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Changes in Formal-Informal Caregiving in Elderly Stroke Survivors

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CHANGES IN FORMAL-INFORMAL CAREGIVING IN ELDERLY STROKE SURVIVORS

by

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ABSTRACT

CHANGES IN FORMAL-INFORMAL CAREGIVING IN ELDERLY STROKE SURVIVORS

Holly Anne Beard
Old Dominion University, 2007
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The purpose of this study is to determine the extent to which the Andersen and Aday Model of Health Services Use to predict cross-sectional and longitudinal differences in the caregiving source among stroke survivors (n=477) over a six-year period. This study involves a secondary analysis of a longitudinal panel study focusing upon three waves of interview data from the HRS/AHEAD study spanning 1998 through 2002. Multinomial logistic regression was utilized to examine caregiving source cross-sectionally at each wave. Clustered multinomial logistic regression was used to examine relationships between predictor variables in the model and caregiving source across waves while holding time constant. The results of this study indicate that cross-sectionally and longitudinally the need domain accounted for the largest proportion of the explained variance. Within the need domain the most consistent predictors of caregiving were the number of activities of daily living and instrumental activities of daily living impairments. The predisposing domain became less significant once enabling and need variables were entered in the cross-sectional models. In the longitudinal models, all of the domains in the Andersen-Aday Model were significantly related to caregiving type. These findings provide information about the caregiving situation post stroke, but also post rehabilitation, which is often the last contact with formal care services. The results of this study have two health policy implications for survivors of stroke. First, the limited number of transitions between different types of caregiving services indicates that there is likely be a fairly large length of commitment for informal caregivers. Second, discharge planning in the hospital or acute rehabilitation provides a ‘teachable’ moment or the key moment for intervention where realistic options for long-term care could be discussed and planned knowing that whatever is chosen will be the arrangement for the caregiver and care receiver for a considerable amount of time.

Beyond individual and provider implications these findings pose serious questions and opportunities for national and state long-term care policy. Understanding the dynamic process of caregiving will inform federal and state policymakers on the type and amount of care desired by older Americans. Ultimately the question is not what type of care is used, but how will the cost of care be distributed and in the long run how can the federal government in partnership with the states and individuals plan for this type of care while creating a sustainable system. Studies about the continuum of care, like this one, provide details about long-term care such as the use of formal and informal caregiving that can be utilized by policymakers to design systems to enhance both formal and informal caregiving.

Co-Directors of Advisory Committee: Dr. Stacey B. Plichta
Dr. Karen Karlowicz
Dr. Bonnie K. Lind

To my husband, William.

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CHAPTER I

Introduction

Problem Statement

Increasingly, individuals that are surviving strokes are older and living longer post-stroke than previous generations of stroke victims. As a result, current stroke survivors are older and more likely to be disabled. These stroke survivors depend upon both the formal care system (paid) and informal (unpaid) caregivers to provide the necessary support to remain in the community and prevent and/or delay permanent institutionalization. Not only does stroke cost the health care system billions of dollars, but the value of the care provided by informal caregivers is also worth billions of dollars (American Heart Association, 2005; Hickenbottom et al., 2002).

Caregiving in general has expanded its scope to include formal paid services to act as an extension of family and kin groups. While the preferred method of caregiving for older Americans remains the informal network of family, extended kin, friends and neighbors (Norgard & Rodgers, 1997; Tennstedt, Sullivan, McKinlay, & D'Agostino, 1990) shifts in the demographic structure of America including the aging of the population (Kane & Penrod, 1995) as well as economic and social change such as increasing rates of workforce participation by women (Biegel & Blum, 1990) have given rise to a dynamic elder care system involving both formal and informal care. The mainstay of elder care is and continues to be informal caregiving, but with these demographic, economic and social changes, it is increasingly important to examine patterns of utilization of both formal and informal caregiving among survivors of stroke.

Since informal caregiving is documented to be burdensome for the informal caregiver (Bugge, Alexander, & Hagen, 1999), it is practically important to understand how formal care interrelate with informal caregiving over an extended period of time in order to formulate programs to best support the providers of informal caregiving. As a subset of the growing elderly population requires increasing formal and informal caregiving services, exploring caregiving use among stroke survivors over time is crucial to understanding how long-term care services are distributed after a hospital stay to enhance quality of life of stroke survivors and caregivers. One *Healthy People 2010* objective is to increase access to quality health services by increasing the awareness of the continuum of long-term care options. Identifying the pattern of caregiving services will ultimately lead to stroke survivors receiving the type of care they need in the setting they prefer (U.S. Department of Health and Human Services, 2000).

Formal caregiving is defined as paid services that typically augment the informal caregiving system to create a care network for the disabled elderly. These formal care services essentially act to extend or replace the family and kin groups providing care. Informal care services are defined as unpaid assistance to physically or emotionally dependent older adults by caregivers who are often, but not limited to family, friends, and neighbors (Kahana, Biegel, & Wykle, 1994).

This study seeks to examine which type of caregiving services elderly stroke survivors receive over time. Specifically, the purpose of this study is to determine the utility of the Andersen and Aday Model of Health Services Use (Andersen-Aday Model) (Andersen, 1995) in describing cross-sectional differences and changes in the caregiving source between formal and informal caregiving among stroke survivors over a six-year period. Towards this end, this study utilizes the Health and Retirement (HRS/AHEAD)/ Assets and Health Dynamics Among the Oldest Old data collected during the study waves between 1998 and 2002 (Health and Retirement Study, 2003). Formal and informal caregiving can be complementary in the provision of elder care and the purpose of the present study is to elaborate on the relationship between these types of care by evaluating utilization trends, not just the potential substitution of care source on a cross-sectional basis.

Examination of the receipt of caregiving services over several years will enhance our understanding of the dynamic process of elder care and the consequences of those receiving those services. Individual preferences, financial obligations, and severity of the disease state are all possible contributors to the dynamics that influence the type of caregiving used over time. Information attained from this study may illustrate the patterns in caregiving choices and assist in forecasting future services for American elderly stroke survivors, which has important policy implications for discharge planning and long-term caregiving support initiatives.

General Demographic Trends Among the Elderly

The demographic characteristics of America's aging population are different from those of previous generations. In 2000, the elderly (65+) were 12.4 percent (35 million) of the total population. Approximately 24.6 million households are headed by the elderly; of these 28 percent (9.9 million) of the elderly over the age of 65 in the US currently live alone (Gist & Hetzel, 2004). Between 1900-2000, the lifespan of Americans had increased from 47 years to 74 years for men and to 79 years for women (2000b). It is projected that by 2030, one in five individuals will be over the age of 65, twice as many individuals aged 65 and older than are living today (Federal Interagency Forum on Aging-Related Statistics, 2000).

The oldest old, those age 85 and older, are the fastest growing segment of the population (Federal Interagency Forum on Aging-Related Statistics, 2000). At this rate of growth, by the year 2050 elders over the age of 85 will have increased from two percent to five percent of the total population (Federal Interagency Forum on Aging-Related Statistics, 2000). This increase in the aged population contributes to the overall number of frail elderly and introduces other factors related to advanced age that would not be present in a younger population of stroke survivors.

Definition of Stroke

There are two types of cerebrovascular disease or strokes: ischemic and hemorrhagic. An ischemic stroke occurs when an artery is blocked due to either a blood clot or atherosclerosis. A hemorrhagic stroke is a stroke that occurs when a blood vessel bursts within the brain (Beers et al., 2003). Stroke survivors face a variety of potential disabilities: paralysis; speech, language, and vision problems; cognitive disabilities; and coordination and muscular problems (Beers et al., 2003). Six months post stroke, 50 percent of survivors have some form of paralysis, 30 percent cannot walk without assistance, 26 percent are dependent in some activities of daily living, and 19 percent have aphasia (American Heart Association, 2007).

