

FACTORS INFLUENCING NURSING HOME  
USE OF OLDER AFRICAN AMERICANS,  
HISPANIC AMERICANS  
AND CAUCASIANS

by

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ABSTRACT

FACTORS INFLUENCING NURSING HOME  
USE OF OLDER AFRICAN AMERICANS,  
HISPANIC AMERICANS  
AND CAUCASIANS

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As the population of older Americans increases, the utilization of nursing homes is an area of concern. The purpose of this study was to identify factors which influence the nursing home utilization of older African Americans, Hispanic Americans and Caucasians. This study focused on selected variables such as caregiver type, relative caregiver race, long-term care insurance and out-of-pocket nursing home expenditures. The study used a longitudinal, non-

experimental approach, guided by a comprehensive literature review and the theoretical application to the Behavioral Model of Health Service Use.

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## CHAPTER 1

### PROBLEM STATEMENT

The number of older Americans is growing rapidly. This has led to consideration of the social service needs of the elderly and their caregivers. The amount of services available to the elderly as well as access to services has been discussed as one of the major concerns of a rapidly aging population (Scharlach, Simon & Dal Santo, 2002). An older person is defined as someone that is sixty-five years of age or older. Erber (2005) operationalizes the specific age categories of older persons as follows: Young-old (ages 65-74), Old-Old (ages 75-84) and Oldest-Old (ages 85 and over). There is no specific biological factor that describes older adulthood as beginning at the age of sixty-five, rather the majority of people define aging in the United States based on when one might begin to receive Social Security benefits (Erber, 2005). The term “Older persons, older adults or elderly” will be used to refer to all age categories for this study unless otherwise specified.

The Baby Boomer generation in the United States is defined as persons born between 1946 to 1964. This generation of individuals will first reach the age of sixty-five in 2010. By 2012, approximately 10,000 people will reach the age of 65 every day (Coming crisis, 2003). Currently, the United States population is

made up of approximately 12 percent of elderly persons. By the year 2030, approximately 20 percent of United States citizens are expected to be over the age of sixty-five (Erber, 2005; Spira, 2006). The aging of the population is important to social work because approximately one in five American citizens will be potentially seeking community and social services as they progress into their later years (Erber, 2005).

Social workers will be key stakeholders in assessing, managing and monitoring the needs of older persons of our society. The social work profession will increasingly become a part of the Long Term Care (LTC) service arena in the near future. Social workers provide skilled services in the areas of psychosocial assessment, documentation, educating clients about community resources, discharge planning, interdisciplinary team participation and coordination of care (Kadushin & Egan, 2004; Lee, 2002; Malinowski, 2002). Social workers are found in myriad LTC settings such as hospitals, home health care, hospice, adult protective services, area agencies on aging, community care centers, assisted living and nursing facilities (Grobman & Bourassa, 2007). Likewise, social workers at all levels of practice (BSW & MSW) and education (BSW, MSW and Ph.D) work with elderly clients. Therefore, gerontological social work practice is important to the future of older Americans and understanding their LTC needs (Kadushin & Egan, 2008).

While the focus of this study is on nursing home use, an overview of LTC is needed. The American Association of Homes and Services for the Aging – AAHSA (2008) projects that 69 percent of Americans will use some form of LTC services before they die. LTC is defined from several perspectives. While many assume LTC refers to nursing home care, Home and Community Based Services (HBCS) as well as assisted living have entered the picture. In the United States, older persons experience one of two types of LTC: formal or informal. Formal LTC is paid care with specifically trained care providers. Informal LTC is unpaid, typically dispensed by a family member, friend or neighbor (Gaugler & Kane, 2007). The use of formal or informal LTC is generally dependent upon the type of care available and the financial situation of the care receiver.

Individuals typically seek LTC services when their ability to manage their self-care changes. Other factors for seeking LTC placements from an individual perspective include change in social, financial and family support systems (Nakashima, Chapin, Macmillian & Zimmerman, 2004). For example, a client may find themselves socially isolated due to a physical health status change. The support system may weaken because the client is no longer able to participate in social activities. Beyond a feeling of social isolation the fact that older persons are living alone can lead to a placement (Nakashima et al, 2004). Liken (2001) found that the desire to find a placement was the most important predictor of

accepting a placement. The loss of one's significant other may also be a factor in choosing a placement (Nakashima et al, 2004).

One's health status is a strong indicator for LTC placement decision-making. Change in behavior, memory, cognition, and physical abilities often lead to LTC placement at all levels of care (Liken, 2001; Nakashima et al, 2004; Ruess et al, 2005). From an individual perspective stress and burden can also lead to the decision to accept a LTC placement. Clients may feel they are a burden on their family and day-to-day caregiver (Koerin & Harrigan, 2002; Lieberman & Fisher, 2001; Liken 2001; Nakashima et al, 2004; Ruess et al, 2005). Older persons receiving formal services state a stronger sense of burden on the caregiver than those that are cared for by their family, friends or neighbors (Nakashima et al, 2004).

The Kaiser Family Foundation (2006) conducted a study to pinpoint the public's view on LTC. Over half of respondents preferred to remain at home, 21% would choose to move in with their family, 17% would choose assisted living and only 4% would choose nursing home care. Percentages such as this show support for all types of LTC options, but particularly HCBS.

HCBS are viewed as an alternative to formal assisted living and nursing home care, but are not distributed in the same manner state to state. The following is a list of the type of services that one might receive in their home as

an alternative to assisted living and nursing home care: personal care assistance such as bathing, dressing, cooking, housekeeping, transportation, shopping, home care aid and other medical professionals, adult day care, respite care, home delivered meals, case management, housing, legal assistance, financial assistance and protective services. (Alkema, Reyes, & Wilber, 2006; Han, Barrilleaux, & Qadagno, 1996; Meng, Friedman, Dick, Wamsley, Eggert, & Mukamel, 2006; Muramatsu & Campbell, 2002; Simmons, 1994; Wiener, Tilly & Alexih, 2002).

The common assumption is that HCBS and home health care are synonymous. While some states have applied for funding options to provide home health care under LTC Medicaid services, other states only provide Personal Care Services that target Activities of Daily Living (ADLs) and other non-medical assistance. Home health care when provided by state HCBS is skilled nursing care provided in one's home environment. The distinction is the type of service, skilled or non-skilled. Traditional home health care following a hospital discharge is provided by Medicare funding and is time-limited based on the elderly person's physical abilities and level of function. Once the person returns to their previous level of function, home health care will discharge the client from home health services. If this functional status is not achieved, then the long-term solution for a person wanting to remain in their home with functional and health care challenges is to opt for HCBS either on a private pay basis or through state funded HCBS programs.

Persons seeking HCBS that do not qualify for Medicaid LTC services can expect to pay an average cost of \$15 to \$20 per hour with a two hour minimum per day for in-home services such as a provider to help with bathing, dressing, cooking and cleaning or respite care. If an older person needs more extensive care than what can be provided at home, another option to meet their needs are assisted living facilities (NCAL, 2003).

The United States has approximately 33,000 assisted living facilities which provide care for 800,000 to 1.2 million older persons (Zimmerman, Mitchell, Chen, Morgan, Gruber-Baldini, Sloane et al, 2007). Assisted living facilities are considered an alternative care option for those that are not ready to enter a nursing home (Cutchin, Owen & Chang, 2003; NCAL, 2003). Assisted living facilities are also known as adult foster care homes, residential care facilities, board and care homes and congregate housing (Quinn et al, 1999). These living facilities provide a home-like environment while providing for basic needs such as food, shelter and 24-hour oversight (NCAL, 2003).

Assisted living facilities are geared to providing the consumer with choice and control over their LTC (Chapin & Dobbs-Kepper, 2001). Facilities offer unscheduled services; this is different from HCBS where the service provider enters the home on a regular, scheduled basis to complete the care needs of the older individual. The level of care varies from the type of services offered such as

skilled nursing or ADL assistance as well as shared or private residences. (Chapin & Dobbs-Kepper, 2001; NCAL, 2003).

When the need for LTC placement arises for HCBS, assisted living or nursing home care, physicians, nurses, case managers, geriatric care managers and social workers play a key role in the decision-making process. The job of the professional is to focus on the well-being, safety and adequacy of care. Typically, the professional's goal of placement is to relieve stress and burden on the client and the family while meeting the needs of the client (Lieberman, 2004). Clients often focus on comfort, privacy, familiarity, dignity and autonomy (Nakashima et al, 2004). Often, there is a conflict between the client's wishes such as remaining at home and the professional's recommendation for a more intensive care approach such as assisted living or nursing home care. When this occurs, social workers are usually included in the decision-making process. Social workers recognize the importance of including the family and the client in the decision-making process. Social workers assist with care planning, supportive counseling as well as social and emotional functioning of seeking LTC whether it is HCBS, assisted living or nursing home care (Malench, 2004).

The role of social work in the LTC arena and specifically nursing homes is an ever-increasing issue. Social work research needs to address nursing home use as the older population continues to grow. Factors influencing nursing home use

of older African Americans, Hispanic Americans and Caucasians will be the focus of this study.

### 1.1 Need for Nursing Home Service

The American Health Care Association (AHCA) (2006) estimates there are approximately 16,000 nursing homes in operation with 1.7 million beds. Approximately 12 percent of nursing home residents are between the ages of 65 and 74. As one advances in age, the likelihood of nursing home residency increases to 45 percent for those over the age of 85. (National Citizens Coalition for Nursing Home Reform, 1999). Currently, the average age to enter a nursing home is 79 years old (AAHSA, 2008).

Most older people fear nursing home placement as nursing homes are thought to be synonymous with death, dying, retreat from society and culture as well as isolation from friends and family (McGinnis-Dittrich, 2005; Solis-Longoria, 2007). While short-term stays in nursing homes are more common, the idea of nursing home placement is still one of the last choices that elders want to make (Andel, Hyer & Slack, 2007; Aud & Rantz, 2004; Grando, Mehr, Popejoy, Wipke-Tevis & Westhoof, 2002; Pourat, Andersen & Wallace, 2001). While nursing homes generally carry a negative connotation, they maintain an important role in aging in American society. Nursing homes are a part of the continuum of care for ill, frail and disabled older Americans (McGinnish-Dittrich, 2005).

With the growing number of elderly people in the United States, it is imperative that focus on nursing home care be considered as the need for nursing home may increase in the future. Social workers, policy makers and care providers need an understanding of nursing home utilization to plan for the future emotional and healthcare needs of older Americans.

The reason for entering a nursing home is often multi-layered, but specific risk factors have been identified. Grando and colleagues (2002) report advanced age, lack of an available caregiver, difficulty with activities of daily living, cognitive status, change in health status, and previous nursing home admission as risk factors for nursing home placement. As demonstrated earlier, the older one is (especially over 85 years of age) the risk of nursing home placement increases (NCNHR, 1999). Other research supports additional risk factors such as female gender, low socioeconomic status, living alone, dementia, increased need for prescription medications, and low levels of social support (Andel, Hyer, & Slack, 2007). Aditay & Sharma (2003) further define nursing home placement risk factors to include “medical, functional, mental and socio-environmental factors” (p. 108). Furthermore, the universal need for placement has been identified as one’s disability with function in activities of daily living (Aditya, & Sharma, 2003). Functional disability could be described as an inability to independently toilet, get in and out of bed or feed oneself. Some older adults fail to regain their functional abilities after a hospitalization, which would add prior hospitalization

to the list of risk factors increasing the length of stay in nursing homes (Lee, 2006).

One's race or ethnicity is also a factor in nursing home utilization. The population of older Americans is becoming more diverse, both culturally and ethnically. There are a growing number of minority elders when compared to their white counterparts. Over the next few years, the minority population is expected to exceed the number of white elders (Lum, 2005). Therefore, attention to race is an important consideration in this study. Previous research has cited that minority families prefer to care for their own because of cultural preferences to receive care from their family (Akamigbo & Wolinski, 2007; Hernandez & Newcomer, 2006; Li & Fries, 2005; Lichtenberg, 2005; Lum, 2005; Radina & Barber, 2004; Scharlach, Giunta, Chow & Lehning, 2008). Angel and Colleagues (2004) state that African American and Hispanic individuals also remain in their homes with family care because of economic forces. Nursing home care is not only very expensive, but it is also lacking in many minority neighborhoods and communities. Likewise, nursing care facilities often fail to meet the cultural needs of their clients, so individuals are forced to choose to remain in their homes because of culture and expense (Angel, 2004). Morrison (1995) argues that the concept of minorities preference to caring for their own is not necessarily because of cultural preference, but because the overall number of minority individuals has been less than that of whites for many years. In other words, the reason

minorities are less represented in nursing homes is simply because there have been a smaller number of minority elders in existence in the past. As the number of minority elders grows, Morrison insists that the number of minorities in nursing homes will grow proportionately.

While many minority individuals may choose to receive family care in their home over formal nursing home care, this phenomena may also be due to a lack of education about LTC options (Li, 2004). For example, African American and Hispanic elders may have more knowledge about folk medicine over traditional LTC options (Davis, 2007). Social workers often assume that minority families would prefer family home care to formal nursing home care due to cultural norms. Research shows that while minorities may define physical or mental disability differently than whites, the choice to use family home care over formal nursing care is often due to lack of knowledge or access to services (Salive, Collins, Foley & George, 1993). Beyond the need for nursing homes and factors associated with nursing home use, cost of nursing home placement must be considered.

### 1.2 Cost of Nursing Home Services

Costs for nursing home care are a major concern for residents and their families. The AAHSA (2008) estimates the average cost for a private room in a nursing home is \$77,745 annually or \$213 per day. A shared room reduces the

cost to \$68,985 annually or \$189 per day. Nursing home care is the highest out-of-pocket expense for older Americans (Montgomery & Kosloski, 1994). Overall, the total cost for nursing home care exceeded \$98 billion in 2001 (Andel et al, 2007). The Centers for Medicare and Medicaid Services (2003) reports a projection of \$217 billion of nursing home expenditures by the year 2017.

Medicare recipients often assume that LTC is covered by Medicare. In fact, Medicare is intended to provide acute care. Medicare is intended to provide a majority of one's healthcare needs, but it is not all-encompassing. Medicare Part A and Part B cover 80% of allowable healthcare expenditures. The remaining 20% must be covered as an out-of-pocket expense or by private supplemental insurance plans. Medicare recipients are also fiscally responsible for monthly premiums and co-insurance (supplemental) payments (US-DHHS, 2008).

