the initial population for a longitudinal study and intervention studies on healthy aging and diversity; 2) provide faculty and students from multiple colleges with opportunities to collaborate on new and innovative interdisciplinary studies that utilize data collected from Registry participants; and 3) leverage the University’s support to build a self-sustaining Institute or Center on Healthy Aging that will become nationally recognized for research and other programs designed to improve the quality of life and quality of care for aging Americans.

## Appendix C. IRB Approval Documentation

# FLORIDA ATLANTIC UNIVERSITY

### CHRISTINE E. LYNN COLLEGE OF NURSING

*Committed to Nurturing the Wholeness of Person & Environment through Caring*

Christine E. Lynn Eminent Scholar

August 27, 2013

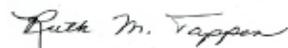
To the Florida Atlantic University (IRB):

I am familiar with Elizabeth Swann's proposed research project entitled *ADULT LEARNING FOR HEALTH AGING: AN INVESTIGATION OF HEALTH LITERACY AND TECHNOLOGY USE IN OLDER ADULTS*. I understand that she will use the HARI data set as archival data for the purposes of her dissertation with the understanding that we retain the title of peer reviewers to the study. As peer reviewers we will be consulted for the interpretation of the data analysis. To achieve this, I have agreed to serve as an outside member of her dissertation committee.

I understand Ms. Swann's research will be carried out following sound ethical principles, as was applied in the original collection of the data. The archived data being requested by Ms. Swann were collected under prior IRB approval and participant involvement in this research study was strictly voluntary and confidential as described in the protocol.

Therefore, as an institutional authority for Health Aging Research Initiative, I agree that Elizabeth Swann's research project may be conducted in collaboration with the Health Aging Research Initiative.

Sincerely,



Ruth M. Tappen, EdD, RN, FAAN  
Christine E. Lynn Eminent Scholar and Professor

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*An Equal Opportunity/Access/Affirmative Action Institution*

## Appendix D. New Vital Sign Questionnaire Instructions, Example, and Scoresheet



### How to Use the Newest Vital Sign

1. **Instructions for the participant.** *"We are asking our participants to help us learn how well participants can understand the medical information that doctors give them. Would you be willing to help us by looking at some health information and then answering a few questions about that information? Your answers will help our doctors learn how to provide medical information in ways that participants will understand. It will only take about 3 minutes."*
2. **Hand the nutrition label to the participant.**  
The participant can and should retain the nutrition label throughout administration of the Newest Vital Sign. The participant can refer to the label as often as desired.
3. **Start asking the 6 questions, one by one, giving the participant as much time as needed to refer to the nutrition label to answer the questions.**
  - a. **There is no maximum time allowed to answer the questions.** The average time needed to complete all 6 questions is about 3 minutes. However, if a participant is still struggling with the first or second question after 2 or 3 minutes, the likelihood is that the participant has limited literacy and you can stop the assessment.
  - b. **Ask the questions in sequence.** Continue even if the participant gets the first few questions wrong. However, if question 5 is answered incorrectly, do not ask question 6.
  - c. **Do not prompt participants who are unable to answer a question.** Prompting may jeopardize the accuracy of the test. Just say, "Well, then let's go on to the next question."
  - d. **Do not show the score sheet to participants.** If they ask to see it, tell them that "I can't show it to you because it contains the answers, and showing you the answers spoils the whole point of asking you the questions."
  - e. **Do not tell participants if they have answered correctly or incorrectly.** If participants ask, say something like: "I can't show you the answers till you are finished, but for now you are doing fine. Now let's go on to the next question."
4. **Score by giving 1 point for each correct answer (maximum 6 points).**  
Score of 0-1 suggests high likelihood (50% or more) of limited literacy.  
Score of 2-3 indicates the possibility of limited literacy.  
Score of 4-6 almost always indicates adequate literacy.