Epidemiology: Stroke in the United States

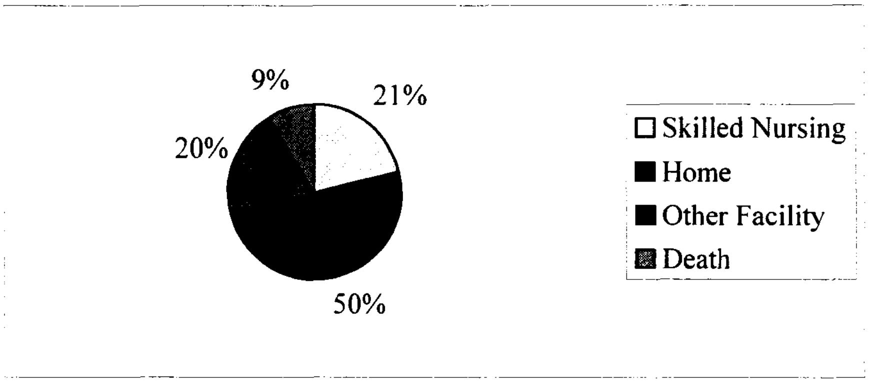
In the U.S. cerebrovascular disease is the third leading cause of death and disability and roughly 700,000 people experience a stroke annually (Centers for Disease Control and Prevention, 2004; Tulchinsky & Varavikova, 2000). A total of 5 million people over the age of eighteen in the United States have experienced a stroke (American Heart Association, 2006). The prevalence of stroke increases with age. The prevalence of stroke in males between the ages 60-79 is 6.5 percent, which increases to 14.8 percent for individuals over eighty. The prevalence of stroke in women between the ages of 60-79 is 6.2 percent which increases to 12.4 percent for individuals over eighty (American Heart Association, 2007).

Non-white minority groups experience a considerably higher incidence of stroke. American Indian/Alaskan Native males (6.1 per thousand) and American Indian/Alaskan Native women (6.6 per thousand) have the highest incidence of stroke followed by African American males (6.6 per thousand) and African American females (4.9 per thousand) (American Heart Association, 2007). Comparatively, the prevalence for white males is 3.6 percent per thousand and white females is 2.3 percent per thousand (American Heart Association, 2007). African Americans are more likely than Caucasians to experience and die from a stroke (Beers et al., 2003).

Among those suffering and surviving strokes, an increasing number are older and more frail. Between the 1970's and 1990's the increasing survival rates of stroke victims have produced a larger non-institutionalized population of stroke survivors who may need substantial post-hospital care. The number of stroke survivors that do not reside in an institution increased from 1.5 million to 2.5 million between 1970 and 1990 (American Heart Association, 2006). Among Medicare enrollees, half (50%) of stroke survivors are discharged home after the initial hospitalization. The remaining stroke survivors are discharged from the hospital to either skilled nursing facilities (21%) or another type of facility (20%), and 9 percent die during the hospital stay (Centers for Disease Control and Prevention, 2003) (see Figure 2).

Figure 1: Discharge Destination of Stroke Survivors > 65

Source: Center for Disease Control and Prevention (2003)



It is estimated that in 1993 there were one million stroke survivors in the U.S. who have associated health or functional problems that may require either formal or informal caregiving services (Hickenbottom et al., 2002). An early study performed in the United Kingdom found that 71 percent of stroke survivors were living somewhat independently and 76 percent resided at home (Greveson, Gray, French, & James, 1991). These findings were confirmed in a smaller study conducted in Australia by Anderson, Linto, and Stewart-Wynne (1995) which reported that 79 percent of stroke survivors eventually return to the community and of those, 43 percent were significantly disabled. While these studies may indicate that many survivors of stroke are returning home, the source of care may be related to the health care system in the countries where the studies were conducted. In the U.S., older stroke survivors who report health problems receive more informal caregiving (18.6 hours per week) compared to individuals of the same age that have not had a stroke (6.1 hours per week) (Hickenbottom et al., 2002).

Cost of Stroke

The care provided to survivors of stroke is costly to both public and informal (unpaid) caregivers. The total estimated cost attributed to stroke was 56.8 billion dollars in 2005 (American Heart Association, 2005). The estimated cost to the Medicare system, which is the primary insurer for Americans over the age of sixty five, attributed to the incidence of stroke, was approximately 3.6 billion dollars for hospital stays alone (Centers for Disease Control and Prevention, 2004). In 2003, data suggested that stroke survivors incurred 12 billion dollars of nursing home costs to the Medicare system (Centers for Disease Control and Prevention, 2003).

Cost of Informal Caregiving

Nationally, it is estimated that 23 percent of American households (22.4 million) provide informal caregiving to individuals over the age of fifty (Family Caregiver Alliance, 2001). Annually, informal caregivers provide approximately $3,700 to $7,900 worth of unpaid care per stroke survivor (Hickenbottom et al., 2002). In total, informal caregivers of stroke survivors are estimated to provide over 61 billion dollars worth of unpaid caregiving services to stroke survivors every year (Hickenbottom et al., 2002).

Prior Research about Caregiving

Most stroke survivors require formal rehabilitation and continued assistance with activities of daily living (Duncan, 1994). Therefore it is expected that most stroke survivors would require a mix of formal and informal caregiving during recovery, rehabilitation, and to address ongoing impairments. Despite the importance of informal caregiving, little is known empirically about predictors of formal service use and informal caregiving over time among stroke survivors (Levine et al., 2006).

Over the past three decades, organizational models such as Litwak's Task Specific Model (Litwak, 1985) or Cantor's Hierarchical Compensatory Model (Cantor & Brennan, 2000) have guided caregiving research (see Appendix B). These models largely provide typologies describing the structure and components of caregiving relationships (Cantor & Brennan, 2000; Litwak, 1985). While these models acknowledge the variety of possible caregiving situations, none provide a conceptual model that facilitates the prediction or explanation of service use. These models essentially illustrate the structure of caregiver selections, but the predictors of these selections are not considered or explored. Furthermore, studies describing the utilization of caregiving services have typically framed the question in terms of the 'substitution' of formal and informal caregiving among the elderly. Although most of the literature focusing on substitution relies on atheoretical approaches, caregiving research in general has utilized the above-described models frequently to describe the caregiving structure among elders.

A common shared feature of the models presented by Litwak and Cantor is that they allow for substitution of care sources when the primary assertions of the models are violated (see Appendix B). Further, these models demonstrate that there are a variety of care situations that include both formal care services and informal care. Cantor and Brennan (2000) have since agreed with Litwak (1985) concluding that "the actual manifestation of support is probably a combination of both preferences for support elements as well as appropriate person matches for the task" (p. 45). The relationship between the two types of care systems are also illustrated by Noelker and Bass (1989) who conclude that there are four types of care structures: 1) a complementary relationship, 2) supplementation, 3) substitution, and 4) the absence of a relationship (no formal service use). A complementary relationship occurs when formal and informal care providers work together to meet the needs of the care receiver. Supplementation occurs when one type of care provides additional support to meet the needs of the care receiver and substitution is when one type of care completely supplants another. The Noelker and Bass model thus incorporates the range of possible formal and informal combinations discussed above. While these models acknowledge the variety of possible caregiving situations, none include characteristics of the elderly person to predict or explain the caregiving use (both formal service use and informal caregiving). Including the characteristics of the older person (both health and functional status) are important to increasing the understanding of the utilization of elder care networks (Cantor & Brennan, 2000). An alternative conceptual framework, the Andersen-Aday Model allows for including the characteristics of the elder and the caregiving structure.

Studies of Caregiving Services

With respect to elder care, substitution involves utilization of formal care services in place of informal caregiving or vice versa. Research on this topic has been driven by the need to determine if increases of funding to formal caregiving would lead to less family care provided to disabled elders. Substitution was first raised in the 1970's to debunk the myth that the elderly were socially isolated from society (Shanas, 1979b). Shanas (1979b) argued that most elders are often surrounded by family, and where there is no available family substitution occurs as paid sources of care are sought to fulfill the duties of family and kin. Even in this early work by Shanas (1979b), the argument that, for most of the elderly population, social service agencies and paid providers do not replace informal care was unequivocally stated based upon work conducted in the 1970's. This was stated even before many of the studies evaluating substitution between formal care services and informal caregiving hypothesized that formal care services were replacing informal care for the nation's elderly. More recent approaches (Cohen, Miller, & Weinrobe, 2001; Greene, 1983; Pezzin, Kemper, & Reschovsky, 1996; Tennstedt, Crawford, & McKinlay, 1993b) expanded on the initial study (Shanas, 1979a, , 1979b) to further explain the relationship between formal care services and informal care in the context of substitution.