Medicare pays for skilled nursing or for rehabilitation in a qualified nursing care facility. This coverage is only allowable after the client has been hospitalized for three consecutive days. Furthermore, the client must be admitted into the skilled facility within 30 days of the hospitalization and then Medicare will cover up to 100 days of skilled care per calendar year and qualifying event. A qualifying event is determined by the three day inpatient hospitalization. This means Medicare at best covers a little over three months of nursing home care

services per year per client. The goal of Medicare is to cover short-term nursing home stays (Pourat, Andersen & Wallace, 2001). This is a key piece of information when discussing LTC needs because many older persons develop chronic conditions requiring longer stays are not covered by Medicare. Therefore, clients must pay for their LTC from their own pocket or seek state-funded Medicaid coverage if they qualify. Medicaid is an important factor to the financial aspect of LTC coverage. In fact, Medicaid provides almost 70 percent of LTC services in the United States (Kitchener, Hernandez & Harrington, 2006). LTC Medicaid is an all-encompassing funding source for those individuals that meet the income criteria.

Nasser (2007) reports the average nursing home patient will exhaust their personal financial resources within six months and must rely on Long Term Care (LTC) Medicaid. Research supports that individuals who pay out-of-pocket and are not on LTC Medicaid are less likely to use a nursing home even when facing health challenges and cognitive impairment (Borrayo et al, 2002). Recently, the Deficit Reduction Act of 2005, which curtailed LTC Medicaid coverage, allowed the federal government to increase the penalties, asset caps and benefits for high-income individuals seeking LTC Medicaid as a payment source for nursing home care. Individuals that have transferred assets such as large amounts of cash and property within five years of the LTC Medicaid application may no longer qualify for LTC Medicaid services. Also, those that transferred their assets for an amount

below fair market value and those that have home equity above \$500,000 are no longer eligible to apply for LTC Medicaid funding (Karp, Sabatino & Wood, 2005). Therefore, more and more Americans are facing the challenge of paying for nursing home care without the assistance of LTC Medicaid funding. Out-of-pocket expenditures for nursing home costs can potentially affect any individual or family from the lower middle or upper income brackets.

To fully understand the brevity of nursing home funding, a discussion of LTC Insurance (LTCI) is needed. Currently, about five percent of older Americans purchase LTCI. LTCI is very expensive and only available to individuals with good overall health at the time of the policy issuance. LTCI insurance is purchased to cover nursing home costs and in some cases home-based nursing. Approximately one-fourth of the elderly in the United States have a yearly income below \$25,000. Even those with an income above \$25,000 the cost of LTCI is often unattainable (KFF, 2006). LTCI is not available for purchase until the age of 50. A policy is only available for those that have a low-risk for LTC needs and chronic health conditions can result in policy denial. “The annual cost of a typical long-term care policy in 2002 was \$1474 if purchased at age 50; increasing steeply to \$2,862 at age 65 and \$8,991 at age 79” (KFF, 2006, p. 1). Unfortunately, LTC insurance is not a feasible solution for many older persons living on fixed incomes with health challenges.

### 1.3 Purpose of the Study

Nursing home utilization and out-of-pocket nursing home expenditures are important issues to consider as the population of older Americans continues to grow. The availability and affordability of nursing home care will become increasingly important in the future. This study will strive to identify factors affecting nursing home use such as caregiver type and relative caregiver race, as well as determining whether purchasing long term care insurance alleviates out-of-pocket nursing home expenditures. Acquiring further knowledge about these topics will further previous research and help social workers, policy makers and families to identify elderly nursing care needs. The overarching research question for this study will be “What factors influence nursing home utilization of older African Americans, Hispanic Americans and Caucasians?”

## CHAPTER 2

### THEORETICAL FRAMEWORK

The Behavioral Model of Health Service Use or Andersen's Behavioral Model of Health Service Use has been cited as one of the most important theoretical approaches to nursing home use (Andel, Hyer & Slack, 2007; Baxter, Bryant, Scarbro & Shetterly, 2001; Charles & Sevak, 2005; Holden, McBride, & Perozak, 1997; Kersting, 2001; Jette, Tennstedt & Crawford, 1995; Muramatsu, Yin, Campbell, Hoyem, Jacob & Ross, 2007; Pourat et al, 2007). The goal of this model is to understand the differing levels of access to health care across groups such as minority groups or persons receiving specific types of health care services. The ability to measure equity of health care services is also a key goal (Andersen & Aday, 1978). This model was intended to explain and define the personal health service use from three broad categories that lead to service use: predisposition to service use, factors enabling or impeding service use and need for care (Andersen, 1995; Andersen & Aday, 1978; Andersen, 1968). This model was selected as it is appropriate for the chosen population and aligns with the variables selected for the study. Furthermore, this model has been cited for its usefulness to guide data collection and analysis from secondary data sources such as national surveys on health care (Andersen & Aday, 1978).

## 2.1 Historical Roots

To fully understand the applicability of this model, a review of the historical roots of the behavioral model of health services use is needed. The behavioral model of health service use was penned by Ronald M. Andersen during work on his dissertation in the late 1960s. Andersen's dissertation focused on understanding how and why families use health care services. The measurement of equitable access to health care as well as policies concerning health care use are key points in Andersen's early work. The model was first applied in Andersen's paper titled, *A Behavioral Model of Families' Use of Health Services* (Andersen, 1968). The Behavioral Model of Health Service Use was written with the idea that healthcare is a right of all Americans regardless of their socioeconomic status or ability to pay for healthcare services (Andersen, 1978). While the right to healthcare continues to be a topic of debate, health service use continues to be an area of concern for researchers and policy-makers. Andersen's model considers that most individuals believe health care services should not only maintain the health status of individuals, but also improve one's health. During the inception of this model, need for health care services were recognized, but the cost of health care services has become more of an emphasis due to the changing landscape of the American health care system (Andersen, 1995). This model introduced three components that guide one to use of health services: predisposing components, enabling components and need component.

Initially, health services were defined as inpatient hospital care and physician services. Further work on the model has included inpatient and outpatient care and physician services as well as hospitalizations, community care, nursing home care and dental care (Andersen, 1995).

## 2.2 Predisposing Component

Andersen (1978) describes predisposition as the likelihood one will use health care services based on individual characteristics such as demographics, social structure, and attitudinal-belief variables. Demographic variables are explained by one's age and gender (Forbes, Stewart, Morgan, Anderson, Parent & Janzen, 2003; Holden, McBride & Perzok, 1997; Kersting, 2001). Social structure is measured as one's education, occupation and race or ethnicity. Other factors are one's status in society and ability to cope with challenges. Health beliefs are attitudes, values and knowledge about services that affect one's health care (Andersen & Aday, 1978; Anderson 1995)

## 2.3 Enabling Resources

Enabling resources consider factors such as personal and family resources and community resources. Examples of these include income (Holden et al, 1997), health insurance, formal and informal caregivers (Forbes, 2003; Scharlach, Giunta, Chow & Lehning, 2008), and also include knowledge and education about

the type of care available (Andersen, 1995; Forbes et al, 2003). The type of relationships and the quality of social relationships between relative and non-relative caregivers is also considered an enabling resource.

#### 2.4 Need

The need for health care services is defined by both perceived need and evaluated need. One's self-perception of their health as well as specific symptoms, abilities and function encapsulate the need factor. Examples of need may be of a personal nature such as the aforementioned self-perception of health status as well as one's specific health status as defined by a diagnosis or one's ability to function with their activities of daily living (Andersen, 1995; Holden et al, 1997; Kersting, 2001). Perceived need is a personal feeling of the individual or their family system. Evaluated need is from a health care professional such as a physician.

#### 2.5 Use of Health Services

Use of health services is broadly defined to include many types of health care such as inpatient hospitalizations, nursing home care and general care of a physician. The actual use of health services is determined by the predisposing, enabling and need factors. Use of health services is considered the outcome of the model (Andersen, 1978; Andersen 1995).

## 2.6 Strengths and Weaknesses of Behavioral Model of Health Service Use

The major strength of the Behavioral Model of Health Service Use is that it provides a useful framework to assess the likelihood that one will use health services based on the identified factors such as predisposing characteristics, enabling resources and need. This model is not only easy to understand, but it provides researchers with a strong theoretical basis for selecting variables (Andel, Hyer & Slack, 2007; Charles & Sevak, 2005; Forbes et al., 2003; Holden, McBride & Perozek, 1997; Jette, Tennstedt & Crawford, 1995; Scharlach, Giunta, Chow & Lehning, 2008; Stathers & Gonski, 1996). Andersen's model has been cited as useful for social work research when predicting the use of adult day care and respite services as well as caregiver support services (Scharlach et al., 2008). This model is flexible, adaptable and useful because it allows researchers to apply the model to a variety of health care service settings with well-documented success from previous research (Andel et al., 2007).

Andersen (1995) cites criticism of his model by sociologist, Bernice Pescosolido, who stated Andersen had abandoned his disciplinary roots and avoided the impact of social relationships on one's health beliefs in his model. This criticism refers to health beliefs which are a component of predisposing characteristics. Further research is needed to fully define an individual's health beliefs. The original model defines health beliefs from a global perspective which

warranted criticism because the family unit and not the individual was the unit of analysis. The current trend is to analyze health beliefs from the individual's perspective. For example, a person's belief about their specific disease or diagnosis is considered. Furthermore, additional criticism has been stated for a lack of consideration for genetic factors as a part of one's predisposing characteristics to use health services. Other factors that warrant further consideration are one's cognitive abilities and psychological characteristics (Bass, Looman & Ehrlich, 1992; Rivnyak, Wan, Stegall, Jacobs & Li, 1989).

Criticism of the enabling resources has also been cited. Gilbert and colleagues (1993) state more attention should be given to organizational factors. For example, the model considers personal and community resources, but does not take into account how these services are organized for the individual. Information about the type of service providers and health care services should be considered. Insurance coverage is another aspect of enabling resources. Mechanic (1979) requested more attention to insurance benefits. This type of concern is especially important for the current health care system in the United States.

The concept of need has received little criticism as compared to predisposing characteristics or enabling resources in the model. There is concern that Andersen has overemphasized need in his model (Coulton & Frost, 1982;

Gilbert et al, 1993; Wolinsky & Johnson, 1991). Critics suggest that need factors should not be weighed heavily by perception, but by evaluation. In other words, a person may perceive their health status is actually worse than it is and seek health care services. In fact, the individual should be evaluated by a health care professional and let the evaluation guide their need instead of their own personal perception. Individuals may perceive themselves as healthy when they actually need additional health services.

In general, the Behavioral Model of Health Service Use was intended to measure use of health care services. Penchansky (1976) states concern that this goal is too broad. Andersen (1995) is working on an emerging model that reconsiders the original tenets of the model while expanding the model to include the environment of the individual and the health care system as well as health behavior and outcomes such as consumer satisfaction with their health care service use. These criticisms aside, the model has been well-researched and well-documented as a valid theoretical approach (Andel, Hyer & Slack, 2007; Charles & Sevak, 2005; Forbes et al, 2003; Holden, McBride & Perozek, 1997; Jette, Tennstedt & Crawford, 1995; Scharlach, Giunta, Chow & Lehning, 2008; Stathers & Gonski, 1996).

## 2.7 Application to Study

The Behavioral Model of Health Service Use is applicable to this study as the variables under study are easily applied to the differing phases of the model. The first factor in the model is predisposing characteristics, such as demographics and social structure. For instance, age is a risk factor for nursing home use (Grando et al, 2002). Therefore, age is a predisposition for nursing home use. As one ages, the likelihood of nursing home use increases. Likewise, other research variables such as gender, race and out-of-pocket nursing home expenditures fall into the predisposing characteristics. The second factor is enabling resources such those available through one's family and community (Andersen & Aday, 1978). Personal and family resources for this study are identified as caregiver type such as a relative caregiver or non-relative caregiver. The enabling resources at the community level can be defined by the presence of long-term care insurance coverage (Achterberg, Stevens, Crebolder, & Philipsen, 1996). In this study, this will be the presence of health care coverage such as a LTCI policy. The third factor is need. Need in this instance is either a perceived need or an evaluated need for health services. (Andersen & Aday, 1978; Andersen, 1995). Need is also described through specific health conditions or function. A lack of function would be viewed as a need for health service use (Achterberg et al, 1996). For the purpose of this study, the concept of need will be considered by the control variables activities of daily living (ADLs) and one's perceived health status. Use

of health care services is realized by the actual number of days spent in a nursing home; therefore it is translated into the actual use of health services as defined by Andersen's model. (See Figure 1).

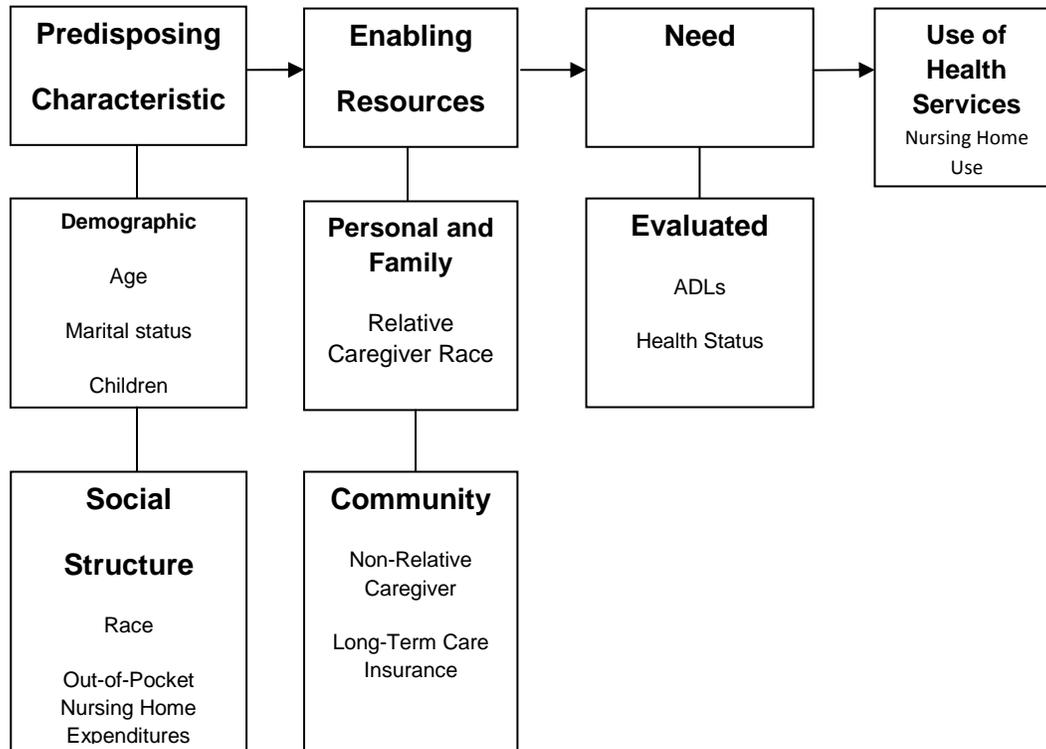


Figure 1. The Behavioral Model of Health Service Use with Independent, Dependent and Control Variables for Factors Influencing Nursing Home Use.