<b>Nutrition Facts</b>			
Serving Size		½ cup	
Servings per container		4	
Amount per serving			
Calories	250	Fat Cal	120
			<b>%DV</b>
<b>Total Fat</b>	13g		20%
Sat Fat	9g		40%
<b>Cholesterol</b>	28mg		12%
<b>Sodium</b>	55mg		2%
<b>Total Carbohydrate</b>	30g		12%
Dietary Fiber 2g			
Sugars 23g			
<b>Protein</b>	4g		8%

\*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

The Newest Vital Sign is copyright Pfizer Inc. Used with permission.



# Appendix E. HARI Research Study Protocol

## FAU Healthy Aging Research Initiative: *The South Florida Quality Aging Registry*

### 1. Project Summary

The goal of this project is to build the infrastructure for a nationally recognized interdisciplinary research program on healthy aging. The rationale underlying the project is compelling. Our country faces a demographic imperative - the aging of our population. Aging is inevitable, and all of us hope to age in a healthy manner with a good quality of life. At FAU we sit in the epicenter of the aging phenomenon, and we have a tremendous opportunity to contribute to research that will make this hope become a reality.

There is no standard definition of "Healthy Aging", most research on aging defines the concept to encompass various aspects of life, including physical, psychological, social, and spiritual, because of the complexity of aging and the factors that can contribute to healthy aging, an interdisciplinary approach is essential.

We will recruit a diverse sample of community dwelling adults from four ethnic groups to participate in the "South Florida Quality Aging Registry", which will serve as the initial population for a longitudinal study and intervention studies on healthy aging and diversity.

### 2. Objectives

This project will focus on improving the quality of life of people as they age. Thus, we propose to study individuals longitudinally and through select measures aimed at revealing mechanisms underlying the aging process. To that end we will gather descriptive data from participants in the registry that will be utilized to:

- a. Examine the social, physical, cognitive, psychological, behavioral, and biological determinants of quality aging using state-of-the-art tools and techniques
- b. Determine if there are cultural or racial/ethnic differences in the determinants of quality aging
- c. Identify subgroups of individuals who may be appropriate candidates for interventions to improve quality of life with aging, such as diet, exercise, and substances with putative "anti-aging" actions. Spin off studies would require separate application to the IRB and additional consent procedures.

### 3. Background & Rationale

The South Florida Quality Aging Registry builds upon a project conducted at FAU with the support of a Robert Wood Johnson Foundation grant which pilot tested the recruitment and characterization of an aging research registry. One hundred and two (102) adults age 55 and older were recruited and completed multidimensional assessments. In order to ensure that our project will fill gaps in previous and ongoing studies and have the potential for NIH funding, we conducted an extensive review of longitudinal studies, and hosted an expert symposium in 2008. Papers based on this symposium are currently in press in a supplement to the Journal of the American Geriatrics Society. The proposed Registry will therefore build on previous research and experience in our pilot project.

In May 2010 the proposal titled "Healthy Aging: Interdisciplinary Research to Improve Quality of Life and Quality of Care for Aging Americans" was selected as a Research Priority Area by Florida Atlantic University. The South Florida Quality Aging Registry constitutes the core study of the initiative.

After extensive review by multidisciplinary faculty participating in the Healthy Aging, the initial testing protocol for data collection was improved and IRB approval achieved. Multiple meetings were held with various community agencies in order to identify and engage sites for participant recruitment. Project staff were recruited, hired and intensively trained in the testing protocol, and several underwent formal phlebotomy training in preparation for implementation.

#### 4. Research Plan

##### a. Study Design

The South Florida Quality Aging Registry for the initial 3-year project period will: 1) enroll 200 participants age 60 and older from each of four different ethnic groups: European American, Hispanic/Latino, African American, and Afro-Caribbean; 2) perform a multifaceted assessment on these participants at baseline and at a 12-18 month follow-up while collecting health and health care utilization by telephone quarterly; 3) collect data that will be used for five initial interdisciplinary studies included in the Healthy Aging Initiative; and 4) collect biological specimens that will be analyzed in future studies designed to examine novel biomarkers associated with healthy aging in people with diverse ethnic backgrounds.