Litwak and Cantor's model also explores the relationship between formal care services and informal care examined in the context of substitution. The discussion about substitution and about supplementation of formal sources of care for informal sources of care has resulted in mixed findings. Typically, these studies treat formal service use and informal caregiving as determinates of each another.

Several approaches have been utilized to estimate substitution of caregiving services (see Table 1).

Table 1: Studies evaluating substitution of caregiving sources

Author	Sample Description	Race/Ethnicity of Sample	Research Design	Findings
Greene (1983)	n=124 Recruited from LTC case management	17% non-white (identification of race based on surnames)	Cross-sectional	Substitution
Moscovice et al. (1988)	n=214 Applicants screened for Medicaid Waiver for home and community based care	N/A	Cross-sectional	No Substitution
Hanley et al. (1991)	n=6400 1982 National Long Term Care Survey	N/A	Cross-sectional	No Substitution
Tennstedt et al. (1993)	n=5855 1984-1991 Massachusetts Elder Health Project	N/A	Longitudinal	Substitution
Pezzin et al (1996)	n=3619 Recruited from the Channeling demonstration	N/A	Cross-sectional	No Substitution
Cohen et al. (2001)	n=693 Long-term care insurance beneficiaries	3% non-white	Cross-sectional	Modest Substitution
Muramatsu & Campbell (2002)	n=3,051 1993 AHEAD	24.8% non-white	Cross-sectional	No Substitution

Two of the early studies to evaluate substitution of caregiving services utilized similar methodologies and samples, but produced different results. The first study conducted by Greene (1983) utilized a random sample (n=124) from a case management provider in Arizona. Similarly, the second study by Moscovice, Davidson, and McCaffrey (1998) examined applicants to a Medicaid waiver program (n=214) to allow nursing home eligible clients to be cared for at home. Data for this study was obtained through the screening mechanism required to apply for medical assistance through the Medicaid program.

Greene suggests that if substitution between formal and informal caregivers did occur in this study, a negative relationship would indicate substitution between the two types of care. Greene (1983) found that formal caregiving was predicted by the amount of informal care ($p < .05$) and ADL functioning ($p < .001$). Informal support was predicted by the level of formal caregiving ($p < .001$), ADL functioning ($p < .001$), and psychological and social functioning ($p < .05$). As hypothesized, the results of this study revealed a negative relationship, which may indicate a substitution effect. Moscovice et al (1988) did not find a negative relationship between formal and informal caregiving, which would suggest that formal care does not substitute for informal caregiving.

Both studies (Greene, 1983; Moscovice et al., 1988), however, measured caregiving cross-sectionally. Using cross-sectional measures fails to acknowledge the dynamic process of caregiving over time. Similarly, both studies used study samples selected based on the use of a case management type of service provider, which may lead to selection bias towards the use of formal care services. The methods applied in these studies have been utilized in more recent research, which is also problematic in terms of obscuring the examination of substitution and supplementation involving informal caregiving over time.

These early methods of measuring substitution were replicated in 1991 using a national database (1982 National Long Term Care Survey) (Hanley, Wiener, & Harris, 1991). Study hypotheses were tested using a two-equation simultaneous model because previous studies (Greene, 1983; Moscovice et al., 1988) asserted that the relationship between formal and informal caregiving should be thought of determining one another (Hanley et al., 1991). As in the earlier research, the 1991 study only examined disabled elderly using paid home care during the interview. Longitudinal trends were not analyzed. This study reported that there was not a significant relationship between informal and formal caregiving, which indicates no substitution. However, the elder's level of functioning was predictive of informal caregiving ($p<.01$).

In a 1996 study, an economic approach was utilized to determine the presence or absence of substitution (Pezzin et al., 1996). Utility functions were used in the estimation equations, and, unlike earlier studies, experimental data were available from The Channeling experiment (1982-1985). The Channeling experiment focused on publicly subsidized home care programs in which elders were prescreened for eligibility for formal caregiving to determine if these services would delay institutionalization. This experiment occurred in the early 1980's and was designed to demonstrate the feasibility of a publicly funded program to prevent institutionalization of disabled elders residing in the community (Kemper, 1992). Random assignment was used to create a control group in order to allow a direct measure of the program's impact and to determine the viability of this program. Unlike previous studies, follow up occurred at three points in time: six, twelve, and eighteen months. Pezzin, Kemper, and Reschovsky (1996) reported that unmarried individuals received a modest decrease in informal care when receiving the subsidized home care program, however, the results were not statistically significant.

One study in this field framed a different approach to examining substitution. Tennstedt, Crawford, and McKinlay (1993b) utilized a longitudinal sample from the Massachusetts Elder Health Project with a sample size of 790 disabled elders. Data were collected four times between 1984 and 1991. Substitution was analyzed by examining the rates of service use and institutionalization using hours of care per type of service and total hours used as measures for analysis. This method differed from the previous studies by comparing the rate of utilization over three time periods for both formal and informal caregiving rather than looking for a negative relationship between formal and informal care. Substitution was examined for each type of care to include both formal and informal sources of personal care, housekeeping, meals, transportation, financial management, and service management. The authors concluded that substitution of formal caregiving for informal caregiving between 1984 through 1991 did occur at a rate of 14 percent to 20 percent (Tennstedt, Harrow, & Crawford, 1996).

More recently, a study has evaluated the presence of substitution between formal and informal care sources and the relationship between long-term care (LTC) insurance (Cohen et al., 2001). This evaluation sought to determine the importance of both a LTC insurance policy and informal caregiving. This study found that informal caregiving decreased with the initiation of policy benefits for about one-third of the caregivers while for two-thirds of the caregivers the level of informal care did not change after benefits from the LTC insurance policy were utilized (Cohen et al., 2001). This study demonstrates the importance of both formal and informal care sources by indicating that there is a balance between formal and informal care sources that may be maintained even after formal care has been utilized.

In 2002, Muramatsu and Campbell examined the relationship between formal and informal caregiving and the level of state spending on Home and Community Based Services (HCBS). Muramatsu and Campbell utilized the first wave (1993) of the AHEAD study with linked data to state spending for HCBS which represented 34 states and 3,051 participants. The authors did not focus the study on one disease state; instead they chose to utilize all participants in the 1993 AHEAD study. Independent variables included in the study corresponded to the Andersen-Aday Model domains (predisposing, enabling and need). Multilevel multinomial logistic regression was employed. The results of this study indicated that use of formal caregiving ($p<.05$) and use of a mix of formal and informal caregiving is associated with HCBS spending ($p<.01$) (Muramatsu & Campbell, 2002). The authors concluded that higher spending on HCBS does not necessarily result in the substitution of formal care for informal caregiving because the utilization of formal care with informal care was also related to higher state spending. Additionally, the relationship between caregiving services is highly dependent upon not only the HCBS expenditures, but the level of ADL functioning.

Overall, the studies described above sought to understand the relationship of formal and informal care in terms of substitution of services. Although taken as a whole the findings were mixed, there were limitations that leave many questions about utilization of formal and informal caregiving unanswered. This is especially true when considering service use by stroke survivors where quantitative information has been scarce to date. What this body of literature does is inform the health services research literature of possible factors that may be important longitudinally. Even though the majority of this initial body of literature is focused on cross-sectional relationships (Cohen et al., 2001; Greene, 1983; Hanley et al., 1991; Moscovice et al., 1988; Muramatsu & Campbell, 2002; Pezzin et al., 1996) the significant predictors and mixed findings related to formal and informal care use suggest that this a complex issue that cannot be resolved with cross-sectional data. While the prior research does not tell the entire story it does provide information about important predictors that should be examined in the future.

Utilization of formal and informal caregiving is constantly changing as a result of myriad of social and economic factors. Results of previous research are confounded by other factors such as level of ADL functioning and mental health status of the care receiver as these factors are indicative of using more formal caregiving services. These changes precipitate the need to continue research in this field to learn how utilization patterns change over time.