Overall, the Behavioral Model of Health Service Use is a nice fit for this study. This model considers all of the chosen variables for the study with support from previous research. The model provides a layout of expected relationships between variables which will be beneficial for data analysis. This model

theoretically approaches research variables such as age, caregiver type, relative caregiver race, long-term care insurance, out-of-pocket nursing home expenditures and nursing home use. Therefore, this model allows for recognition of the need and cost of nursing as defined in the problem statement.

## CHAPTER 3

### LITERATURE REVIEW

Research surrounding nursing home use has often focused on specific health care diagnoses that lead to nursing home care. Additionally, researchers have considered how a relative (informal) caregiver experiences placing a family member in the nursing home, but little work has been done to identify if there is a relationship between nursing home use when there is a non-relative (formal) caregiver in comparison to relative caregiver. Likewise, substantial work has been done to identify the overall out-of-pocket expenses surrounding healthcare in general, but only a small amount of literature focuses specifically on out-of-pocket nursing home expenditures and the potential usefulness of purchasing long-term care insurance plans. This review will strive to further define the need for nursing home care as well as explore the potential costs associated with such care.

A combination of quantitative and qualitative studies were reviewed for this study. The reviewed research included articles that sampled elderly individuals (over the age of 60) and most of which were conducted within the past 10 years. Several articles exceeded the 10 year time limit and were included because of their historical value and assistance in understanding nursing home

care over the past 18 years (Bishop, 1999; Foley, Ostefeld, Branch, Wallace, McGloin, Cornoni-Huntley, 1992; Forbes, Hoffart & Redford, 1997; Holden, McBride & Perozek, 1997; Jette, Tensnstadt, & Crawford, 1995; Montgomery & Kosloski, 1994; Peek, Coward, Lee & Zsembik, 1997; Rudberg, Sager & Zhang, 1996; Salive, Collings, Foley & George, 1993; Wingard, Williams-Jones & Kaplan, 1990). Databases in the content areas of Social Work, Sociology, Gerontology, Economics, Nursing, Health and Medicine were considered for this review. Studies were reviewed that considered nursing home care in general. During this study, 40 studies were chosen that addressed factors influencing nursing home use of older adults.

Eleven of the 40 articles reviewed relied on an Andersen's Behavioral Model of Health Service Use as their underlying theoretical perspective to support their empirical findings (Anzel, Hyer & Slack, 2007; Baxter, Bryant, Scarbro & Shetterly, 2001; Borrayo, Salmon, Polivka & Dunlop, 2002; Charles & Sevak, 2005; Holden et al, 1997; Jette et al, 1995; Muramatsu, Yin, Campbell, Hoyem, Jacob & Ross, 2007; Radina & Barber, 2004; Scharlach, Giunta, Cow, & Lehning, 2008; Taylor, Osterman, Acuff & Ostbye, 2006; Wallace, Levy-Storms, Kington & Andersen, 1998). Montgomery & Kosloski reference Pearlin's Stress Process Model for caregiving as their theoretical perspective. All but eleven studies used secondary data sets (Anzel et al, 2007; Foley et al, 1992; Grando, Mehr, Popejoy, Wipke-Tevis & Westhoff, 2002; Jette et al, 1995; Lichtenberg,

2006; Montgomery & Kosloski, 1994; Noonan, Tennstadt & Rebelsky, 1999; Radina & Barber, 2004; Scharlach et al, 2008; Scharlach, Kellam, Ong, Baskin, Goldstein & Fox, 2006). Regression was used as the primary statistical method to analyze data in all but five studies which utilized qualitative methods to analyze data (Forbes et al, 1997; Grando et al, 2002; Lichtenberg, 2006; Noonan et al, 1999; Scharlach et al, 2006). Two studies used mixed method approaches (Feinberg & Newman, 2006; Lichtenberg, 2006).

Overall, the reviewed studies identified five factors as influencing nursing home use of older Americans. Risk factors for nursing home use, caregivers, race and ethnicity, health care coverage and out-of-pocket nursing home expenditures influence nursing home use. This list is not all-inclusive, but serves as a guide to the most important factors identified throughout this review.

### 3.1 Risk Factors for Nursing Home Use

Substantial research has identified specific risk factors that lead to nursing home use in older adults (Andel et al, 2007; Aditay & Sharma, 2003; Angel et al, 2004; Foley et al, 1992; Grando et al, 2002; Kersting, 2001; Lee, 2006; Rudberg, Sager & Zhang, 1996). Older persons enter nursing homes with two options: long-term care or short-term care. No matter the length of stay, there are risk factors that lead to the placement. Risk factors for placement include advanced age, lack of caregiver, difficulty with activities of daily living of functional

difficulty, cognitive status, changes in health status, previous nursing home admission, female gender, low socioeconomic status, living alone, dementia, increased need for prescription medications, low levels of social support, prior hospitalization, and living in a rural community (Aditay & Sharma, 2003; Andel et al, 2007; Buhr, Kuchibhatla & Clipp; 2006; Foley et al, 1992; Grando et al, 2002; Lee, 2006).

Factors associated with short-term stays include improved health status, short-term cognitive changes, and increased ability to complete one's ADLs, presence of terminal illness, lack of funding and even gender (Andel et al, 2007, Aud & Rantz, 2004; Grando et al, 2002; McBride & Perozek, 1997; Pourat et al, 2001). Gender is particularly a concern for men. Men that enter a nursing home on a short-term basis often have a shorter stay due to death (Angel et al, 2004). Some individuals may experience a short-term nursing home stay because they find adequate care in the community and return to their home-based services.

One's race or ethnicity is also a factor in short-term placement. African American and Hispanic elders are less likely to choose short-term nursing home care due to preference to receive care at home from family. Akamigbo & Wolinsky (2007) found African Americans and Hispanics are more likely to qualify for Medicaid and if they do enter a nursing home their stay is typically permanent. This same study found whites are more likely to forego nursing home

stays in favor of seeking assisted living. Angel and colleagues (2004) found the Mexican immigrants moving to the United States late in life were less likely to access nursing home care.

Differing risk factors for African Americans and whites have been cited. Kersting (2001) found African Americans had an increase in nursing home care when the following factors were identified: living below the poverty line, difficulty with activities of daily living, increased age and lack of relative caregivers. Whites were found to display these risk factors: advanced age, lower income level, being female, poor perceived self-health and decreased ability to perform activities of daily living. Findings such as these point to a broad-based understanding of what influences nursing home use, but does not provide exhaustive evidence based on one's race, gender or family situation.

### 3.2 Caregivers

Caregivers are an integral part of the elderly accessing nursing home care. Research shows as early as 2010 there will be a shortage of caregivers (Quinn, Johnson, Anders, McGinnis & Ramesh, 1999). For the purpose of this review, caregivers are defined as over 18 years of age and falling into the informal or formal caregiving role (LaPlante, Kaye, & Harrington, 2004 & Li & Fries, 2005). Caregiving for many older adults is one of the most complex and unmet areas of need. Many older adults do not have access to caregivers because of lack of

community resources or the caregiver's inability to meet the day to day needs of the older adult. LaPlante and colleagues (2004) project that over 85% of all assistance is provided by family and friend caregivers, which are typically defined as informal (relative) caregivers. Formal (non-relative) caregivers are those provided through agencies or by social service programs. The Baby Boomer generation is less likely to use relative caregivers than previous cohorts because they have fewer children (Charles & Sevak, 2005). Therefore, nursing home use with this generation may increase.

Male and female caregivers differ in the type of services they are willing or able to provide to the care receiver. Female caregivers are more likely to assist with personal care needs, meal preparation and household chores while male caregivers are more likely to help with finances and shopping (Jette, Tenddstadt & Crawford, 1995).

Li (2004) reported that caregivers with friends and neighbors involved in the caregiving process are more likely to use support services such as Home and Community Based Services which typically provide non-relative caregiving. Feinberg & Newman (2006) report female caregivers caring for their parents have an increased risk of living in poverty and using public assistance later in their life. Public policy often looks to the family first, but community resources are often limited, leading to caregiver burden. Caregiver burden is often a derivative of

lack of services or limited community resources (Li et al, 2005). Home and Community Based Services in some states have allowances for family members to become paid providers for their loved one. The state will pay the family member to attend to the client's activities of daily living and other home care needs (Kitchener, Ng, & Harrington, 2007).

Wallace and colleagues (1995) in their study comparing Latinos and Non-Latinos access to paid in-home assistance found paid assistance did not alleviate informal caregiving, but instead provided a supplement to the caregiving. Radina & Barber (2004) found Hispanic caregivers seek non-relative caregiving services when they feel burdened by the caregiving process, have a small family network to rely on, and a higher acculturation to mainstream United States culture.

Li (2004 & 2005) reports specific barriers to providing care such as a lack of adult day care, lack of respite care and inability to provide all personal care needs of the older adults. Access to caregiving in the home is essential to decrease the need for institutionalization (LaPlante et al., 2004). Scharlach and colleagues (2008) found the care receiver was more likely to seek professional caregiving services because it was not viewed as a violation of cultural norms if the decision was made for the care receiver.

Consequently, a higher level of need from the older adult equates to a higher level of burden as experienced by the caregiver (Li et al., 2005). This often

leads to assisted living or nursing home placement if the caregiver does not receive proper support. Another study found that relative caregivers living with a care receiver have a higher level of burden than relative caregivers living 20 or more minutes of driving distance from the elder (Chou, Yueng & Chi, 2001). Stewart and colleagues (2006) found that whites and African-Americans were concerned about the burden of caring placed on the caregiver, but African-Americans were less likely to seek respite care.

In general, minority caregivers have been cited to use formal caregiving services less than whites (Lum, 2005; Scharlach, et al, 2006). When considering caregiving from a racial perspective, Hispanic elders have the most complex and supportive caregiver networks, both formal and informal. Overall, Hispanic families are better able to coordinate formal and informal services when compared to African American and white families. Regardless of the race of the caregiver, specific trends seem to unfold; the higher amount of caregiver burden corresponds with a higher level of need in the care receiver. Higher levels of caregiver burden are likely to increase nursing home use (Li et al., 2005).

### 3.3 Race and Ethnicity

While the previous section discussed caregiving in general and how also touched on how racial and ethnic minorities deal with caregiving, this section will discuss race and ethnicity from a cultural perspective considering how one's race effects their decision-making for nursing home care.

Race and ethnicity is well documented as a contributing factor to nursing home use (Akamigbo & Wolinsky, 2007; Angel, Angel, Aranda & Miles, 2004; Baxter, et al, 2001; Kersting, 2001; Lichtenberg, 2006; Lum, 2005; Pourat et al , 2001; Radina & Barber, 2004; Salive et al, 1993). African American, Asian and Hispanic families are more likely to keep their loved ones at home and provide care informally (Davis, 2007; Li, 2004; Lichtenberg, 2005; Lum, 2005; Radina & Barber, 2004). Lichtenberg (2005) found that African American families are less likely to pursue nursing home care for fear of social stigma. African American elders often live with their extended family. Some research has demonstrated that elders are concerned that accepting a nursing home placement could lead one's community to pass judgment on the family's ability to provide for the aging parent. Often, the community in which an older person resides provides additional informal care in lieu of formalized care options (Lum, 2005).

While previous research (Salive et al, 2993) has shown African Americans are less likely to pursue nursing home care new studies are uncovering an

emerging trend. Akamigbo & Wolinsky (2007) found that African Americans are increasing their use of nursing homes as whites are choosing to pursue assisted living or placements in more affluent facilities. The decrease in the number of white elders in nursing homes is increasing bed space for minority elders. Similarly, African Americans may have access to nursing home care, but the type of facility available to them may be of lower quality or funded only by Medicaid monies (Akamigbo & Wolinsky, 2007; Lichtenberg, 2006).

Scharlach and colleagues (2008) found that Latino cultures are also more likely to expect family involvement over formal services. Hispanic elders use nursing home care at substantially lower rates than non-Hispanic white elders (Baxter, et al, 2001). Likewise, Asian families were found to expect fulfillment of filial responsibilities for aging parents. Asian families often experience structural problems because they cannot find service providers or facilities that meet the cultural needs of their loved ones (Li, 2004).

Overall, the use of nursing home care is challenging for many racial and ethnic groups because acceptance of formal services may translate into family failure within their subculture. While some research (Kolb, 2007) is beginning to show an increase in nursing home use by minorities, African Americans, Asian, Latinos, Hispanics and other ethnically diverse groups prefer a family approach

over any type of institutional care even when provided in the home (Lichtenberg, 2005; Radina & Barber, 2004; Scharlach et al, 2008).

### 3.4 Health Care Coverage

Health Care coverage is an important consideration for nursing home use. There is a common misconception that Medicare funds nursing home care when in fact it pays for only a small portion of nursing home services each calendar year if specific medical criteria are met. Many also assume that one's private supplemental insurance will cover nursing home expenses. Supplemental policies only cover what is allowable under Medicare guidelines, thus after Medicare no longer pays for nursing home care, the supplemental policy will not pay for services. A discussion of Medicare, Medicaid and Long-Term Care Insurance is provided.

#### *3.4.1 Medicare*

Medicare is a health insurance plan intended for persons over the age of 65 or those that are disabled and meet the qualifications for Medicare coverage. Medicare essentially has three parts. Part A is hospital insurance coverage which includes inpatient hospitalization, skilled nursing facilities and home health needs such as intravenous nursing care. Part B is medical insurance for needs such as physician visits, outpatient hospital visits, some home health care such as physical

rehabilitation and laboratory needs. Part D is prescription drug insurance coverage. Once the age requirement is met, further eligibility criteria are based on the number of quarters one has worked. Each Medicare recipient must have completed 40 quarters of work and paid taxes on at least 40 quarters of work to be eligible for Medicare coverage (US-DHHS, 2008).

Medicare is intended to provide a majority of one's healthcare needs, but it is not all-encompassing. Medicare Part A and Part B cover 80% of allowable healthcare expenditures. The remaining 20% must be covered as an out-of-pocket expense or by private supplemental insurance plans. Medicare recipients are fiscally responsible for monthly premiums and co-insurance (supplemental) payments (US-DHHS, 2008).

Medicare recipients often assume that LTC is covered by Medicare. In fact, Medicare is intended to provide for acute care needs. Medicare pays for skilled nursing or for rehabilitation in a qualified nursing care facility. This coverage is only allowable after the client has been hospitalized for three consecutive days. Furthermore, as previously discussed, Medicare has specific criteria per year and qualifying event that must be met before services will be covered. On average, Medicare will cover about three months of nursing home care per year per qualifying event. The goal of Medicare is to cover short-term nursing home stays (Pourat et al, 2001). This is a key piece of information when

discussing nursing home care of the elderly as many older persons develop chronic conditions that are not covered by Medicare. Therefore, clients must pay for their nursing home care from their own pocket or seek state-funded Medicaid coverage if they qualify.