##### b. Research Methods

After going through the screening and consent process participants will be assessed individually with the testing protocol described below:

#### Testing Protocol

##### Day 1

##### Socio-demographic Measures

- Health and Retirement Study demographic questionnaire
- Cross Cultural Measure of Acculturation (CCMA)
- Lubben Social Network Scale (LSNS-6)
- Social support (ESSI)
- Use of technology
- Berkman Measure of social engagement

##### Health Questionnaires

- Health and Retirement Study health history questionnaire (a new version including revised questions about pain is available on appendix 1)
- Medications, herbals and supplements questionnaire
- Medication Discrepancy Tool (medication compliance)
- Mini Nutritional Assessment (MNA)
- Block Brief 2000 FFQ (nutritional intake)
- Food security

##### Functional Status Measures

- Vulnerable Elders Survey (VES-13)

- Health Survey (SF-36)
- Functional Activities Questionnaire (FAQ)
- Life-Space Assessment (LSA)
- Self Assessment of communication (SAC)
- Minnesota Leisure – Time Physical Activity Questionnaire (MLTA)
- Vocal Performance Questionnaire
- Swallowing problems (SWAL-QOL). A new version including screening question to suggest the presence of a swallowing problem is available on appendix 2, only participants who have a positive screening will proceed with the SWAL-QOL)
- Driving questionnaire
- The newest vital sign (Health literacy, this measure is available on appendix 3)

#### Quality of life and psychological measures

- Center for Epidemiological Studies Depression (CES-D)
- The Spielberger State-Trait Anxiety Inventory (STAI)
- Connor - Davidson Resilience Scale
- The Big Five Inventory
- COPE Scale EdOpeCC (health priorities)
- Attitude scale (health priorities)
- Open ended questionnaire about perceptions of healthy aging
- Questions about perceptions of body image

#### Physical Performance Measures

- Height
- Weight
- Waist circumference
- Postural blood pressure and pulse
- Body Mass Index
- SPPB: Gait Speed (4m usual pace)
- SPPB: Balance (Side by side stand; Semi Tandem Stand; Tandem stand)
- SPPB: Lower extremity strength (1 chair stand; Repeated chair stands; 30s Chair Stand)
- Timed Up and Go Test
- Grip Strength test
- Measure of Range of movement (Modified sit and reach; Back Scratch; Modified total body rotation)

#### Biological Measures

##### *Specimen analysis (immediate to sample collection)*

The following assays will be performed:

- Complete Blood Count with Differential
- Comprehensive Metabolic Panel
- Thyroid Stimulating Hormone
- Vitamin D 25-hydroxy
- Iron
- Total Iron Binding Capacity
- Hemoglobin A1C
- C-Reactive Protein

- Vitamin B-12

**Specimen stored for future analysis**

- Plasma. 3 aliquots (0.5ml each) stored at -80 C
- White Blood Cells. 3 aliquots (0.5ml each) stored at -80 C
- Red Blood Cells. 3 aliquots (0.5ml each) stored at -80 C

**Day 2**

**Quality of life and psychological measures**

- Reed Spiritual perspective scale
- Fatigue Severity Scale
- Pittsburgh Sleep Quality Index (PSQI)
- Epworth Sleepiness Scale (ESS)
- AUDIT for alcohol abuse
- ASSIST for substance involvement screening

**Memory and Cognition**

- MMES -2
- Clock Drawing Test (CDT)
- Semantic Interference Test (SIT)
- Category Fluency: Animals , fruits and vegetables
- Trail Making Test (A and B)
- Digit Span (forward and backwards)
- Block Design
- Boston Naming Test
- Miami Naming test

**Physical Performance Measures**

- Fullerton's Functional Fitness test (Upper body strength arm curls; 2 minute step test; 6 minute walk)
- Measures of dual tasking (walking while recalling names of animals, walking while and stopping to pick up objects from the floor, walking while carrying a light box)

**Quarterly telephone or in person Follow-up**

- SFQAR follow up questionnaire
- Vulnerable Elders Survey (VES-13)

**c. Study Population**

Criteria for inclusion:

- Minimum age 60
- Speak English or Spanish

- Capable of ambulating with minimal assistance and / or an assistive device such as a cane or a walker
- Be a member of the ethnic groups under study (African American, European American, Hispanic and Afro Caribbean)
- Obtain an adjusted MMSE score minimum for eligibility or pass the assessment of decisional capacity

**d. Screening and recruitment process**

- Complete description and flow chart of the screening process and assessment of decisional capacity are available have been approved by the IRB.