This study examines the idea that formal and informal caregiving may be complementary in the provision of elder care. It is this assertion that creates the need to evaluate utilization trends, not just the potential substitution of care source on a cross-sectional basis. Cantor and Brennan (2000) reiterate this thought, "Only through such longitudinal investigations can we truly understand the complexity of preference, specialization, and substitution in the provision of social care for current and future cohorts of elderly persons " (p.45). The purpose of the present study is to elaborate on the relationship between formal care services and informal elder care by filling the gap in the literature. The practical purpose of this type of evaluation is to inform future policy by developing better predictors of trends in service use that consider both formal and informal sources.

Minority representation in caregiving research about people surviving a stroke

Strokes disproportionately impact minority elders in the US. Not only do minority elders have a higher prevalence of stroke, they are most often discharged to a skilled-nursing facility or to another facility after hospitalization for a stroke (Centers for

Disease Control and Prevention, 2004). Furthermore, the severity of stroke for minority men is greater than that for white men, as is indicated by the difference in death rates being 81.7 versus 54.2 (American Heart Association, 2005).

There is limited research regarding the relationship between formal care services and informal caregiving among minority stroke survivors even though there is a great deal of literature addressing racial/ethnic differences during the stroke rehabilitation process (Goldstein, Matchar, Holt-Lindquist, Samsa, & Horner, 2003; Horner, Hoenig, Sloane, Rubenstein, & Kahn, 1997; Horner, Swanson, Bosworth, & Matchar, 2003; Stansbury, Jia, Williams, Vogel, & Duncan, 2005).

Literature evaluating differences between white and non-white stroke survivors and their subsequent use of services and outcomes focuses on the immediate use of rehabilitation services after a stroke by stroke survivors, but neglects to examine the received caregiving after a stroke. Results of these studies point towards little difference between white and non-white stroke survivors in the utilization of rehabilitation services. Specifically, non-white Medicare patients were found to be just as likely to use physical or occupational therapy as white stroke patients after controlling for other factors (Horner et al., 1997). A more recent study evaluating Veterans Administration (VA) stroke patients also found no difference in utilization of rehabilitation services (Goldstein et al., 2003). These studies are limited by the sampling methods and VA patients are a select group of stroke survivors. The authors do not necessarily conclusively state that there are no racial/ethnic differences in the utilization of rehabilitation services. Horner et al. (1997) states that some measurement bias may be present in the use of physical and occupational rehabilitation services and in the most recent study only VA hospital patients were evaluated (Goldstein et al., 2003). While these studies seem to indicate relatively no difference in the utilization of rehabilitation services between white and non-white patients, stroke caregiving research is in its infancy. Both the rehabilitation and caregiving research realms parallel each other in that they examine utilization of health services after a stroke incident and additional research in both is needed to determine conclusively the presence or absence of differences between white and non-white stroke survivors among a variety of care services.

Racial and ethnic differences in formal service and informal caregiving utilization post stroke are important for three reasons: 1) minority (African American and Hispanic) elders utilize and provide informal care services more often than white elders (Bass & Noelker, 1987; Kemper, 1992; Mui & Burnette, 1994), 2) minorities have a higher prevalence of stroke than white Elders, and 3) racial minorities have been underrepresented in research on stroke survivors (Han & Haley, 1999).

Significance of the Study

This study approaches the question of utilization of caregiving services (formal and informal) using an explanatory model of health behavior to move beyond the caregiving typologies (Task Specific Model and Hierarchical Compensatory Model) (Cantor & Brennan, 2000; Litwak, 1985) to illustrate the dynamic caregiving patterns among stroke survivors. This research will strengthen the understanding of relationships between formal and informal caregiving by elderly stroke survivors beyond the initial rehabilitation period. Further, the utilization of a nationally representative data source with an oversampling of non-white minority elders and the application of a conceptual framework to guide the study will address these particular gaps in the current literature.

Finally, this study seeks to examine the dynamic nature of caregiving over time in stroke survivors.

Increases in survival rates of stroke victims contribute to the need to improve the understanding of factors influencing utilization of formal and informal caregiving. The growing documentation of informal caregiving as burdensome for informal caregivers (Bugge et al., 1999), supplies the rationale and highlights the practical need to understand longitudinal interrelationships between formal and informal caregiving to develop programs and policies that best support care providers. This study will enrich the understanding of the patterns and predictors of caregiving services use among stroke survivors. This has important policy implications for discharge planning and long-term caregiving support initiatives. Caregiving support programs may have the ability to delay or prevent institutionalization of older, frail stroke survivors. This delay or avoidance of formal care translates into savings for the payers for institutional long-term care, which include the state and federal government, insurers, and individuals and families.

In this study, the Andersen-Aday Model is applied to longitudinal data to predict caregiving use and the subsequent change of caregiving utilization over time among stroke survivors. Previous studies have been cross-sectional in nature, but exploring formal and informal caregiving services among stroke survivors longitudinally is crucial to understanding how long-term care services are utilized after a hospital stay to enhance quality of life of stroke survivors and their caregivers. This study seeks to help address this gap in the literature by conducting analyses of data on stroke survivors in a longitudinal database (the HRS/AHEAD study) in order to examine predictors of formal and informal caregiving. Cross-sectional and longitudinal analyses are performed to make comparisons both to previous research and to determine the amount of change within the three waves of this study.

The current literature regarding stroke survivors has largely focused upon initial hospitalization and rehabilitation and has not addressed the longer term outcomes beyond the first year of stroke rehabilitation (Anderson et al., 1995; Chiu, Shyu, & Chen, 1997; Chumbler, Rittman, Puymbroeck, Vogel, & Qnin, 2004; Counsell, Dennis, & McDowall, 2004; Eaves, 1998; Penrod, Kane, Kane, & Finch, 1995; Shaw et al., 2003). Little is known about the long-term utilization of services by stroke survivors beyond the rehabilitation period. The study addresses this gap in the literature by conducting analyses of a six-year longitudinal database about stroke survivors containing information that was collected in three (two-year) waves in order to examine predictors of change in the mix of formal and informal caregiving.

Examination of racial and ethnic differences in the use of formal and informal caregiving is necessary because the incidence of stroke in African Americans (including both men and women) is almost double that of whites (American Heart Association, 2005). Additionally, the overall disability level of older African Americans is greater than that of white elderly (Geronimus, Bound, Waidmann, Colen, & Steffick, 2001). Compared to previous studies in which minority stroke survivors were under-represented, the current study involves the secondary analyses of a nationally representative database in which African American and Hispanic respondents were oversampled, thus increasing the power of the study to address racial and ethnic variation.

The National Institute of Neurological Disorders and Stroke (NINDS) promotes multidisciplinary research examining the process of recovery from strokes (National

Institute of Neurological Disorders and Stroke, 2002b). This research will address the goals by the above-mentioned federal agency by examining stroke survivors and their patterns of caregiving utilization and explore non-white minority subgroups and their caregiving utilization patterns.

The NINDS states that stroke survivors must be followed (2002a), "...beyond the traditional three to six months in order to address long-term recovery and rehabilitation utilization." (Panel 6C, Resources Needed #2). The current literature regarding stroke survivors largely has focused upon the initial hospitalization and rehabilitation and has not addressed the longer term outcomes. As was indicated by NINDS, most studies only evaluate stroke patients three to six months post-stroke. Thus, little is known about the long-term utilization of services by stroke survivors beyond the rehabilitation period (Anderson et al., 1995; Chiu et al., 1997; Chumbler et al., 2004; Counsell et al., 2004; Eaves, 1998; Penrod et al., 1995; Shaw et al., 2003) .

Research Questions

This study tests the explanatory power of the Andersen-Aday Model of Health Services Use in the utilization of caregiving services among stroke survivors. The Andersen-Aday Model consists of three domains that are used to explain health services use: predisposing, enabling, and need. The study uses multivariate statistical analyses of the longitudinal data from the Health and Retirement Study/Assets and Health Dynamics Among the Oldest Old (HRS/AHEAD) to address the following three research questions:

1) What is the pattern of formal and informal caregiving among elderly stroke survivors over a six-year period?

2) To what extent does the Andersen-Aday Model (predisposing, enabling, and need variables) explain the receipt of formal and informal caregiving both cross-sectionally and longitudinally?