### *3.4.2 Medicaid*

Medicaid was established as a joint federal-state program to provide medical assistance to persons that meet physical health and income guidelines. Medicaid is available to low-income families and children, as well as to the aged, blind and disabled persons (Abshire, Farrell, Olive, Sitchler, and Wright, 2005; Karp, Sabatino & Wood, 2005). Older persons receiving Medicaid typically fall into one of two categories. They are either low-income or they have some type of physical care need that will qualify them for Medicaid such as the decreased ability to complete activities of daily living or the need for constant medical attention in a nursing facility.

Long-Term Care Medicaid (LTC Medicaid) is an important factor to the financial aspect of nursing home coverage. In fact, Medicaid provides almost 70 percent of LTC services in the United States (Kitchener et al, 2006). Further detail about Medicaid coverage is discussed in the out-of-pocket nursing home expenditures section.

### *3.4.3 Long-Term Care Insurance*

In the United States only about five percent of Americans purchase long-term care insurance (LTCI). LTCI is very expensive and only available to individuals with good overall health at the time the policy is purchased. LTCI is not available for purchase until the age of 50. A policy is only available for those that have a low-risk for LTC needs and chronic health conditions can result in policy denial. In 2000, the cost for LTCI ranged from \$2800 to \$8900 per year based on the age at policy issuance (KFF, 2006). Unfortunately, LTC insurance is not a fiscally feasible solution for many older persons living on fixed incomes with health challenges. The cost of LTCI prevents many from seeking coverage.

Mellor (2001) found that some older persons choose to forego purchasing a LTCI policy if they prefer to receive care from their children. Some older adults feel LTCI would decrease their child's likelihood to care for them so they choose to not purchase the policy and rely strictly on family assistance for the general LTC needs. Likewise, this study found poorer individuals were less likely to purchase LTCI than wealthy individuals if they believed their family member would provide for their LTC needs. LTCI is an important factor when considering health care coverage as it may help alleviate LTC expenses for individuals and governmental programs.

### 3.5 Out-of-pocket Nursing Home Expenditures

Costs for nursing home care are a major concern for residents and their families. The American Association of Homes and Services for the Aging (AAHSA) (2008) estimates the average cost for a private room in a nursing home is over \$77, 000 per year and over \$200 per day. A shared room will reduce the cost of residency, but only to about \$180 per day. Nursing home care remains one of the highest out-of-pocket expenses for older Americans (Montgomery & Kosloski, 1994). Overall, the total cost for nursing home care exceeded \$98 billion in 2001 (Andel et al, 2007). The Centers for Medicare and Medicaid Services (2003) reports a projection of \$217 billion of nursing home expenditures by the year 2017. Nasser (2007) reports the average nursing home patient will exhaust their personal financial resources within six months and must rely on LTC Medicaid.

Research supports that individuals who pay out of pocket and are not on LTC Medicaid are less likely to use a nursing home even when facing health challenges and cognitive impairment (Borrayo et al, 2002). The Deficit Reduction Act of 2005 allowed the federal government to increase the penalties, asset caps and benefits for high-income individuals seeking LTC Medicaid as a payment source for nursing home care. Individuals that have transferred assets such as large amounts of cash and property within five years of the LTC Medicaid

application may not qualify for services (Karp et al, 2005). Also, those that transferred their assets for an amount below fair market value and those that have home equity above \$500,000 are no longer eligible to apply for LTC Medicaid funding. The recent changes to Medicaid regulations have a direct impact on the out-of-pocket nursing home expenditures. Persons that previously qualified for LTC Medicaid will now be paying out-of-pocket for their nursing home costs (Graboswki & Gruber, 2007). Elders over the age of 85 have the highest out-of-pocket nursing home cost (Stewart, 2004). This particular age group is also the fastest growing of all age groups over 65 years. The full impact of this issue remains to be seen as the population of older adults continues to grow and less governmental programs are available to help with their nursing home care needs.

### 3.6 Summary

Research has demonstrated risk factors, caregiving issues, race and ethnicity, health care coverage and out-of-pocket nursing home expenditures influence nursing home use. Each of these factors provides an understanding of this complex social phenomena. Overall, these factors have helped to understand the need for nursing home care as well as the potential cost of this health care service.

### *3.6.1 Gaps in the Literature*

The literature surrounding nursing home use for persons with dementia, Alzheimer's disease or other specific health care maladies such as stroke and cancer is vast. Literature is also well established dealing with caregiver burden and strain. For the purpose of this review, adequate information was uncovered surrounding nursing home use, but there are still areas which warrant further empirical research. Areas of further inquiry have been identified through this review: relative versus non-relative caregivers; usefulness of long-term care insurance and out-of-pocket nursing home expenditures.

Relative and non-relative caregivers are a key area of focus for future research. This review provided good documentation surrounding formal versus informal caregiving. While previous research has focused on relative (family/informal) caregivers, little work has been done to determine if having a relative caregiver decreases the amount of time spent in a nursing home. Likewise, one could question if having a non-relative (formal) caregiver increases the amount of time spent in a nursing home. This information is especially important as the literature has demonstrated that both long and short-term nursing home stays are a part of nursing home utilization.

Racial minorities have been underrepresented in nursing homes for years. Much of the research indicates that racial minorities prefer to remain in their

home and receive care from the relative caregivers. Therefore, future research should consider if having a relative caregiver impacts the amount of time spent in a nursing home for racial minorities. Understanding the factors surrounding the type of caregivers present in the home of an older adult would allow social workers, physicians and other health care professionals to better understand the current and future caregiving needs of elders.

Health care coverage is a long-standing issue surrounding any type of health care service. Specifically, nursing home care operates with a different set of rules in regard to coverage than other types of care accessed by older adults. For example, a simple hospital stay is covered by Medicare and a supplemental policy. Nursing home care, on the other hand is only covered by Medicare for a short period of time and then the individual must pay out-of-pocket or rely on a LTCI policy. There is limited information about the efficacy of LTCI policies. As the population of older adults increases, it is important to have an understanding of how LTCI affects nursing home use. For instance, does having a LTCI policy increase the length of stay in a nursing home? Along the same line of thinking, persons with LTCI policies are purchasing the policy hoping to reduce the amount of out-of-pocket nursing home expenditures. Further inquiry to determine if those with LTCI policies spend less out-of-pocket on their nursing home care is needed.

This review sought to identify factors surrounding nursing home placement. This study will extend the current research and address current gaps in the literature to better understand factors influencing nursing home utilization. The overarching research question for this study is: “What factors influence nursing home utilization of older African Americans, Hispanic Americans and Caucasians?”

## CHAPTER 4

### METHOD

The purpose of this study was to determine the factors that influence nursing home use of older African Americans, Hispanic Americans and Caucasians. Secondary data from the Health and Retirement Study (HRS) was used to conduct a longitudinal analysis of nursing home utilization of older Americans by using data gathered from 2000, 2002 and 2004. The choice to use secondary data instead of collecting primary data was made because the HRS has a large sample, provides an accurate representation of America's aging population and contains longitudinal data. Collecting primary data for this study would be difficult due to time constraints and expense. The HRS data focused on variables selected in this proposed study.

#### 4.1 Description of the Health and Retirement Study

The HRS is a national longitudinal study of Americans over the age of 50 years old. The HRS seeks to understand how one's physical and mental health, financial status, insurance coverage, labor market status, family support systems and retirement planning effects the aging process (UM, 2008). The HRS is supported by the National Institute on Aging (NIA) with additional support from

the Social Security Administration (SSA). Data collection for this survey began in 1992 and data continues to be collected every 2 years through the University of Michigan's Institute for Social Research.

## 4.2 Sample

### *4.2.1 Sample Design*

On average, the HRS samples approximately 22,000 individuals in approximately 15,000 households. When possible, the HRS samples not only identified the respondent but also their spouse or partner. In 1992, the HRS identified over 69,000 housing units through screening. Respondents are identified through a multi-stage, clustered area probability sampling design. This sampling procedure includes four distinct selection stages. The first stage involves probability proportionate to size (PPS) selection of U.S. Metropolitan Statistical Areas (MSAs) and non-MSA counties. This stage is followed by a second stage sampling of area segments (SSUs) within sampled primary stage units (PSUs). The third stage of sample selection is preceded by a complete listing (enumeration) of all housing units (HUs) that are physically located within the bounds of the selected SSU. The third sampling stage is a systematic selection of housing units from the HU listings for the sample SSUs. The fourth (final) stage in the multi-stage design is the selection of an age-eligible person within the sample HU (UM, 2008).

This study will use data spanning the 2000, 2002 and 2004 waves of data collection. These three waves contain five sub-samples:

1. HRS sub-sample: This sub-sample comprises household residents of the United States born between 1931 and 1941. This sub-sample was originally established in 1992 as previously discussed and has been sampled every 2 years since. Household residents and their spouses or partners represent this sample (UM, 2008).
2. AHEAD sub-sample: This sub-sample consists of household residents of the United States and were born in 1923 or earlier. Spouses and partners are included in this sub-sample. The AHEAD sub-sample identified about half of its respondents in the 1992 screening, while the other half was identified through the Health Care Financing Administration's (HCFA) enrollment data. AHEAD was initially a study separate from HRS, but was combined in 1998 as it closely aligns with the goals of the HRS. The first interview for this sub-sample began in 1993-1994. Data was gathered again in 1995-1996, 1998 and then every 2 years thereafter (UM, 2008).
3. War Baby (BB) sub-sample: This sub-sample comprises household residents of the United States born between 1942 and 1947, and those who did not have a spouse or partner born before 1924 or between 1931 and 1941 as persons born during this time frame were already included in the HRS and AHEAD sub-samples. This sub-sample was identified through

the 1992 screening and interviewed for the first time in 1998, interviews have continued every 2 years since. Spouses and partners (excluding the aforementioned birth dates) were also included (UM, 2008).

4. The Children of the Depression (CODA) sub-sample: This sub-sample consists of household residents of the United States born between 1924 and 1930. The first interview occurred in 1998 and has continued every 2 years thereafter. Members of this sub-sample were identified through HCFA enrollment files. Spouses and partners were also included (UM, 2008).
5. Early Baby Boomer (EBB) sub-sample: This sub-sample comprises household residents of the United States born between 1948 and 1953 (ages 51-56 in 2004). The EBB sub-sample was obtained through screening over 38,000 households. Ninety-three percent of those screened were deemed eligible for the study. This sub-sample was sampled again in 2006. HRS will continue data collection biennially (UM, 2008).

The HRS conducts their interviews every two years, but only adds a new cohort to their study every six years. The HRS sub-sample, AHEAD sub-sample, War Baby sub-sample, Children of the Depression sub-sample and Early Baby Boomer sub-sample are all specific cohorts represented in the HRS (UM, 2008).

#### *4.2.1.1 Oversampling of Racial Minorities*

The HRS is nationally-representative sample, but also recognizes that racial minorities experience aging and retirement in a different fashion. Therefore, African American and Hispanic American elders are over-represented in this study. To determine how extensive the over-sampling should be, HRS consulted the 1990 Census data. While the HRS continues to use the 1990 Census data as a benchmark for racial criteria, the U.S. Census Bureau has made changes to their sampling procedures. In 1977, five racial categories were established: American Indian or Alaskan Native, Asian or Pacific Islander; Hispanic origin and Not of Hispanic Origin, African American/Black and White. Another category listed as “Some Other Race” was also listed. Due to the increase of diversity in racial composition in the United States, a request was made in 1997 to increase the number of categories to now include the following racial and ethnic classifications: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander and White; Hispanic or Latino, Not Hispanic or Latino and Some Other Race. Census respondents are also able to select one or more races in which they self-identify (U.S. Census Bureau, 2009). The aforementioned categories were used for the first time in 2000, but the HRS continues to base their racial classifications on the 1990 Census categories.

#### *4.2.1.2 African Americans*

The 1990 Census data suggest that the expected total of completed interviews from an equal probability sample of U.S. household would contain approximately 10% age-eligible African American households. Within the 84 PSUs which comprise the first stage of the SRC National Sample Design, a supplemental sample of SSUs was selected from second stage strata of Census block groups containing 10% or more of the 1990 Census households with a African American heads. Therefore, eligible persons in residential areas eligible for the second stage sample supplement (more than 10% African American households per block group) have a greater probability of selection than persons in areas which have less than 10% African American households. Through the use of this procedure, the representation of eligible African American household units was expected to increase from 10% to about 18.6% of the total HRS sample (UM, 2008). More current information indicates that the African American population over the age of 65 currently represents approximately 9.2 percent of the total United States population. The HRS dataset includes twice as many samples of African Americans when compared to the current population for this minority group (U.S. Census Bureau, 2008).

#### *4.2.1.3 Hispanic Americans*

For an equitable probability sample of U.S. households, 1990 estimates from the Current Population Survey would suggest that 5% of the HRS households would include a respondent of Hispanic origin. Approximately 58% of these Hispanic households are of Mexican ancestry. The design objective for the HRS was to obtain a two-fold oversampling of Mexican-American households. The Hispanic supplement required additions to the PSU sample, especially in the West and Southwest. In addition to expanding the primary stage of the sample, supplemental sampling of SSUs in areas with Hispanic density of 10% more was used to assure sufficient sample size to permit subgroup analysis. Unlike the Black oversample eligibility, these SSUs were restricted to households containing an age-eligible Hispanic household member. The Hispanic supplement was designed to increase the representation of Hispanics, including the Mexican-American subgroup, from 5% to 8% of the total HRS sample (UM, 2008). Currently, the population of Hispanic Americans over the age of 65 represents approximately 5.7% of the total United States population. The current method has given the Hispanic population representation that is almost two times the amount of Hispanics actually represented in the current United States population (U. S. Census Bureau, 2008)

### 4.3 Instrumentation

The HRS questionnaire uses a box-and-arrow format to collect data. This method allows the study questions to flow in a logical sequence and guide the interviewers and interviewees through the process. The questionnaire is based on the Programs Specifications (Specs) and computer instructions are used to electronically produce the instrument for Computer Assisted Telephone Interviewing (CATI). The questions have been checked and edited to ensure what is asked accurately represents as close as possible what is experienced by the interviewee (UM, 2008).

The questionnaire is intended to show all possible questions that can be asked and all of the possible responses to each question. Not every question is asked of each respondent. The following conditions were considered: the type of respondent (married vs. non-married; sampled individual vs. proxy respondent) and/or the way the respondent answered questions (UM, 2008). For instance, if a respondent responds to a question in a particular manner, the interviewer may be instructed to “jump” to a contingency question in order to continue the interview process. Both open and closed-ended questions are included in the questionnaire to obtain intended information.