Recruitment strategies will be multifaceted and based on our experience in the pilot project as well as the advice of experienced subject recruiters for longitudinal studies. Research assistants (including FAU graduate students) represent the diverse ethnic backgrounds involved in the Registry, and are trained in recruitment strategies, which include:

- Working with the leadership of senior centers, senior living communities, churches, and synagogues to gain their support in developing effective strategies to recruit in their populations;
- Conducting educational programs at these sites to discuss healthy aging and generate interest in participation;
- Wide distribution of attractive, easy to read flyers through mailings and postings; 4) ensuring easy access to recruiters by phone;
- Conducting in-person assessments at local sites, or participant's homes if they so desire to avoid transportation challenges;
- Providing reimbursement for transportation when needed;
- Providing various incentives to enroll and continue participating, including periodic newsletters and free educational events.

The effectiveness of these strategies in the recruitment of large samples of minority participants is evident in Drs. Tappen, Williams and Rosselli's previous research. Several strategies will be used to enhance participant retention over time. Our goal will be to retain 85% of participants over the first three years. We will provide participants with regular newsletter updates, opportunities to participate in free educational seminars, and develop a participant only website to keep them informed of latest developments in aging research and maintain their interest in ongoing participation.

**d. Analysis Plan**

The data collected from Healthy Aging Research Registry participants will be entered directly onto Excel spreadsheets and then it will be uploaded into SPSS and SAS for quantitative analyses. Dr. Tappen will oversee preparation of datasets for analysis by the research teams. The research coordinator will be responsible for data checking under Dr. Tappen's supervision. Full information maximum likelihood procedures (FIML) will be used to address missing data where appropriate. Qualitative data collected will be transcribed by the research assistants and uploaded into Atlas.ti or MAXqda for analysis which will, in some cases, include frequency counts that can be entered into the quantitative datasets.

**5. Benefits**

By participating in the registry, participants will gain knowledge of their ranking in relation to established norms for age/gender group on tests of physical performance, nutrition, memory and depression. We will also provide a report of the blood test this knowledge can be used as a

motivational tool to maintain health, and promote positive behavior change, as well as to measure future changes.

In addition, everyone enrolled in the registry will receive newsletters and other information about aging as well as about different educational and research programs that are available to members of the registry. Also participants will have the opportunity to contribute to research that can hopefully benefit society by advancing knowledge about how to age successfully.

Upon completion of every session the participant's effort will be acknowledged with a \$10 gift certificate to a local store.

## 6. Risks

Some participants may feel some distress during a testing situation. This distress should not be high. If in any case a participant experiences high levels of distress, he/she will have access to mental health counseling.

There is a small chance that participants could become self conscious during the physical assessments.

Effects of the physical performance tests could include: mild muscle discomfort during and up to 3 days after performance of the physical testing, sprains, strains, tears of the muscle and/or connective tissue during the performance of the test may also occur. There is also a remote possibility of a fall and fracture during these assessments. The investigators will follow a specific protocol for fall prevention.

However in the event of a fall they will assess the severity of the accident and proceed accordingly. Minor injuries (e.g. small skin cuts) will be treated on the spot with basic first aid measures to stop bleeding and prevent infection. In case of complications like limitation of mobility or head injury, emergency services will be contacted by calling 911. Regardless of the severity, all falls will be documented in the participant's file and reported to the Project Manager who will do follow up with you.

Slight increases in blood pressure, shortness of breath, and/or dizziness during the physical performance testing might happen. Additionally, participants could experience an unexpected heart rate and/or blood pressure response and/or irregular heart beat. In rare cases, this could result in a heart attack. Should an unexpected event occur during testing, the investigator (s) will initiate standard procedures to immediately contact emergency services by calling 911.