3) Are there differences between non-Hispanic Whites and minorities (African Americans and Hispanics) in terms of the specific Andersen-Aday model domains (predisposing, enabling, and need) that influence utilization of formal and informal caregiving?

CHAPTER II

Conceptual Model and Research Hypotheses

This chapter presents a literature review that defines and contextualizes the Andersen and Aday Model of Health Services Use (Andersen-Aday Model) and its implications for use in this research on the use of formal and informal long-term care. Previous studies of formal care services and informal caregiving suggest that variables included in the predisposing, enabling, and need variables are important factors explaining both formal and informal service use. The Andersen-Aday Model is used to enhance the explanatory power of the study, provide a basis to predict future behavior, and provide understanding about the subject matter (Reynolds, 1971).

The Andersen-Aday Model of Health Services Use

This study utilizes the Andersen-Aday Model developed by Ronald Andersen in 1968 (1995) (see Figure 4). Since the first publication of this model in the 1960's, Andersen, with the assistance of various colleagues, has continually enhanced the model to address a variety of health care utilization problems (Aday & Andersen, 1974; Andersen, 1995; Andersen & Newman, 1973). The model is based on assumptions positing that health outcomes are influenced by environmental factors, population characteristics, and health services utilization. According to Andersen (1995), this model "suggests that people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care" (p. 1). The underlying logic for designing and conducting this study is that the predisposing, enabling, and need factors are associated with the utilization of formal service use and informal caregiving, which potentially impact the long-term health outcomes, cost of care, and quality of life of the stroke survivor. The primary concepts in this model contribute to the further understanding of health care utilization. The concepts include: environmental factors, population characteristics, health behaviors, and health outcomes. For the purposes of this study only the population characteristics and health behavior concepts will be described since they are the most relevant.

Population Characteristics

The population characteristics identified by the Andersen-Aday Model examine the individual level factors that influence the utilization of health services consisting of predisposing, enabling, and need domains. These domains, defined by this model, focus on the individual characteristics of the participants under study.

Domain 1: Predisposing

Predisposing factors are those variables that are preexisting for each individual. As defined by the Andersen-Aday Model, predisposing factors include demographic characteristics, social structure, and beliefs (Andersen, Rice, & Kominski, 1996). The demographic characteristics include age and gender. The second type of predisposing factor is the position of individual within a social structure. This model defines the measures of social structure by educational attainment, occupation, and race/ethnicity (Andersen et al., 1996). Oversimplification can occur when using race/ethnicity as a measure of social structure as many variables interact and are influenced by this factor (Bradley et al., 2002). The interactions between race/ethnicity and other variables should be examined further to prevent the production of general statements that may not truly capture the role of race/ethnicity in health care utilization. The last factor in the predisposing domain involves health beliefs. This factor is the most difficult to measure within the predisposing domain as it includes individual health beliefs and values (Andersen et al., 1996). Also included are the awareness of health and health services.

It should be noted that many of the variables included in the predisposing domain are considered to be of low mutability (Andersen, 1995), meaning that the demographic and social factors are not prone to change by policy interventions. However, it is important to understand whether these factors are associated with health services use because interventions can then be more efficiently targeted to individuals or populations with those characteristics found to be significantly related to use of informal and formal caregiving over a period of time.

There are a number of studies that have measured variables in the predisposing domain in the Andersen-Aday Model. Of the studies that have been guided by this model, it has been shown that there is support, cross-sectionally, for the importance of the predisposing characteristics in predicting elders' utilization of formal or informal care services. However, the predisposing variables do not explain a great deal of the total variance in previous studies. Specifically, estimates of the proportion of variance in service utilization explained by predisposing factors were found to account for only .02 to .07 of the variance based upon prior research using the Andersen model (Bass & Noelker, 1987; Miller, McFall, & Campbell, 1994).

Age

A predictor of service use among older adults is advanced age. Several reasons may account for this finding since age is an eligibility criteria for many health insurance and community based programs, the fact that frailty increases as one ages, and the availability of informal support systems changes with age (Kadushin, 2004).

Additionally, frail persons over the age of sixty-five are more likely to use institutional services than similar disabled individuals under sixty-five years of age (Bauer, 1996). The contribution of age to explain service use in the context of the Andersen-Aday Model is supported in a few studies (Crets, 1996; Mui & Burnette, 1994; Muramatsu & Campbell, 2002). Age has been suggested as one of the most influential predictors in the predisposing domain since it is related to increased frailty of an older person (Kadushin, 2004).

Educational Attainment

Educational attainment of the care recipient is not directly related to service attainment, but a higher educational level may mean increased income potential and therefore may be more likely to afford access to privately paid for service or having long-term care insurance to pay for caregiving expenses. Years of education has been found to be related to using only formal and using formal only in conjunction with informal caregiving (mixed caregiving) (Norgard & Rodgers, 1997).

Race/Ethnicity

Race has been consistently found to be positively associated with the use of both informal and formal care services. The care choices among African American, Hispanic, and Native American elderly are particularly interesting because these groups also have a higher prevalence of stroke. African American males and females are more likely to use informal caregiving services compared to white elders (Kasper, Shore, & Penninx, 2000; Norgard & Rodgers, 1997). Institutional rates among non-white minorities differ compared to race white elderly. Hispanics and African Americans have a lower probability of nursing home placement (Bauer, 1996). Hence, African Americans and Hispanics depend on formal care services less often and turn to informal care sources (Kemper, 1992).

In some studies African American women caregivers have been shown to provide more informal care than white women (Navaie-Waliser, Spriggs, & Feldman, 2002; Navie-Waliser et al., 2001) and were more likely to provide more informal care in general and to friends in addition to family members (McCann et al., 2000). Hispanic elders are more likely to utilize informal caregiving as well (Coleman, 1993; Kemper, 1992; Weiss, Gonzalez, & Kabeto, 2005). The perception that African American elders receive more informal care than their white counterparts may be a slight misconception since the larger social network among African Americans may also indicate increased disability among this group (Li & Fries, 2005). A caveat to previous findings are three studies which found African American elderly were less likely to utilize informal care when compared to white elderly (Hopp, 1999; Miller et al., 1994; Norgard & Rodgers, 1997). The finding from Norgard and Rodgers (1997) is of particular interest because the sample was drawn from an earlier cross-section of the AHEAD study, and indicated that white males were the group most likely to utilize informal care sources (Norgard & Rodgers, 1997).

Knowledge about long-term caregiving patterns among minority elders is incomplete because the research that has been conducted on a cross-sectional basis to understand utilization patterns of formal and informal caregiving among minority elders is extremely limited. In the literature evaluating substitution of informal caregiving, two studies included minority participants ranging from three percent to twenty-four percent of the sample (Cohen et al., 2001; Greene, 1983; Muramatsu & Campbell, 2002). One study with a larger representation of minorities (17%) based the definition of race/ethnicity on participant surnames, which does not accurately reflect the true racial/ethnic background of the study participant (Greene, 1983). However, in the caregiving stroke literature, minority elders have been included in several qualitative studies (Eaves, 1998; Pierce, 2001) about caregiving within the family.

Gender

Previous studies suggest that women are more likely to receive formal care services and less likely to receive informal caregiving (Norgard & Rodgers, 1997). Conversely, men are more likely to receive informal caregiving when compared to receiving no caregiving (Muramatsu & Campbell, 2002).

Domain 2: Enabling

Enabling factors are those resources that, when present, assist in obtaining health services. Enabling factors have been likened to the concept of supply and demand fundamental to economic theory (Foreman, Yu, Barley, & Chen, 1998). As it relates to access to health services and further to the concept of enabling factors, an available supply of health services whether formal or informal is imperative to accessing those services. The resources available to achieve health care access can originate from two sources: community and personal sources (Andersen et al., 1996). Personal enabling factors are those resources unique to specific groups or individuals such as: long-term care insurance, income level, marital status, available transportation, and source of care (Andersen et al., 1996). It is the personal enabling factors that will be evaluated in this study.

Enabling factors have been consistently examined in studies evaluating predictors of caregiving source and are found to contribute to the overall explanation of variance. Estimates of the proportion of variance in service utilization explained by enabling variables based upon prior research using the Andersen model were found to account for .02 to .08 of the variance (Bass & Noelker, 1987; Miller et al., 1994).