#### 4.4 Data Collection Procedures

Data collection for the HRS is set-up to obtain the best and most accurate data from the best possible respondent. The sampled individual is the target of the data collection, but when the sampled individual was not present or chooses not to participate, proxy respondents are allowed. The proxy respondent is chosen based on their relationship to the sampled individual and their ability to accurately answer questions regarding family situations, health and finances. Proxy respondents may be requested if the sampled individual is unable to participate due to physical or cognitive limitations. Proxy respondents are likely to be spouses, partners or children of the sampled individual (UM, 2008).

##### *4.4.1 Baseline Interviews*

All baseline interviews for the HRS, AHEAD, CODA and WB sub-samples are conducted in the home of the sampled individual through a face-to-face interview format. The HRS sub-sample baseline interviews began in 1992; the AHEAD sub-sample baseline interviews began in 1993 and 1994; the CODA and WB sub-sample baseline interviews began in 1998 and the EBB sub-sample baseline interviews began in 2004 (UM, 2008). The EBB sub-sample also completed telephone interviews when deemed appropriate by the interviewer.

#### *4.4.2 Follow-up Interviews*

Follow-up interviews are typically conducted by telephone. Exceptions to this include sampled individuals that do not have telephones in their homes, if the sampled individual is unable to understand or complete the interview over the phone due to their physical or cognitive limitations, or if respondent was in the first wave of the HRS data collection and in the baseline sample for the CODA and WB sub-samples. All other follow-up interview are completed by telephone (UM, 2008).

#### 4.5 Protection of Human Subjects

The HRS addresses human subject concerns in their Institutional Review Board Information report (UM, 2008). This report contains information on informed consent, confidentiality, voluntary participation and possible risks due to participation in the study. IRB approval was received prior to conducting this study.

#### 4.6 Study Design

A longitudinal, non-experimental design was used for this study. Data collected over the 2000, 2002 and 2004 waves of the HRS have been included. This study was non-experimental because there is no control group and the

variables will not be manipulated (Vogt, 2005). The goal of this study was to predict relationships between the chosen variables.

#### *4.6.1 Threats to Internal Validity*

*1. History.* History is a concern when events occurring simultaneously during the time of the study could cause a change in the outcome of the study (Shadish, Cook & Campbell, 2002). For this proposed study, history was an issue due to the longitudinal nature of the study. For example, persons residing in nursing homes may experience change in their LTCI policies which could lead to an increase in out-of-pocket nursing home expenditures. Because data is collected over a long-term time period (6 years) history could be a possible cause for changes in the outcome of the study. History cannot be controlled for as by definition it manifests in extraneous and uncontrollable events that are co-occurring with the research process.

*2. Maturation.* Maturation is problematic due the nature of the passage of time (Shadish et al, 2002). The HRS focuses on the aging population. Each year a person ages, the likelihood of extraneous events complicating their existence may surface. For example, as one ages their ability to remember specific details between the two year time-lapse of HRS interviews may decrease. Therefore, respondents may be providing less

accurate data because of the passage of time or their own natural changes through the aging process. Maturation cannot be controlled for as it is simply a part of the aging process and passage of time. These events extend beyond the control of a research design.

3. *Attrition.* Attrition is the loss of participants over the course of the research study (Vogt, 2005). Attrition is a concern with the HRS because of the age of the respondents and the longitudinal nature of the study. For example, respondents may actually die during the process which is more probable in the over 85 years of age category. Likewise, as respondents' age, they may have less of a desire to participate in a telephone or face-to-face interview. Also, their proxy may have deceased or no longer want to participate in the lengthy interview process. While attrition is a valid concern, the HRS samples a large number of individuals and continues to add additional cohorts such as the Early Baby Boomer sub-sample at pre-determined time-intervals.

4. *Social Desirability Bias.* Social desirability bias is the tendency of respondents to say what they think the interviewer would like to hear (Rubin & Babbie, 2003). This threat to internal validity is of concern in the HRS due to the face-to-face interview process. Respondents may be tempted to withhold certain information or state information in a way that

would yield them a positive or desirable result from the interviewer. For example, the HRS study asks respondents to provide details about their insurance providers. An individual using Medicaid to pay for their nursing home expenses may not want to fully divulge this information for fear of the potential social stigma associated with Medicaid as it is often viewed negatively as a welfare program. Therefore, the respondent may not share how they are paying for their nursing home services in effort to remain socially desirable in their communication.

#### *4.6.2 External Validity*

External validity is defined as “the extent to which the causal relationship depicted in a study can be generalized beyond the study conditions” (Rubin & Babbie, 2001, p. 296). Because the HRS is a national longitudinal study and uses probability sampling, the sample is representative of the aging population. The findings of this study were generalizable and applicable to the aging population in general.

#### 4.7 Variables

Six variables were the focus of this study: Nursing Home Utilization, Out-of-pocket Nursing Home Expenditures, Caregiver Type, Caregiver Race and Long-Term Care Insurance. These variables were chosen because they were discussed as factors influencing nursing home care in current gerontological

literature. All HRS variables sought to gather information from the respondent over a two-year time period. For example, “how many nights over the past two years did you spend in a nursing home?” is a question from the HRS database.

#### *4.7.1 Nursing Home Utilizations*

Nursing home is defined as receiving care in a nursing facility. This excludes home-health care received in the person’s home or any other type of residence where nursing care is provided. Nursing home utilization is operationalized in the HRS, when respondents are asked how many nights they spent overnight in a nursing home in the past two years. Nursing home utilization was measured as a ratio level variable.

#### *4.7.2 Out-of-pocket Nursing Home Expenditures*

Out-of-pocket nursing home expenditures are operationalized in the HRS, by respondents being asked how much they spent out-of-pocket for nursing home costs over the past two years. The cost of nursing home care is a major concern for older Americans (AAHSA, 2008) Out-of-pocket nursing home expenditures was measured at the ratio level as the actual dollar amount spent.

#### *4.7.3 Caregiver Type*

Caregiver type is operationalized as relative or non-relative caregiver. A relative caregiver is any individual that is a part of the respondents’ family

including spouses, partners, children or extended family and provides assistance in the respondent's home. A non-relative caregiver is an individual that provides assistance in the respondents' home and is a paid caregiver from an agency, organization or professional caregiver service. Caregivers have been identified extensively in the literature as an integral part of the aging process (Quinn et al, 1999). Caregiver type was measured as a nominal level variable.

#### *4.7.4 Relative Caregiver Race*

Relative Caregiver race is operationalized in the HRS by gathering data on the racial category of respondent's spouse/caregiver. Four options for racial identification are provided: Caucasian, African American, Hispanic American and Other for all other races. Relative Caregiver Race was measured as a nominal level variable.

#### *4.7.5 Long-Term Care Insurance*

Long-Term Care Insurance (LTCI) is operationalized in the HRS, as respondents that did or did not purchase a LTCI policy to cover their nursing home expenses. LTCI was measured as a nominal level variable.

#### *4.7.6 Control Variables*

Control variables are "extraneous variables that you do not wish to examine in your study" (Vogt, 2005, p.62). Race, Age, Activities of Daily Living

and Health Status are chosen as control variables for this study to ensure these particular variables do not produce unwanted effects in the statistical interpretation of data.

#### *4.7.6.1 Race*

Race is of the respondent measured in the HRS, by asking respondents to identify their racial heritage. Racial minorities have historically been thought to seek nursing home services less than Caucasians (Akamigbo & Wolinsky, 2007; Baxter et al, 2001; Li, 2004). HRS offers four options for racial identification, Caucasian, African American, Hispanic and Other for all other races. Race was measured as a nominal level variable.

#### *4.7.6.2 Age*

Age was chosen because literature supports that as one ages, their likelihood of nursing home utilization increases (NCNHR, 1999). Age is important to control for to ensure its influence does not conflict with the influence of other study variables on nursing home utilization. HRS specifically asks the age of the respondent, and therefore was measured at the ratio level.

#### *4.7.6.3 Activities of Daily Living*

Activities of Daily Living (ADLs) have long-standing support in the literature as an indicator of nursing home utilization (Aditya & Sharma, 2003;

Grando et al, 2002). ADLs are measured in the HRS by asking respondents if they are able to walk, get in/out of bed, toilet, dress and bathe. ADLs were controlled for to ensure one's ability to perform ADLs does not have an unwanted effect on the regression model. An ADL scale was used to determine if ADL difficulty exists for the respondent. The scale ranges from zero to five with "zero" indicating no difficulty and "five" indicating difficulty with all five areas of ADL ability. ADLs was measured as a ratio level variable.

#### *4.7.6.4 Health Status*

Health Status is measured in the HRS, by asking respondents to rank their overall health. Respondents are asked to select from "excellent, very good, good, fair and poor" as options for their health status. Health status was chosen as a control variable because one's health could affect their nursing home utilization as supported by current literature (Grando et al, 2002). Health Status was measured as an ordinal level variable.

#### *4.7.6.5 Number of Children*

The number of children for respondents is measured in the HRS, by asking respondents to provide the actual number of children in their family. Previous research has indicated that children affect how one receives care and potentially

uses LTC (Chou et al, 2001). The number of children was measured at as a ratio level variable.

#### *4.7.6.6 Partner Status*

Partner status is measured in the HRS, by asking respondents to define if they are part of a married part of a partnered couple or not part of a married couple. Partners often differ in how they dispense care their loved ones (Jette et al, 1995). Therefore partner status was included as a control variable. Partner status was measured as an nominal level variable.

#### *4.7.6.7 Insurance Coverage*

Insurance coverage is considered extensively in the HRS, but this study specifically considered those with Medicare and Medicaid. Therefore, Insurance Coverage is measured in the HRS, by asking respondents if they receive Medicare or Medicaid coverage for nursing home care. Insurance Coverage was measured at the nominal level.

### 4.8 Overarching Research Question

The overarching research question for this proposed study is “What factors influence nursing home use of older African Americans, Hispanic Americans and Caucasians?” The following hypotheses were written to address the overarching research question. Andersen’s Behavioral Model of Health Service Use helped to

guide the selection of the research question and the hypotheses. Andersen's model provides a theoretical framework which details specific characteristics that lead to health service use. In this study, nursing home utilization is the identified health service use and the selected variables of study are the predisposing, enabling and need characteristics that lead to health service use.

#### 4.9 Hypotheses

1. Older persons with relative caregivers spend less time in the nursing home than those with non-relative caregivers (Charles & Sevak, 2005; Scharlach et al, 2008) .
2. Racial minorities with relative caregivers spend less time in a nursing home than Caucasians with relative caregivers (Akamigbo & Wolinsky, 2007; Kersting, 2001; Lum, 2005; Salive et al 1993; Scharlarch et al, 2006).
3. Older persons with long-term care insurance spend more time in the Nursing Home than those without long-term care insurance (Mellor, 2001)
4. Older persons with long-term care insurance spend less on out-of-pocket nursing home expenditures than those without long-term care insurance (Grabowski & Gruber, 2007; Stewart, 2004).

## 4.10 Data Analysis

### *4.10.1 Descriptive Statistics*

Descriptive statistics were run on all variables in this study. Means were run to demonstrate the average number of nights spent in a nursing home and to determine the average amount of out-of-pocket expenditures for nursing home care. Frequencies were run on race, age groups, caregiver, type, relative caregiver race, long-term care insurance and out-of-pocket nursing home expenditures.

### *4.10.2 Multiple Regression*

Multiple regression is a statistical procedure used to evaluate the effects of multiple predictor variables on a criterion variable (Vogt, 2005). Multiple regression was used to test the hypotheses. The regression model was run with all waves combined to produce findings for all three waves in one regression model.

## CHAPTER 5

### RESULTS

The study variables were analyzed to test the hypotheses designated for the study. The finding for each hypothesis follows.

#### 5.1 Utilized Sample Description

Data from the 2000, 2002 and 2004 waves of the HRS were used for this study. The sample was limited to individuals age 65 and older and that have spent more than one night in a nursing home. The distribution of race, age, caregiver type, relative caregiver race, long-term care insurance coverage (LTCI), and out-of-pocket nursing home expenditures are included in Table 1.

Table 1. Sample Description for Study

Descriptor		Raw	%
	N of Sample	984	100.0
Race	Caucasian	852	89.6
	African American	56	5.9
	Hispanic	40	4.2
	Other	3	0.3
Age	65 -74	246	25.0
	75-84	394	40.0
	85 & over	344	35.0
Caregiver Type	Relative Caregiver	186	18.9
	Non-Relative Caregiver	77	7.8
	Absent Caregiver	721	43.8
Insurance Type	Medicare	984	100.0
	LTC Medicaid	195	19.8
	LTCI	84	8.5
Relative Caregiver Race	Caucasian Caregiver	150	15.2
	African America Caregiver	25	2.5
	Hispanic Caregiver	7	0.70
	Other Caregiver	2	0.2
Out-of Pocket Nursing Home Expenditures		175	17.8

### *5.1.1 Race*

The racial breakdown of the sample was provided. The sample was comprised of approximately 89% of Caucasians, 6% African Americans, 4% Hispanic Americans and 3% falling into the other races category over a two year time period.

### *5.1.2 Age*

The age of respondents in the sample were considered. The mean age of the sample was approximately 80 years old. A breakdown of ages was included to better understand the sample demographic. In the 65 to 74 age category, there were 246 individuals, comprising 25% of the sample that spent time in a nursing home over a two year time period. In the 74 to 84 age category, there were 394 individuals or 40% that spent time in the nursing home and the 85 and over age category, there were 344 individuals or 35% that spent time in a nursing home over a two year time period.

### *5.1.3 Caregiver Type*

The study considered two types of caregivers, relative caregivers and non-relative caregivers. In this sample, approximately 19% of individuals had a relative caregiver over a two year time period. Approximately 8% of the sample

had a non-relative caregiver while approximately 44% reported no caregiver (absent caregiver) available over a two year time period.

#### *5.1.4 Insurance Type*

The study considered three types of insurance coverage: Medicare, LTC Medicaid and LTCI. In this sample, 100% of the sample reported Medicare coverage over a two year time period. Approximately 20% of the sample reported LTC Medicaid coverage and 8.5% of the sample reported coverage of a LTCI plan over a two year time period.

#### *5.1.5 Relative Caregiver Race*

This study considered how the race of relative caregivers affected the number of nights spent in a nursing home over a two year time period. Caucasian relative caregivers represented 15.2% of the sample over a two year time period. African American relative caregivers made up 2.5% of the sample, Hispanic American relative caregivers comprised 0.7% of the sample and races falling into the “other” category represented 0.2% of the sample over a two year time period.

#### *5.1.6 Number of Nights in Nursing Home*

Means were calculated for the number of nights spent in a nursing home and out-of-pocket nursing home expenditures. An average of 44 nights was spent in the nursing home over a two year time period.

### 5.1.7 Out-of-pocket Nursing Home Expenditures

Those with out-of-pocket nursing home expenditures represented 17.5% of the sample as per Table 1. Means were calculated for the amount of out-of-pocket nursing home expenditures. Those reporting out-of-pocket nursing home spending spent an approximate average of \$11059.00 over a two year time period as per Table 2.