With respect to taking a blood sample, one risk is the development of infection at the site (usually the inside of the elbow). Other risks include excessive bleeding, feeling lightheaded or fainting. There is also a risk of a bruise under the skin. The person drawing the blood is well trained and performs the procedure using standard disinfection methods. Precautions taken are standard - disinfection of the site of needle insertion and use of sterile technique throughout the procedures. The person taking the blood will ask if you are taking medication / vitamins or have any conditions that may increase the likelihood of bleeding. Participants should also not give blood if they are anemic. Our investigators are trained to respond to possible complications by following safety procedures. In the case of fainting they will assist you to reclining position and monitor your vital signs. Emergency services will be contacted immediately if:

- Participant don't become alert quickly
- Participant fell and sustained an injury
- Participant is not able to breathe normally
- Participant's blood pressure is less than 90/60 mmHg

- Participant's pulse is less than 40 beats per minute

In some cases, test results will reveal abnormalities. If this happens the Participant will be contacted by a member of our team who will explain the meaning of the result in simple terms and answer your questions. Significant, unexpected abnormalities will be reported to your primary care provider, if you give us permission to do so. If mood assessment results reveal anxiety and depression the participant will be referred to a local mental health service in the community if he/she agrees to referral.

Information will be kept confidential to the extent provided by federal, state, and local law. However data will have to be disclosed upon request of the Institutional Review Board, the university, or government officials responsible for monitoring this study.

#### 7. Informed Consent Process:

This study includes two different consent processes (please see approved the screening procedure):

- Written Informed Consent for MMSE (already approved by the IRB)
- Written Informed Consent for SFQAR (new versions reflecting the latest changes are enclosed to appendices 4 and 5)

In both cases, participants will be informed of the purpose of the study, research methods and risks/benefits. The voluntary and confidential aspects of this study will be emphasized. All questions will be answered before the consent is signed. Participants will be given a copy of signed documents. The consent process will be conducted by a bilingual Research assistant whenever participants prefer to speak Spanish.

#### 8. Informed consent document:

Written consent forms for screening and study have being developed, translated to the Spanish language and approved by the IRB (please see new versions of the consents on Appendices 4 and 5).

#### 9. Research Materials, Records, and Privacy:

The participants' records will be handled with strict attention to maintaining confidentiality. All data collected during the course of the proposed study will be stored under lock and key in the Research Assistant's office. The College of Medicine has assigned freezer space to store human blood specimens.

Electronic files will be password-protected to allow access only to project personnel. All Florida Atlantic University personnel participating in the protocol will complete the Human Subjects Training established by the University's Division of Research, Office of Research Integrity and the FAU Institutional Biosafety Committee. Any additional personnel who may join the project will complete this training before they handle any subject data. This training includes content on the ethical conduct of research involving human subjects as described by the principles of the Belmont Report; human subject protection policies, as explained in federal policy (45 CFR 46), including issues pertaining to subjects, consent, data and IRB (Institutional Review Boards); IRB roles, responsibilities, and processes as related to the Florida Atlantic University policies.

To manage and protect data collected, only data in a summary form will be openly accessible to funding agencies or appear in publications. No individual identities will be used in reports or publications that will emerge from the proposed study. Research participants will be informed that

they are free to decline to answer any questions that they do not wish to answer or to stop participating in the study at any time. When they withdraw their participation, the individual will be asked to provide their unique identification number so that the data that they have provided will be immediately removed from the database.

#### 10. Resources

The College of Medicine has provided adequate office space for the staff and for the storage of research materials.

A total of 6 research assistants who are FAU graduates or doctoral and masters students have been trained in recruitment strategies and performance of the measures to be used for data collection. Three members of the staff are certified in phlebotomy and qualified to process biological specimens. Two are proficient in the Spanish language. Procedure manuals have been developed to guide all research activities including emergency and event reporting procedures. Several community resources have been identified in case that the assessments create or reveal participant's need for psychological counseling.

Several institutions located in the counties of Dade, Broward and Palm Beach are cooperating with the project (please see letters of cooperation) and currently are providing accommodations for participant recruitment and testing.

## REFERENCES

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