Living Situation

One enabling factor as defined by Andersen and colleagues is living situation (living alone vs. not living alone) and this has been used to explain use of caregiving resources (Crets, 1996). Co-residence with another person heavily influences whether or not an elder received formal or informal care. Tennstedt, Sullivan, McKinlay and D'Agostino (1990) report that elders residing alone are twenty-eight times more likely to utilize formal care services. Having family (spouse or child) available to provide care increases the total hours of care for the elder and reduces the likelihood of receiving formal care services (Kemper, 1992). It has also been suggested that there is a relationship between the rapport between the care receiver and caregiver which influences the decision to utilize informal care (Wielink & Huijsman, 1999).

Marital

Having spousal support can sometimes indicate the possibility and/or the availability of informal (unpaid) supports. Often caregivers of the frail elderly are resident spouses caring for a more disabled partner. It is often thought that a married care receiver is less likely to require institutional or formal (paid, community-based) supports. However, it has been shown that marital status, surprisingly does not prevent admission into institutional care (Bauer, 1996). Within the Andersen-Aday Model context, marital status has not been found to be a significant predictor (Kadushin, 2004). Interestingly, Muramatsu and Campbell (2002) found that married elders are less likely to utilize formal care services when compared to no assistance, but marital status was not a significant predictor for informal care or mixed caregiving.

Long-term Care Insurance and Income

The ability to finance both community and institutional caregiving services through insurance programs or private funds can impact the level and type of services utilized among caregivers and care receivers. Benefit periods rather than the needs of the stroke survivors and their caregivers are sometimes used to guide the use of paid services (Levine et al., 2006). However, this assumption can be refuted with home health care clients as there is not necessarily a relationship between payment source and discontinuation of services such as home health care (Han, Remsburg, Lubitz, & Goulding, 2004). Only two types of insurance products will finance long-term care services: 1) a long-term care insurance policy and 2) Medicaid. Long-term care is not financed by any traditional health insurance policy, but for qualifying recipients Medicaid will pay for custodial care and certain community-based services. Income eligible stroke survivors would be able to obtain paid services through this program and Medicaid status is positively associated with use of long-term care services (Kadushin, 2004). Additionally, the amount of state expenditures used for home and community based care is associated with a higher probability of using formal care services ($p<.05$) (Muramatsu & Campbell, 2002). Although most people in the U.S. do not have long-term care insurance for various reasons, having a long-term care insurance policy does enable people to obtain services in the community or within a facility and is one potential predictor of paid service use. Services that are not paid for through insurance programs can still become available to those who can privately pay for these services. Additionally, a lower income may also indicate the possibility that the stroke survivor may be more dependent on informal (unpaid) caregiving. Previous studies found that informal caregiving was associated with a lower income of the elderly (OR= .111; $p<.01$) (Norgard & Rodgers, 1997) while a higher income was associated with the utilization of more formal care services ($p<.05$) (Kemper, 1992).

Domain 3: Need

The need domain can take two forms: evaluated and perceived. Evaluated need factors include objective statements diagnosed by a licensed professional. Conversely, perceived needs are those needs determined by personal beliefs about health. The need domain has been consistently measured and found to be a significant predictor of health services use in the elder care literature. Estimates of the proportion of variance in service utilization explained by need variables based upon prior research using the Andersen model are .04 to .15 of the variance (Bass & Noelker, 1987; Miller et al., 1994). Perceived needs are those self-reported questions about activities of daily living (ADL), instrumental activities of daily living (IADL), urinary incontinence (UI), and presence of a memory related disease.

Level of Functioning

Level of functional disabilities, as measured by deficits in ADL and IADL, is an important predictor of service use. Functional activities such as eating, bathing, toileting, dressing, and ambulation are considered ADL and shopping, using the telephone, housekeeping, using transportation, taking medication, and handling finances are IADL's

(Lawton & Brody, 1969). In fact, ADL deficits have been highly significant in most studies evaluating formal and informal caregiving (Kadushin, 2004; Mui & Burnette, 1994; Norgard & Rodgers, 1997). Overall, the use of caregiving services (formal an informal) increases with disability level (Kemper, 1992). Beyond the obvious relationship between formal service use and level of functioning, these factors are also highly associated with use of informal caregiving. ADL assistance in all five areas was found to be related to an increased probability of using informal care (Kemper, 1992). When the level of ADL and IADL frailty are evaluated separately, increased IADL impairments are associated with use of informal care (Norgard & Rodgers, 1997). Increased level of need indicated by ADL and IADL dependence are related to increased use of formal care (Norgard & Rodgers, 1997; Tennstedt et al., 1990). Across time the increased disability of an elder was associated with the use of formal care services (Liu, Manton, & Aragon, 2000).

Urinary Incontinence

Stroke survivors often experience UI for many months after the stroke incident. Between 17 to 60 percent of stroke survivors have difficulty with UI beyond the initial weeks post stroke (Brittain et al., 2000; Jorgensen, Engstad, & Jacobsen, 2005; Nakayama et al., 1997). Urinary incontinence leads to a slight increase in the total hours of care and is slightly higher for informal caregiving (Kemper, 1992). While the demands of an incontinent stroke survivor increase the amount of time needed to care for the individual, UI by itself may not be a predictor of whether an individual is institutionalized (Lutz, 2004). The relationship between caregiving source and UI is influenced by other factors including being able to ambulate and the availability of resources to support informal caregiving (Lutz, 2004).

Memory and Cognitive Impairment

Cognitive impairment (including memory impairment) or behavioral problems have been found to increase total hours of informal care (Kemper, 1992). Level of mental functioning has been measured using a variety of variables to act as proxies for this potential determinate of care. Kosloski and Montgomery (1994) included the presence of Alzheimer's disease and found that it related to use of adult day services. Mui and Burnette (1994) utilized a measure of cognitive functioning (Short Portable Mental Status Questionnaire) to determine level of functioning, while Crets (1996) utilized a similar scale to determine emotional and cognitive impairment. As one would expect less cognitive impairment was associated with in-home services ($p<.01$) and more cognitive impairment was associated with nursing home care ($p<.05$) (Mui & Burnette, 1994). Measures of cognitive functioning vary across the literature and there is no consensus on the amount of influence this variable has on place of care (Kadushin, 2004).

Dependent Variable: Health Care Utilization

There are two types of health utilization examined in the Andersen-Aday Model: personal health practices and the actual use of formal health services (Andersen et al., 1996). Personal health practices include, but are not limited to, health promoting activities such as eating a well balanced diet, performing regular exercise, and restriction/reduction of alcohol or tobacco use (Andersen et al., 1996). Use of formal health services is the actual measure of utilization of health services. The actual use of health services is defined as the use of caregiving services.

The actual use of caregiving services has been measured using a variety of different methodologies to describe the type or quantity of formal, informal, and mixed caregiving. Measurement approaches range from categorical to hours/days of caregiving. Mui and Burnette (1994) categorized the use of caregiving services as the use of in-home care, community based care, and nursing home care. Coleman (1993) measured the use of informal care by the average hours provided on a daily basis and Tennstedt, Crawford, and McKinlay (1993b) measured the use of caregiving services by using the number of hours of care provided by formal or informal sources of care. Similarly, Pezzin, Kemper, and Reschovsky (1996) utilized hours of caregiving as the dependent variable. Hanley, Wiener, and Harris (1991) measured caregiving by the number of days a formal care provider visited the care receiver, but only included disabled respondents who reported utilizing formal care services. Miller, McFall, and Coleman (1994) used a three-part categorical variable indicating no caregiving, informal only, and mixed caregiving. The authors did not include a formal only category in the multivariate analyses and presented two contrasts: informal help only compared to no help and mixed help compared to informal help.

Norgard and Rodgers (1997) created three distinct categories indicating whether the respondent received any help, informal help, or formal help with ADL with the reference category informal sources. This created three dependent variables which were evaluated in separate analyses. Jette, Tennstedt, and Branch (1992) based the definition of care utilization on IADL only and completely excluded ADL.