Table 2. Mean for Number of Nights in Nursing Home and Out-of-Pocket Nursing Home Expenditures

Variable	N	Mean	SD
Nights in Nursing Home	984	44.09	106.23
Out-of-pocket Nursing Home Expenditures	175	\$11059.36	25528.58

### 5.2 Hypothesis 1

Hypothesis 1 predicted that older persons with relative caregivers would spend less time in a nursing home when compared to those with non-relative caregivers. To test this hypothesis, a multiple linear regression was calculated to predict the number of nights spent in a nursing home over a two year time period

based on caregiver type (see table 4). After controlling for age, ADL level, health status, insurance type and race, the effect of caregiver type was found to be insignificant ( $\beta = .400$ ,  $p = .095$ ). Thus, the null hypothesis was accepted as regression demonstrated that caregiver type did not have a statistically significant impact on the number of nights spent in a nursing home. Therefore, older persons with relative caregivers did not spend significantly less time in the nursing home when compared to those with non-relative caregivers.

### 5.3 Hypothesis 2

Hypothesis 2 predicted racial minorities with relative caregivers spent less time in a nursing home than those with Caucasian relative caregivers. To test this hypothesis, a multiple linear regression was calculated to predict the influence of the number of nights spent in a nursing home over a two year time period based on relative caregiver race (see table 4). After controlling for age, ADL level, health status, insurance type and race, the effect of caregiver race was found to be insignificant ( $\beta = -.1081$ ,  $p = .305$ ). Thus, the null hypothesis was accepted as regression demonstrated that caregiver race did not have a statistically significant impact on the number of nights spent in a nursing home. Therefore, older racial minorities with relative caregivers did not spend significantly less time in the nursing home when compared to those with Caucasian relative caregivers.

### 5.4 Hypothesis 3

Hypothesis 3 predicted that those with long-term care insurance spent more time in the nursing home over a two year time period when compared to those without LTCI. To test this hypothesis, a multiple linear regression was calculated to predict the influence LTCI on the number of nursing home nights. After controlling for age, ADL level, health status, insurance type and race, the effect of LTCI was found to be insignificant ( $\beta = .549, p=.069$ ). Thus, the null hypothesis was accepted as regression demonstrated that the presence of long-term care insurance did not have a statistically significant impact on the number of nights spent in a nursing home. Therefore, those with LTCI did not spent more time in the nursing home when compared to those without LTCI.

Table 3. Regression Analysis of the Influence of Caregiver Type, Relative Caregiver Race & LTCI

Predictor	R <sup>2</sup>	F	$\beta$	SE
	0.672	2.050		
Caregiver Type			.400	32.590
Relative Caregiver Race			-.247	13.780
LTCI			.549	55.774

Table 4 provides an overview of the average number of nights spent in a nursing home by those with relative caregivers, non-relative caregivers racial minorities with relative caregivers over a two year time period.

Table 4. Mean number of nights spent in nursing home by Caregiver Type & Relative Caregiver Race

Descriptor		N	Mean	SD
Caregiver Type				
	Relative Caregiver	18 6	42.6	91.08
	Non-Relative Caregiver	77	50.41	122.83
	Absent Caregiver	72 1	43.8	108.07
Relative Caregiver Race				
	Caucasian	15 0	34.22	62.98
	African American	25	31.08	36.25
	Hispanic	7	63.14	133.4
	Other	2 13	13	1.41

Individuals with non-relative caregivers had the highest mean number of nights in the nursing home over a two year time period. Those with relative

caregivers spent an average of 42 nights in a nursing home compared to those with non-relative caregivers which spent an average of 50 nights in a nursing home over a two year time period. Those without a caregiver (absent caregiver) reported an average of 43 nights in a nursing home of a two year time period.

Information regarding racial minorities with relative caregivers indicated a difference in the mean number of nights spent in a nursing home over a two year time period based on one's racial group. Hispanics reported the highest average number of nights with a mean score of 63 nights over a two year time period. African Americans and Caucasians were the next highest mean scores with Caucasians spending an average of 34 nights while African Americans report an average of 31 nights in the nursing home over a two year time period. Those falling into the "other" category had the lowest mean with a score of 13 nights spent in the nursing home over a two year time period.

Table 5 provides an overview of the average number of nights spent in a nursing home over a two year time period by those with LTCI, Long-Term Care Medicaid and Medicaid.

Table 5. Mean number of nights spend in Nursing Home by Insurance Type

Insurance Type	N	Mean	SD
LTCI	84	32.65	58.13
Long-Term Care Medicaid	146	69.7	156.56
Medicare	963	43.35	103.16

Those with LTCI spent less time in the nursing home over a two year time period when compared to those with Medicaid and Medicare coverage. Those with LTCI spent an average of 32 nights in the nursing home over a two year time period while those with Long-Term Care Medicaid spent an average of 69 nights in the nursing home over a two year time period. Medicare recipients spent an average of 43 nights in the nursing home over a two year time period. Further about these findings will be discussed in the following chapter.

#### 5.5 Hypothesis 4

Hypothesis 4 predicted that those with LTCI spent less on out-of-pocket nursing home expenditures than those without LTCI. To test this hypothesis, the number of individuals with both LTCI and those with out-of-pocket nursing home

spending were considered. 84 individuals in the sample reported having LTCI over a two year time period. The total number of individuals from the sample with out-of-pocket nursing home expenditures was 175 over a two year time period. The mean amount of out-of-pocket nursing home expenditures was \$11,059.00 over a two year time period. (See Table 2). The range of expenditures was from \$25.00 to \$187,200.00 over a two year time period. Of the 84 respondents with LTCI, only 9 of them had out-of-pocket nursing home spending over a two year time period. Therefore, there was not a large enough sample of those with both LTCI and out-of-pocket nursing home spending to produce a correlation and a regression analysis was not possible. Of the 84 individuals with LTCI, 75 did not report out-of-pocket nursing home spending over a two year time period. Had a regression model been possible, the influence of LTCI on out-of-pocket nursing home spending would have been run with the control variable insurance type.

Table 6 provides an overview of the mean amount of out-of-pocket nursing home spending over a two year time period based on insurance type.

Table 6. Mean Out-of-pocket Nursing Home Spending by Insurance Type

Descriptor	N	Expenditure
Medicare	151	\$11,273
LTC Medicaid	15	\$14,385
LTCI	9	\$12,960

There were 151 individuals with Medicare coverage that spent money on their nursing home care. Their average out-of-pocket expenditure was \$11,272.00 over a two year time period. There were 15 individuals with LTC Medicaid that also spent money out-of-pocket on their nursing home care. Their average expenditure was \$14,385.00 over a two year time period. There were 9 individuals with LTCI that also spent money out-of-pocket on their nursing home care. Their average out-of-pocket expenditure was \$12,960.00 over a two year time period.

Table 7 provides an overview of those with out-of-pocket nursing home spending over a two year time period compared to their racial category.

Table 7. Mean out-of-pocket nursing home expenditures by race of sample

Descriptor	N	Expenditure
Caucasian	157	\$12,112
African American	11	\$1,615
Hispanic	6	\$7,374
Other	1	\$2,400

There were 157 Caucasians individuals that experienced out-of-pocket spending on their nursing home care over a two year time period. Their average expenditure was \$12,112.00 over a two year time period. There were 11 African Americans individuals that experienced out-of-pocket spending on their nursing home care. Their average expenditure was \$1,615.00 over a two year time period. There were six Hispanic individuals that experienced out-of-pocket spending on their nursing home care over a two year time period. Their average expenditure was \$7,374.00 over a two year time period. There was one person representing the “other” racial category that experienced out-of-pocket spending on their nursing home care. The expenditure for this person was \$2,400.00 over a two year time period.

## CHAPTER 6

### DISCUSSION

This chapter will provide an explanation of the major findings from the previous chapter. Implication and recommendations for social work practice, research and policy will be discussed. In conclusion, the limitations of this study will be presented.

#### 6.1 Explanation of Major Findings

This study revealed findings concerning the number of nights spent in a nursing home, out-of-pocket nursing home expenditures and provided insight into several variables that influenced nursing home use and out-of-pocket nursing home spending.

##### *6.1.1 Caregiver Type*

This study focused on the impact of caregiver type on the number of nights spent in a nursing home. This allowed for a comparison of relative and non-relative caregivers and those without a caregiver (absent caregiver). While this study did not find a statistically significant difference in the amount of time spent in a nursing home between relative and non-relative caregivers and those

without a caregiver, it was demonstrated that those with non-relative caregivers reported a larger mean score for the number of nights spent in the nursing home. This is consistent with previous research that reports relative caregivers decrease one's chances of nursing home entry compared to those with non-relative caregivers (Charles & Sevak, 2005). These findings align with the Behavioral Model of Health Service Use in that caregiver type was found to be an enabling factor that leads health service use, in this case nursing home care. In other words, the presence of a non-relative caregiver acts as an enabling factor which leads to nursing home use.

#### *6.1.2 Relative Caregiver Race*

This study found that racial minorities with relative caregivers reported disparity in the number of nights spent in a nursing home. While there was not a statistically significant difference, on average, Hispanic individuals spent a greater number of nights receiving care in a nursing home. This contradicts previous research which states that Hispanic American individuals are less likely than Caucasian to use formal care services (Baxter et al, 2001; Scharlach, 2008). Hispanic Americans have been cited as more likely to use formal and informal services because they possess more complex and supportive caregiver networks when compared to other racial groups (Li et al, 2005). Previous research supports that minorities will display more representation in nursing home as the

demographic in the United States continues to change (Morrison, 1995). This may be an explanation of why Hispanic Americans reported a higher average number of nights in the nursing home in this study.

Caucasians have been cited to use formal care services such as a nursing home care in greater frequency than other racial groups (Lum, 2005; Scharlach, 2006). In this study, with the exception of Hispanic Americans, it was found that African Americans and those in the “other” category spent less time in nursing homes compared to Caucasians when looking at the average number of days. It is also possible that Hispanic Americans assimilate to mainstream American culture more rapidly than other racial group and therefore, they may be more likely to use nursing home care.

While this study did reveal some information about the differences in how racial minorities with relative caregivers use nursing home care, there remains an unclear picture of why different racial minorities access nursing home care.

The findings surrounding relative caregiver race for Caucasians, African Americans, Hispanic Americans and those in the “other” category are consistent with the Behavioral Model of Health Service Use which indicates that one’s race is a predisposing factor and potentially leads to nursing home use.

### *6.1.3 Long-Term Care Insurance*

The findings that dealt with LTCI provide a snapshot of the influence of LTCI on the amount of time spent in a nursing home. While the findings surrounding this variable were not statistically significant, there were consistencies found within this study that support previous research. Nationally, about 5% of the United States population purchase LTCI. In this particular sample, 8.5% reported having LTCI. While this sample is slightly above average in owning a LTCI policy, this was not indicative of significantly spending less time in a nursing home. This study revealed that those with LTCI have a smaller average number of days in a nursing home when compared to Medicaid recipients. Previous research discusses that some older Americans may opt to not purchase LTCI policies so that their children can take care of them; may be unable to afford LTCI policies; lack of planning for their long-term care (LTC) needs and because if needed, LTC Medicaid may be a viable option for them if LTC is needed (Mellor, 2001).

The average number of nights spent in a nursing home for those with LTC Medicaid was over two times the average number of nights spent for those with LTCI. This is an important finding in regard to the cost outlaid by the LTC Medicaid program. Persons with LTC Medicaid appear to have fewer restrictions in regard to the how long they spend in nursing homes. The average number of

days covered by Medicare is not an important factor as Medicare coverage automatically limits the number of days one can spend in a nursing home per calendar year. LTC Medicaid covers over 70% of LTC services in the United States (Kitchner, et al, 2006). This finding supports the fact that LTC Medicaid will likely continue to financially strain the LTC system in the United States.

Theoretically, LTCI is not an enabling factor for nursing home use as indicated by the Behavioral Model of Health Service Use. Those that have LTCI do not consistently use their LTCI policy benefits to spend time in the nursing home.

#### *6.1.4 Out-of-pocket Nursing Home Expenditures*

Out-of-pocket nursing home expenditures were considered in conjunction with LTCI. For this reason, the number of individuals that met the criteria of having both LTCI and out-of-pocket nursing home spending was too small to produce a statistical regression analysis. Although, there were not statistically significant findings to report, the fact that so few individuals with LTCI reported out-of-pocket nursing home expenditures is important. This would indicate that individuals purchasing LTCI are actually alleviating the likelihood of out-of-pocket spending on their nursing home care.

Out-of pocket expenditures and racial category were also considered. Caucasians reported the highest out-of-pocket nursing home spending equaling approximately \$12,000 over a two year time period. Hispanic Americans spent approximately \$7300, African Americans spent approximately \$1600 and those in the “other” category spent approximately \$2400. From previous research, Caucasians have been documented to spend money on their nursing home care when compared to other racial groups. While these expenditure are significant, it is likely that individuals were spending toward their nursing home care in effort to qualify for LTC Medicaid. As previously discussed, many individuals must “spend down” their financial resources in order to qualify for LTC Medicaid. These finding would support the higher number of Caucasians and Hispanic Americans that reported longer nursing home stays in comparison to African Americans and the “other” category of racial groups.

Likewise, Medicare recipients had the lowest out-of-pocket nursing home spending when compared to those with LTC Medicaid or LTCI. Not surprisingly, those with LTC Medicaid reported the highest average out-of-pocket spending on their nursing home care with an approximate expenditure of over \$14,000 over two year time period. Those with LTCI reported an approximate expenditure of \$13,000 over a two year time period. Those with Medicare reported an approximate expenditure of \$11,000 over a two year time period. Again, these findings support the governmental structures in place to ensure that LTC

Medicaid recipients use their own financial resources to pay for their LTC needs before applying for governmental funding.

Due to the inconclusive nature of the findings surrounding out-of-pocket nursing home expenditures, it is difficult to assume that this variable demonstrated alignment with the Behavioral Health Model of Service Use. Therefore, further inquiry into this variable and application of this theory is needed to demonstrate sound theoretical application.

## 6.2 Implications and Recommendations for Social Work

Social workers are skilled in working with families and older adults, therefore, the findings of this study are essential to social workers individually and the social work profession at large. Social workers must continue to increase their knowledge about nursing home use as well as the impact of the caregivers and insurance coverage as the population of older Americans continues to increase.

### *6.2.1 Practice*

This study is beneficial to social workers, particularly those that work as Medical Social Workers in hospitals, home health, geriatric care management and nursing homes as well as those that help with decision-making for families. This study provides a beginning picture of how caregiver type affects the amount of

time spent in a nursing home. Social workers may make assumptions about relative caregivers and their ability to care for their loved one and not realize the likelihood of a relative caregiver placing their loved one in a nursing home. Likewise, social workers may assume that persons with non-relative caregivers would be less likely to spend time in a nursing home. This study demonstrated that those with non-relative caregivers reported a higher average number of nights in the nursing home. Awareness of caregiver type and how it affects movement to and from a nursing home is important for discharge planning, interdisciplinary team education, care coordination and overall assessment of the client situation.

Social workers should also be aware of the importance of educating caregivers. Caregivers are often the most valuable resource in the life of a client. Social workers are trained to be aware of all resources and understand the healthcare system. It is all too easy to assume that clients and their families know and understand the maze of the U.S. Healthcare systems. Social workers should work continually to be educated about changes in healthcare coverage surrounding Medicare and LTC Medicaid as well as LTCI. In addition to knowing about and understanding healthcare coverage, social workers should be educated about all aspects of the aging process, types of LTC available and how to translate knowledge into useful information for clients and their caregivers.

Social workers should be well-versed in medical terminology and understand as much as possible how language barriers affect a client and the caregiver. Social workers often assume that clients and their caregivers understand what is going on around them. In actuality, understanding the terminology and language of the medical field is daunting. Social workers should advocate for caregiver education as well as working to ensure that clients and caregivers have resources such as interpreters available to explain options.

This study demonstrates how important culturally competent practice is among social workers. The United States continues to increase its diversity, therefore, as racial minorities age, social workers are responsible for understanding the differences in how an older African American person ages in comparison to an older Hispanic American person or an older Asian American person and so on. The implications for assessment, care coordination and service delivery are greatly impacted by one's racial group and ethnicity. Therefore, social workers must be educated about the differences in racial groups, their beliefs about aging and their willingness to accept LTC and nursing home care.

Social workers frequently educate clients and their families about insurance coverage. Social workers must have an understanding of Medicare, LTC Medicaid and the role that LTCI will play in the future of nursing home care. Social workers need to be more proactive in encouraging families and clients to

save and plan for their future LTC needs. Regulation of medical expenses and LTC costs do not appear to be coming in the near future. Therefore, social workers stand to provide valuable information to clients on how to navigate the LTC system and ensure that older clients receive the best and most appropriate care while maintaining fiscal responsibility and dignity.

Social workers that are not currently interested in gerontological social work should be educated about the need for social workers in this key area of practice. Social work educators should work to produce gerontologically competent social workers that can positively impact society, families and clients. Social work programs should focus portions of their curriculum on the aging process, how to assess and coordinate care for older clients and the impact of aging on society as a whole.

### *6.2.2 Research*

This study revealed several areas where further research is warranted. While information was obtained about the caregiver type, the difference between relative and non-relative caregivers warrants further research. Those with relative caregivers reported a smaller number of nights when compared to those with non-relative caregivers, but the reasons behind this was not uncovered. Further research to look at the differences between relative and non-relative caregivers is

needed. This type of research will help social workers and families to make decisions about nursing home and other potential types of LTC.

Racial minorities with relative caregivers revealed that Hispanic Americans reported a higher average number of nights in the nursing home. This information is contradictory to other research about this racial group. Research surrounding racial minorities should continue as the racial landscape of the United States continues to change. As the aging population increases, culturally competent research is essential to understand how the aging process affects racial minorities as well as how their families make decisions about nursing home care and other LTC options.

The impact of LTCI on out-of-pocket nursing home expenditures requires further inquiry. There is very limited past research dealing with LTCI and out-of-pocket nursing home spending. Further research is paramount. As healthcare costs continue to increase, it is likely that nursing home costs will also increase in tandem. Further research in the out-of-pocket nursing home expenditures as well as effectiveness of possessing LTCI policies is needed. This type of research will help protect the financial future of individuals and governmental programs such as Medicare and LTC Medicaid.

Further research surrounding factors influencing nursing home use is needed as the number of older persons continues to increase. Additional factors

may arise that are not currently understood. For instance, the gender of a caregiver may be indicative LTC needs.

### *6.2.3 Policy*

From a policy perspective, this study dealt with insurance coverage, specifically LTCI. Insurance coverage for nursing home care continues to be a paramount issue for the aging population. For instance, many assume that nursing home care is covered by Medicare. As previously discussed, Medicare covers 100 days of nursing home care per qualifying event and calendar year. This misconception may lead many individuals a false sense of security where their LTC planning is concerned. Mellor (2001) reported that some older Americans forego purchasing LTCI because they underestimate their need for LTC and/or believe it is their children's responsibility to provide for older person's LTC needs. No matter what the reason, most older Americans are ill-prepared for the debilitating cost of nursing home care.

LTCI is gaining in popularity and is beginning to offer more options for those purchasing policies. Benefits such as inflation protection, lifeline systems, home modifications, transportation to and from medical appointments, and even training for caregivers are possible add-ons to some of the newer types of LTCI policies. For example, an inflation protection rider can be added to one's policy to protect the amount of coverage in the event that the actual cost of care

increases. In other words, if nursing home care costs \$150 per day at the present time and the policy holder does not use the policy for several years the daily rate for nursing home cost may be \$200 per day. The inflation protection will ensure the yearly rate of LTCI cost will be sufficient to cover the increase in costs for LTC care. Policy holders have the option of adding these types of features (US-DHHS, 2008).

In general, LTCI policies range in their lifetime maximum benefit from \$100,000 to \$300,000. This is considerably less than the typical health insurance policy that has a lifetime maximum range from \$1,000,000 to \$2,000,000 (US-DHHS, 2008). Therefore, it is important for LTCI policy holders to make good estimations about how much LTCI they believe they will need as they age. In addition to lifetime maximums, newer LTCI policies are now offering policy holders to buy in certain percentages of coverage that appeals to them. For example, policies can now be purchased to include options such as only covering 75% of one's daily nursing home care needs or 50% of one's daily home care needs (US-DHHS, 2008).

To increase LTCI policy options, 18 states (California, Colorado, Connecticut, Florida, Idaho, Indiana, Kansas, Minnesota, Missouri, Nebraska, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, and Virginia) have opted to offer Partnership Programs. Partnership programs are

LTCI policies that also allow the policy holder to access LTC Medicaid if their lifetime maximum is reached before their death. For example, an individual may enter a nursing with a lifetime maximum of \$100,000 of benefits on their LTCI policy. The individual stays in the nursing home for 1 ½ years. After this time, the policy holder is informed that their LTCI policy will no longer cover them because the lifetime maximum of the LTCI policy has been reached; the nursing home encourages the individual to seek LTC Medicaid to cover their nursing home costs. If this person has purchased a policy from a partnership program, they may be eligible to retain their personal assets up to the same amount as the lifetime maximum of the LTCI policy. In this example, this individual may be able to qualify for LTC Medicaid and still retain approximately \$100,000 of their own personal assets while receiving LTC Medicaid coverage without penalty of Medicaid Estate Recovery (US-DHHS, 2008). LTC Medicaid and Medicaid Estate Recovery will receive further discussion in the following paragraphs.

LTC Medicaid coverage is another issue that merits concern. For those individuals that do not purchase LTCI and do not have children to provide for them, their only remaining option for nursing home care coverage may be LTC Medicaid. LTC Medicaid does cover a vast majority of nursing home care, but at some point may strain the federal and state budgets beyond repair due to the increasing number of older persons seeking this type of coverage. LTC Medicaid

has recently begun to tighten its qualification standards so that it is more difficult to qualify.

To qualify for LTC Medicaid, individuals usually fall into one of two categories. They are either low-income or they have some type of physical care need that will qualify them such as the decreased ability to complete their activities of daily living or need of constant medical attention in a nursing facility. Approximately 53 million people rely on LTC Medicaid to meet their needs (Karp et al, 2005). While LTC Medicaid may be a viable option for many, some individuals are not educated to the financial ramifications of using LTC Medicaid.

LTC Medicaid has always had provisions for states to recoup a portion of the benefits paid to beneficiaries. In other words, upon the death of the LTC Medicaid recipient, the state of residence may choose to recoup the amount of money spent on nursing home care or other associated LTC services. This process is known as the Medicaid Estate Recovery Program (MERP). Since 1993, states have increased their frequency of recovery for services rendered. After the nursing home resident dies, the state may choose to place a lien on the resident's properties or even request cash benefits such as savings or retirement be repaid to cover the cost of LTC services such as nursing home care, home and community based service, hospice care, prescription drug services while a resident of a facility funded by LTC Medicaid.

In the past, individuals have attempted to transfer their assets to their children in effort to bypass their responsibility to provide for their LTC needs out of their own pocket. As previously stated, The Deficit Reduction Act of 2005 increased the asset caps and penalties surrounding LTC Medicaid applications. This information is important to this study as it further emphasizes the importance for planning for LTC. Social workers can be helpful in assisting families and older persons in understanding LTC in general as well as how Medicare, LTC Medicaid and LTCI options affect one's nursing home care options.

In general, LTCI remains very expensive and only something those with significant income can afford. Policymakers may need to look at regulation of the cost of LTCI or present other alternatives for individuals to pay toward their future LTC needs.

### 6.3 Study Limitations

This study had several limitations. The discussion and recognition of these limitations will help to better define this study and the shortcomings, but also provide a starting point for future research and inquiry.

The use of secondary data is one of the major weaknesses of this study. Unfortunately, using the data available from the HRS limited this research in the ability to fully uncover the impact of all study variables. For instance, because

HRS only collected data about the race of family caregivers, it was not possible to consider how the race of the non-relative caregiver might impact the caregiving process. In general, HRS collects useful data surrounding caregivers, but additional information such as the gender of the caregiver would be useful for future research. Another limitation in regard to caregiver data collection involves relative caregivers. The ability to identify the exact relationship between the care receiver and caregiver would be useful. For example, if a son or daughter is providing care to a parent, being able to look at the gender as well as the type of relative caregiver relationship would be very beneficial from a research perspective.

Because of the use of secondary data, several threats to internal validity were identified. History was a potential limitation because of the length of time for data collection as well as the length of time the respondent may have spent in the nursing home. For example, one's insurance type such as Medicare, Medicaid or LTCI could have changed during their nursing home stay causing an increase in out-of-pocket nursing home spending. Maturation is also a limitation because the respondents in the study are naturally aging and therefore may be providing less accurate data or decrease in their desire to participate in research such as this. Social Desirability Bias is also a limitation as data was gathered face-to-face. Respondents may have been tempted to answer questions of a sensitive nature in a manner in which to please the interviewer. Sensitive information may have to do

with out-of-pocket spending or insurance type. This threat to internal validity cannot be dismissed.

This study was unable to demonstrate a relationship between LTCI and out-of-pocket nursing home expenditures. The lack of data surrounding this topic kept this study from revealing a strong conclusion about if purchasing LTCI reduces the amount of out-of-pocket nursing home spending. Further inquiry into this topic is of great importance as revealed in the discussion of policy implications.

In addition to the aforementioned limitations, the HRS is antiquated in their sampling methods surrounding racial minorities. As previously stated, the HRS uses the 1990 census data standards for selection of racial minorities. While oversampling remains to be a useful method, future research such as this would greatly benefit from great dispersion in the categories for racial minorities. For example, instead of using the “other” category to represent any person that is not Caucasian, African American or Hispanic, it would be beneficial to create specific categories for Asian Americans, American Indians, and other Hispanic/Latino groups. As the ethnic diversity in the United States continues to increase, future research should strive to understand the aging process for as many racial groups as possible.

#### 6.4 Conclusion

The purpose of this study was to identify factors which influence nursing home use of older African Americans, Hispanic Americans and Caucasians. The study was supported by the literature review and the Behavioral Model of Health Service Use. While this study did not demonstrate any statistically significant findings, areas of further research were identified. Further research is needed to determine if LTCI truly does decrease out-of-pocket nursing home expenditures. Also, further inquiry in regard to caregiver type and race is needed to understand how relative and non-relative caregivers impact nursing home service use.

APPENDIX A

HRS INSTITUTIONAL REVIEW BOARD INFORMATION

## **Institutional Review Board Information**

### **Health and Retirement Study**

UM Health Sciences IRB Protocol H03-00002774-M8

Approved through 6/05/09

Principal Investigator: Weir, David R.

Sponsor: NIA U01 AG009740

Dates: 9/20/90 – 12/31/11

Website: <http://hrsonline.isr.umich.edu/>

#### **I. Background**

##### **Purpose**

The HRS is designed to provide a uniquely rich, longitudinal data set for the community of scientific and policy researchers who study the health, economics and demography of aging. Since its inception in 1990, the design and execution of a series of nationally representative surveys has involved researchers in the fields of economics, sociology, psychology, demography, medicine and public health.

##### **Survey Design**

The HRS is a national longitudinal study based on core biennial interviews of nearly 20,000 individuals representing the US population over age 50. Hispanics and African-Americans were over-sampled. Every six years, the HRS enrolls a new birth cohort in order to maintain a steady-state representation of the over 50 US population. Baseline interviews with existing birth cohorts were conducted in 1992, 1993, 1998, and 2004, with plans to enroll the next 6-year cohort in 2010. Participants are followed through the life course with biennial surveys and supplemental data collections. Data are de-identified and made publicly available at no charge to users.

HRS also collects supplemental data - typically, in the off-years. Some examples of off-year supplemental studies are: Human Capital Mail Survey (HUMS), Consumption and Activities Mail Survey (CAMS), Diabetes Mail Survey. HRS also has partnered with Duke University to conduct the Aging, Demographics and

Memory Study (ADAMS) which gathers data from in-home clinical assessments of dementia on a subset of the HRS sample.

### Survey Topics

HRS covers a wide range of topics, including:

- Health conditions and physical functioning
- Income, assets and net worth, and pensions
- Employment status and job history
- Family structure and transfers of time and money
- Health insurance, health care utilization and spending
- Psychosocial traits, states, and experiences
- Attitudes, preferences, expectations and subjective probabilities
- Cognitive performance-based testing
- Physical performance-based testing
- Demographic characteristics
- Housing; access to services and services use (community and nursing home)
- Retirement plans and perspectives; pension plans
- End-of-life changes in health and distribution of assets reported by next-of-kin

### Data Availability

A simple registration process on line will allow interested researchers to download HRS public use data files, at no charge. Available files, detailed on the website, include early and final release datasets, cross wave files, imputation files and researcher contributions.