Previous research has shown that categorizing these caregiving types is a sound methodology to measure use of caregiving services. However, this categorization has not been utilized in a sample of older people who have survived a stroke or with multiple waves of the HRS/AHEAD data. The categorization utilized by Norgard and Rodgers (1997) will be duplicated in this study with only respondents who have survived a stroke and using more current data which may provide more relevant results since there have been numerous policy changes that have occurred since the previous work has been published. This study will measure health care utilization among stroke survivors as the use of formal only, informal only, mixed caregiving, and no caregiving based upon the respondents need for assistance with ADL.

Applications of the Andersen and Aday Model of Health Services Use

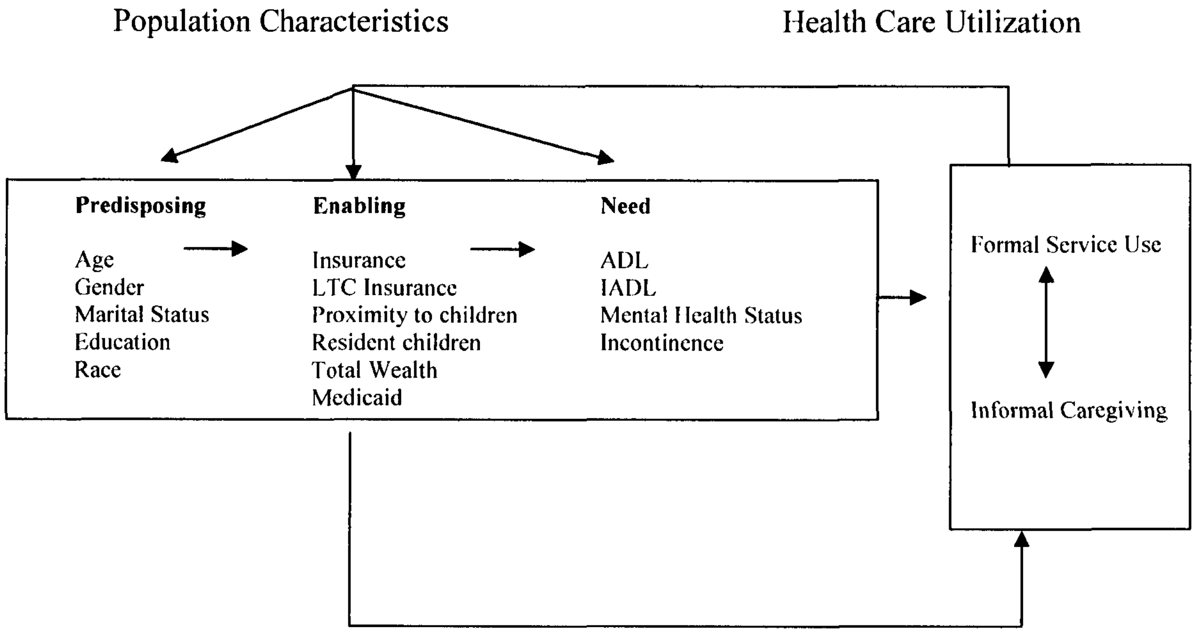
The Andersen-Aday Model has been used in previous research studies to evaluate elements of health care utilization covering a wide range of topics including informal caregiving (Bradley et al., 2004; Coleman, 1993; Kosloski & Montgomery, 1994; Mui & Burnette, 1994; Norgard & Rodgers, 1997). Bradley et al (2004; 2002) apply the framework of the Andersen-Aday Model to explain the characteristics of individuals who intend to use informal supports and to further incorporate psychosocial domains as a potential explanatory factor influencing the use of caregiving services. Other authors have chosen to explore caregiving service use within the confines of the Andersen-Aday Model. For example Kosloski and Montgomery (1994) utilized the Andersen Model to explore the utility of this framework to explore cross-sectional differences in the use of a variety of services with particular attention paid to the interaction between predisposing and need variables. Coleman (1993) and Mui and Burnette (1994) used the model's three domains (predisposing, enabling, and need) cross-sectionally to describe hypothesized predictors of caregiving supports of participants in The Channeling experiment. Norgard and Rodgers (1997) and Miller, McFall, and Campbell (1994) utilized this framework to further assess the importance of race and ethnicity as a predictor of formal and informal service use. The study by Miller, McFall, and Campbell (1994) collected data in 1982 and 1984 to examine whether the source of caregiving changed over the two years.

These previous works examining predictors of caregiving services use have found that the domains within this model do explain some aspects of formal and informal caregiving use, but not all. Overall the Andersen-Aday Model has been found to explain small amounts of variance within health care access studies. In the previous research evaluating caregiving, need factors have typically been found to drive the explained use of caregiving services among the frail elderly.

As applied to this study, the Andersen-Aday Model holds that characteristics of the stroke survivor in three domains (predisposing, enabling, and need) will predict or explain the health services utilization measured by formal care service use and informal caregiving among stroke survivors. The most current version of the Andersen-Aday Model (1995) (see Figure 2) was chosen because it includes a longitudinal dimension. Feedback loops allow for a longitudinal analysis of access to health services, which is essential to the ability of this study to identify transitions between formal care services use and informal caregiving over time. Although previous research has examined formal care service use and informal caregiving separately and cross-sectionally, it cannot be inferred from these previous findings that they address the longitudinal change in caregiving source over time. The Andersen-Aday Model provides the ability to explain formal service use and informal caregiving by the suggested causal order of the predisposing, enabling, and need domains (Andersen, 1995). Further, it is suggested that the domains also improve the ability to predict service use because of the independent nature of the domains (Andersen, 1995). This version of the model is particularly well suited to this study because the feedback loops will allow any changes in the utilization of formal service use and informal caregiving between 1998 and 2002 to be identified and examined.

The Andersen-Aday Model has been criticized as not capturing the unique interactions between the factors (Bradley et al., 2002). Despite some criticism of the use of this theory to understand utilization of health services, it is one of the most frequently used models today.

Figure 2: Andersen-Aday Model of Health Care Services Use



Research Questions and Hypotheses

Research Question 1

What is the pattern of formal and informal caregiving among elderly stroke survivors over a six-year period?

This question is descriptive in nature; consequently there are no hypotheses generated for this question.

Research Question 2

To what extent does the Andersen-Aday Model (predisposing, enabling, and need variables) explain the receipt of formal and informal caregiving both cross-sectionally and longitudinally in terms of: 1) the relative amount of variation accounted for in caregiving use explained by the different Andersen model domains, and 2) identification of specific variables in each Andersen model domain that are more likely to be associated with caregiving type?

Cross-Sectional Hypotheses: Bivariate

1) Domain 1: Predisposing Characteristics
    A. Older stroke survivors (75+) will be more likely than younger stroke survivors to receive formal or mixed caregiving than informal caregiving, and will be less likely to receive no caregiving.
    B. African American stroke survivors will be more likely than white stroke survivors to receive informal care, while white stroke survivors will be more likely to receive formal, mixed, or no caregiving.

  C. Male stroke survivors will be more likely than female stroke survivors to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.
  D. Stroke survivors with less than a high school education will be more likely than stroke survivors with more than a high school education to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.

2) Domain 2: Enabling Characteristics
  A. Stroke survivors with Medicaid will be more likely than those without Medicaid to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.
  B. Stroke survivors with long-term care insurance will be more likely than stroke survivors without long-term care insurance to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.
  C. Stroke survivors who have children residing within ten miles will be less likely than stroke survivors who do not have children residing within ten miles to receive formal or no caregiving than informal caregiving, and more likely to receive mixed caregiving.
  D. Stroke survivors with resident children will be less likely than stroke survivors without resident children to use formal or no caregiving than informal caregiving, and more likely to receive mixed caregiving.

   E. Unmarried stroke survivors will be more likely than married stroke survivors to receive formal, mixed, or no caregiving than informal caregiving.
   F. Stroke survivors who have a smaller total wealth (less than \$38,000) will be less likely than stroke survivors who have a larger total wealth (greater than \$38,000) to receive formal or mixed caregiving than informal caregiving, and more likely to receive no caregiving.
   G. Stroke survivors who are poor (total wealth < \$38,000) and have Medicaid will be more likely than stroke survivors who are not poor and do not have Medicaid to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.
   H. Stroke survivors who are poor (total wealth <\$38,000) and do not have Medicaid will be less likely than stroke survivors who are not poor and do not have Medicaid to receive formal, mixed, or no caregiving than informal caregiving.