HRS, through support from the Social Security Administration, also provides access to a cleaned and ready-to-use version of the public data, known as the RAND-HRS Data. RAND-HRS Data are available as a single file which includes the public use data from all waves of the HRS, or separate files for each wave of data. RAND-HRS Data are distributed in SAS, STATA, and SPSS formats, with accompanying documentation. These files are maintained at RAND, and made available for download via the HRS website. Weir, David R. Health and Retirement Study Page 3 of 10 NIA U01 AG009740

HRS provides a rich set of restricted access data, which multiply analytical opportunities. Restricted access datasets include linkages with Social Security earnings and benefits records, employer provided pension plans, Medicare records, National Death Index records, and sensitive participant information such as detailed occupation and industry data and detailed geographical files. These

files are restricted due to concerns for participant confidentiality. Eligible researchers may apply for use of these data by following procedures outlined on the website <http://hrsonline.isr.umich.edu/rda>

### Data Support

On-line support to data users is available on the HRS website. See Documentation Products at <http://hrsonline.isr.umich.edu/meta/index.html> or email your data question to [HRSQuest@isr.umich.edu](mailto:HRSQuest@isr.umich.edu)

## **II. Restricted Data**

In order to protect the confidentiality of its respondents, the HRS limits access to certain types of data to users who meet rigorous qualifications guaranteeing the protection of the data. Secure data enclaves at the University of Michigan and elsewhere help to broaden access to these restricted data to users who might not otherwise qualify.

Restricted data are derived from many different sources including respondent interview data, administrative linkages with Social Security or Medicare records, employer surveys, and detailed cause of death records from the National Death Index.

Access to these files is limited to researchers who apply for use and meet eligibility requirements. Due to their sensitive nature and the resulting increased risk to participant confidentiality, these files may not be distributed to the general public. Additionally, some restrictions regarding merger of these data apply.

### Overview of Restricted Access Files

- *Social Security* data linkage includes income and benefit data
- *Medicare* data linkage includes information on health care costs, use of services and diagnosis
- *National Death Index* linkage includes death information such as detailed cause and month/year of death
- *Pension detail* data include information from coded employer-provided summary plan descriptions
- *Industry/Occupation* data include participant provided information on occupation and industry details

- Geographical detail data include participant-provided information on state/country of birth and current residence, as well as state, county, ZIPcode and Tract/BNA of the interview site
- Date of Interview data provide day, month and year of participant interview
- Human Capital Mail Survey data include imputation of 2001 tuition expenditures by participants
- Race/Ethnicity data include participant provided race and ethnicity at the time of their enrollment

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#### Overview of Restricted Data Access Eligibility

Researchers must meet the following requirements to obtain access to HRS restricted data:

- Tenure or tenure-track affiliation with an institution with a DHHS Federal-Wide Assurance of Protection for Human Subjects
- Current receipt of federal research funds as Principal Investigator or Co-Investigator
- Written research proposal
- Written data security plan
- Human Subjects approval – expedited or full board
- Institutionally counter-signed agreement for use of restricted data

### **III. Off Year Mail Surveys**

The HRS produces supplemental data on a variety of topics by conducting off-year mail surveys that enhance, expand or otherwise complement the HRS Core data collection. By design, HRS reflects the many analytical and policy interests in various disciplines. HRS off year mail survey data products provide increased opportunities for data analysis.

These data products are distributed from the HRS via the webpage for public access data <https://ssl.isr.umich.edu/hrs/>. Some of the files require additional procedures due to their sensitive nature and the resulting increased risk to participant confidentiality.

#### Consumption and Activities Mail Survey

Begun in 2001, and repeated on the same households in 2003 and 2005, CAMS is the first large-scale national longitudinal study of consumption. It collects data on household expenditures in over twenty categories of spending that cover nearly all of consumption, and on the use of time across more than thirty activities. The sample is a random sample of about forty percent of HRS households.

#### Human Capital Investment Mail Survey (HUMS)

The 2001 HUMS collected important information designed to facilitate research in a number of areas including parental investment in the human capital of their children, the allocation of parental resources across their offspring, and the effect of educational expenditures on mid-life savings of parents. The current release contains questions about high school attendance, college attendance, and the proportion of college expenses (tuition, food, housing) paid for by the parent of the child.

#### Diabetes Study

HRS conducted a Diabetes Study in 2003, designed to collect self-reported questionnaire data on aspects of treatment and self-management of diabetes, and to collect a clinical biomarker of glucose control: glycosylated hemoglobin, or HbA1c. The survey questions were drawn from several sources, including validated instruments from the Michigan Diabetes Research and Training Center. Blood spot assays for HbA1c were performed by Flexsite Diagnostics, Inc. Both data collections were done through mail surveys.

#### HRS 2005 Prescription Drug Study

The HRS 2005 Prescription Drug Study is the first wave of a two-wave mail survey designed to track changes in prescription drug utilization during the phase in of Medicare Part D, the prescription drug benefit. The baseline wave was intended to capture prescription drug use, coverage, and satisfaction prior to the implementation of Medicare Part D, as well as awareness of the new drug benefit and the subsidies available for it. Weir, David R. Health and Retirement Study  
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#### **IV. Aging, Demographics, and Memory Study (ADAMS)**

The University of Michigan is collaborating with Duke University, via subcontract to Duke. Duke University collaborators conduct the clinical assessments. IRB approval has been gained at each Duke and UM.

This new national study provides data from a single standardized diagnostic protocol on many aspects of dementia including: antecedents, prevalence, outcomes, costs of care, caregiver time and burden, and cognitive impairment, not demented (CIND).

##### ADAMS Sample

The 856 individuals, 70 years of age or older, from all over the country are a subsample from the ongoing participants in the Health and Retirement Study (HRS). These respondents received extensive clinical and neuropsychological assessments in their homes by a team of professionals. These clinical assessments were used to determine whether an individual had dementia, or a less significant level of cognitive impairment (cognitive impairment, not demented [CIND]). In addition, the sub-type of dementia (e.g., Alzheimer's disease or vascular dementia) was determined.

##### Links to the HRS Data

The ADAMS data come directly from people who have been participating in the HRS and who are surveyed every two years. The available longitudinal data that can be linked to the ADAMS data include: demographics, health, health care utilization, informal care, economic resources and family involvement.

##### ADAMS Data Availability

The ADAMS data are currently available after completing the permission protocol we use for researchers using our Sensitive Data. This is not as rigorous as our requirements for using our restricted data, but involves a more thorough registration process than accessing our public use data.

Additional ADAMS information can be found at <http://hrsonline.isr.umich.edu/adams>

#### **V. Human Subjects Review Specific Information**

##### Subject Population

The HRS subject population is a randomly selected national sample of almost 31,000 persons born in 1953 or earlier and their spouses. In 2010, HRS will add a sample of approximately 3,600 persons born between 1954 and 1959, and their spouses. HRS subject population does not include participants under the age of

18, some participants may be cognitively impaired and in these cases a proxy informant is sought, does not follow subjects into prison or detention facilities, and does not intentionally consist of pregnant women. The HRS subject population contains the demographic groups in proportions listed in the Inclusion Enrollment Report

<u>Inclusion Enrollment Report</u>				
PART A. TOTAL ENROLLMENT REPORT: Number of Subjects Enrolled to Date (Cumulative) by Ethnicity and Race				
Ethnic Category	Sex/Gender			
	Females	Males	Unknown or Not Reported	Total
Hispanic or Latino	1,586	1,176	2,762	**
Not Hispanic or Latino	15,620		11,999	27,619
Unknown (individuals not reporting ethnicity)	243		265	508
Ethnic Category: Total of All Subjects*	17,449	13,440	30,889	*
Racial Categories				
American Indian/Alaska Native	145	105		250

Asian	180	122	302	
Native Hawaiian or Other Pacific Islander	9	7	16	
Black or African American	2,764	1,809	4,573	
White	13,722	10,882	24,604	
More Than One Race	173	92	265	
Unknown or Not Reported	456	423	879	
Racial Categories: Total of All Subjects*	17,449	13,440	30,889	*
PART B. HISPANIC ENROLLMENT REPORT: Number of Hispanics or Latinos Enrolled to Date (Cumulative)				
Racial Categories	Females	Males	Unknown or Not Reported	Total
American Indian or Alaska Native	37	28		65
Asian	9	7		16

Native Hawaiian or Other Pacific Islander	0	0	0	
Black or African American	53	33	86	
White	1,263	948	2,211	
More Than One Race	9	3	12	
Unknown or Not Reported	215	157	372	
Racial Categories: Total of Hispanics or Latinos**	1,586	1,176	2,762	**

Confidentiality Measures

Names, addresses, and contact information are maintained in a separate control file for future contact purposes. This identifying information is necessary to maintain due to the longitudinal nature of the study. This information is only provided to Survey Research Center staff and our collaborators when it is necessary to perform their duties with respect to the Health and Retirement Study – e.g., interviewing, sample reconciliation, mailing of respondent reports, etc. Other access is not permitted as this information is strictly controlled within the Survey Research Center. These data are stored electronically on a secure network server and only authorized personnel can access them. In addition, all ISR personnel and affiliates must sign an ISR Pledge of Confidentiality, which explicitly prohibits disclosure of study participants.

Before release, HRS data files are subject to a three-stage iterative process to ensure data confidentiality. In the first stage, before raw data files are created, a

disposition list is created of variables to be removed or masked for confidentiality. In the second stage, the remaining variables are tested for any possible identifying content. If problems are found, stage 1 is corrected and repeated. When testing is complete, the data files are subject to final review and approval by the HRS Data Protocol committee.

The HRS distributes its data to the public via a secure website maintained on the premises of ISR. Registration is required of all users who wish to download the data files. After online registration is completed, individual passwords are sent via email, allowing the user to logon to the data distribution area of the website to download data.

With respect to linked data or data deemed to be too sensitive in nature or in conjunction with other survey information, these data are considered restricted and are released only by a rigorous application procedure outlined on our website: <http://hrsonline.isr.umich.edu/rda/>

And, lastly, the HRS holds a Federal Certificate of Confidentiality granted by the National Institute of Mental Health, which gives HRS a shield against being forced to disclose study participants in a court of law.

### Risks

The HRS is a non-invasive social science protocol. The main risk to respondents is possible re-identification. Our stringent procedures are outlined above. HRS collects physical measures and biomarkers. Specifically, HRS includes for willing participants height, weight, blood pressure, grip strength, air flow, timed walk, tandem walk, as well as saliva samples for genotyping, and finger-prick blood draws for Hemoglobin A1c, cholesterol, C-reactive protein, and future unspecified uses. The ADAMS project also collects other health measures, such as (a) medical history, medications, history of cognitive changes, and family history; (b) the administration of the neuropsychological test battery; (c) a brief physical examination which includes measurements of blood pressure and heart rate, and self-reported height and weight; (d) a standardized neurological examination; and (e) a 5-7 minute standardized video tape segment to cover portions of the mental status and neurological examinations.

### Consent Statements

Most of the interviews will be conducted by telephone. Consistent with on-going HRS practice (telephone and some personal interviews) all respondents are read a confidentiality statement when first contacted, and give oral or implied consent by agreeing to do the interview. The confidentiality statement is as follows:

*“This interview is completely voluntary. If we should come to any question that you don't want to answer, just let me know and I will go on to the next question. The answers you give will be kept confidential.*

*We are required to report to State Officials credible evidence of serious harm or abuse to any person, but we will not ask you questions about such topics. A Department of Health and Human Services Certificate of Confidentiality covers this research in order to help ensure your privacy. This certificate can help protect the investigators from being forced to release any research information that identifies you.”*

### **Request for Social Security Administration Linkage**

Written consent is required of the respondent to obtain Social Security Administration data. A copy of the current permission statements is attached. The authorizations were developed with Social Security Administration. After reading the preamble below, participants are presented (if in person) or mailed (if telephone interview) the form for review and signature.

*One of the most important parts of our study is to understand the financial situations of people in their retirement years. This is an important and challenging part of our research, and in order to obtain complete data for this research, we are asking our participants to complete a form authorizing us to obtain social security data on earnings and benefits.*

The following statements are read to respondents prior to obtaining their Medicare and Employer information. Provision of information in response is considered consent.

### **Request for Medicare and Medicaid Identification and Linkages**

#### **MEDICARE NUMBER RECORDED?**

*We would like to understand how people's medical history affects their financial status, and how use of health care may change as people age. To do that, we need to obtain information about health care costs and diagnoses for statistical purposes. The best place to get this information without taking up a lot more of your time is in the Medicare files. Could you give me your Medicare number for this purpose?*

*(Under the Privacy Act of 1974, providing your number is a voluntary decision. The benefits you may be receiving under this program will not be affected in any way by your decision.)*

#### **MEDICAID NUMBER RECORDED?**

*We would like to understand how people's medical history affects their financial status, and how use of health care may change as people age. To do that, we need to obtain information about health care costs and diagnoses for statistical purposes. The best place to get this information without taking up a lot more of your time is in the (Medicaid/STATE NAME FOR MEDICAID) files.*

*Could you give me your Medicaid number for this purpose?*

*(Under the Privacy Act of 1974, providing your number is (also) a voluntary decision. The benefits you may be receiving under this program will not be affected in any way by your decision.)*

#### *Request for Employer Identification and Contact Information*

*READ TO ALL RESPONDENTS: We would like to obtain complete information about fringe benefits for employees like you. In order to do this, we need the full name and address of your employer.*

*For whom do you work [now/ on your main job]?*

*What is the (company's/organization's) name?*

*What is the address of the place where you work [I will need the mailing address, city, state, and zip code.]?*

#### *Physical Measures, Saliva, and Dried Blood Spot Collection*

In 2006 during face-to-face interviews, HRS began collecting expanded health information in the areas of physical performance, salivary DNA and dried blood spots for specific and non-specific assays. Three separate consent forms were used to collect these data (see attached). Additionally, HRS maintains a separate full-board IRB for our DNA repository (HUM00002562, approved through 7/23/09).

*Mail Surveys:* Consent is inferred by completion and return of questionnaires. Each package mailed to a sample household will contain a cover letter describing the purpose of the study and the voluntary nature of participation.

*ADAMS:* Duke obtains written informed consent typically from the respondent and the informant. If the consent is to be truly informed, this portion of the protocol can easily take 10-20 minutes to complete. In situations where significant cognitive impairment is suspected, a separate signature is sought to document permission to forward a summary of findings to the respondent's personal physician.

The University of Michigan retains all rights to the data, including the stored genetic samples.

#### Respondent Payments

The HRS typically will provide participants with a \$50 payment for their participation. When participants agree to an in-person interview that includes collection of physical measures and biomarkers, payment is \$60. For the Off Year Mail Survey data collections, respondent payments are \$10 TO \$25. This payment is provided at the initial re-contact for longitudinal sample members, and after completion of the interview for newly enrolled participants.

For in-person interviews that include a leave-behind questionnaire – typically a deeper exploration of a substantive area already included in the Core survey (such as disability vignettes), an additional \$20 payment is provided upon receipt of the returned questionnaire.

Additional payment of \$50 will be made to participants providing retirement documents after the Core survey.

Because of the increased demand on participants for the ADAMS project, we currently provide payment of \$80 to participants and \$50 to caregivers of participants.

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**VII. Related Documents**

HRS Social Security record linkage permission form

2008 Physical Measures permission form

2008 Biomarker permission form

2008 DNA permission form

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