3) Domain 3: Need Characteristics
   A. Stroke survivors who have more ADL impairments will be more likely than stroke survivors with fewer ADL impairments to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.

B. Stroke survivors who have more IADL impairments will be more likely than stroke survivors with fewer IADL impairments to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.

C. Stroke survivors who report urinary incontinence will be more likely than stroke survivors who do not report urinary incontinence to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.

D. Stroke survivors who report a memory related disease will be more likely than stroke survivors who do not report a memory related disease to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.

E. Stroke survivors who have a higher depression score will be more likely than stroke survivors who have a lower depression score to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.

Multivariate and Longitudinal Hypotheses

It is hypothesized that when considered in the same model the following variables in the Andersen-Aday Model will be significant predictors of caregiving type (formal, mixed or no caregiving) when compared to informal only caregiving. It is hypothesized the need domain followed by the enabling and predisposing domains will explain the largest amount of variance and remain significant when controlling for other variables in the model. Table 2 presents the hypothesized relationships (whether the odds will increase or decrease) between each variable in the Andersen-Aday Model domains and type of caregiving.

Table 2: Multivariate Hypotheses

		Direction of OR Compared to Informal Caregiving		
Domain	Variable	Odds of Formal	Odds of Mixed	Odds of No Caregiving
Predisposing	Age 75+	Increase	Increase	Decrease
	Female	Increase	Increase	Decrease
	Less than high school	Increase	Increase	Decrease
	African American	Decrease	Decrease	Increase
Enabling	>$38,000	Increase	Increase	Decrease
	Has Medicaid	Increase	Increase	Decrease
	Has children within 10 miles	Decrease	Increase	Decrease
	Has resident children	Decrease	Increase	Decrease
	Married	Decrease	Increase	Decrease
	Has LTC insurance	Increase	Increase	Decrease
Need	More ADL impairments	Increase	Increase	Decrease
	More IADL impairments	Increase	Increase	Decrease
	Reports UI	Increase	Increase	Decrease
	Reports memory related disease	Increase	Increase	Decrease
	Higher depression score	Increase	Increase	Decrease

Research Question 3

Are there differences between non-Hispanic Whites and minorities (African Americans and Hispanics) in terms of the specific Andersen-Aday Model domains (predisposing, enabling, and need) that influence utilization of formal service use and informal caregiving?

This series of hypotheses will replicate the previous section for White and non-White participants separately. These are exploratory hypotheses to investigate the ability of the Andersen model to predict differences between these two groups. However, it is expected that there will be differences between white and African American stroke survivors.

CHAPTER III

Methodology

Research Design

Description of Data Set and Sampling Methods

The HRS/AHEAD dataset used in this study is derived from a longitudinal panel study spanning the period from 1993 through 2002. The HRS (Health and Retirement Study) is sponsored by the National Institute of Aging (grant number NIA U01AG009740 and is conducted by the University of Michigan. This particular study will include a subset of the HRS/AHEAD dataset that includes four age cohorts representing individuals born in 1923 through 1947 who reside in the U.S. Excluded from the initial data collection were individuals in long-term care facilities and individuals residing in jails. However, participants that entered a long-term care facility during the duration of this study were followed and interviewed. Interviews were the main mode of data collection. Both in-person and telephone interviews were utilized.

The HRS/AHEAD data consists of three birth cohorts in the sample. The baseline data is the HRS 1992, Wave I. The HRS 1992 baseline data represents the birth cohort 1930-1941. Since 1992, three birth cohorts have been added to the dataset. The study of Assets and Health Dynamics Among the Oldest Old (AHEAD) respondents was added in 1993-1994 to represent individuals born in 1923 and earlier. The Children of the Depression (CODA) cohort was added in 1998 to represent individuals born between 1924 and 1930. The War Babies (WB) cohort was also added in 1998 to represent the 1942-1947 birth cohort. The HRS and AHEAD (includes WB and CODA) were merged into one file in 1998. All of the cohorts are included in the 1998, 2000, and 2002 data file.

In order to achieve a nationally representative sample of the sample cohorts, the researchers at the University of Michigan utilized a dual-frame sample design. Households were selected for participation through two methods: an Area Probability sample and the Health Care Financing Administration (HCFA) Enrollment Data Base (EDB) file (Heeringa, 1995).

The sample for the HRS in 1993 was achieved by using a national area probability sample. This sample was selected from the 1990 census data using a multi-stage sampling technique and was chosen using household addresses. It is from the national area probability sample originating from the 1990 census data that African Americans, Hispanics, and Florida residents were over sampled.

The second source of participants came from the HCFA EDB file (Heeringa, 1995). The HCFA EDB file is part of the Social Security Administration's Master Beneficiary record (Heeringa, 1995). This database contains identifying information for individuals enrolled in the Medicare program. Information such as names, addresses, date of birth, gender, race, and county of residence were available in this file (Heeringa, 1995). Five percent of the EDB file was selected. As with the area probability sample, this sample was selected using multi-stage methodology. This sample was obtained in similar fashion as the area probability sample. Similar geographic areas were utilized to determine the sampling frame. In total, 2000 participants over the age of seventy-seven years of age were selected from the HCFA EDB database (Heeringa, 1995). Participants were selected from the HCFA EDB file for the AHEAD cohort in order to achieve a representative sample of the oldest-old cohort. Respondents were categorized into two groups. The first group consisted of individuals born after 1913 and was primarily interviewed via telephone. The second group consisted of respondents born in 1913 or earlier and was mainly interviewed in-person. During the first wave of the AHEAD study, 72 percent of the first group was interviewed by telephone and 70 percent of the second group was interviewed in-person (Heeringa, 1995). For more detail about the sampling methodology of the HRS/AHEAD refer to Technical Description of the Assets and Health Dynamics Survey Sample Design by S. G. Heeringa (1995).

Sample Size and Characteristics

This study involves a prospective, longitudinal panel study focusing upon three waves of interview data spanning 1998 through 2002. The specific three waves were selected for study to provide the most recent cohorts of data having comparable measures. Earlier waves had notable differences in instrumentation that would have made comparisons difficult.

The sample includes those participants who identified themselves as having a stroke in 1996 or later. Overall, 477 respondents reported having a stroke. In the 1998 interview, 23.1 percent (n=110) had a stroke in 1996, 50.1 percent (n=239) had a stroke in 1997, and 26.8 percent (n=128) had a stroke in 1998. Several respondents had multiple strokes during the three waves (see Table 3). In 2000, 53 respondents indicated that they had another stroke since the last interview and 34 respondents indicated another stroke in 2002. In total, 18.2 percent of stroke survivors had more than one stroke during the study period.

Table 3: Year of Most Recent Stroke

Year of most recent stroke	Wave I n= 477	Wave II n= 346	Wave III n= 264
1996	110	--	--
1997	239	--	--
1998	128	6	1
1999	--	32	1
2000	--	15	3
2001	--	--	17
2002	--	--	12

The number of subjects available at each wave is presented in Table 3. Across the three waves of interviews, there are 264 subjects for analysis representing a retention rate of 55.3 percent. Seven participants were not interviewed in 2000, but re-entered the study in 2002. By 2000, 108 participants had died and 23 were not interviewed. By 2002, an additional 82 participants had died. Thus the 264 respondents interviewed in 2002 represents 91.9 percent of living stroke survivors.

Table 4: Attrition of participants (n=477)

Year	Interviewed	%	Known Dead	Lost to Follow-up (includes no response & alive and do not know alive or dead)
1998	Wave I: n=477	100	-	-
2000	Wave II: n=346	72.5	108	23
2002	Wave III: n=264	55.3	82	0

At each wave approximately 30 percent of interviews were not directly with the participant, using a proxy instead (see Table 5).

Table 5: Proxy Interview Status

Year	Proxy Interview n	%
1998	144	30.2
2000	97	28.0
2002	75	28.4

Demographics

The sample consists of four birth cohorts: AHEAD, CODA, HRS, and War Babies. The majority of the sample for this study is from the AHEAD and HRS cohorts. Approximately 80 percent of the sample in 1998 and 2000 and 75 percent of the sample in 2002 are from these two birth cohorts (see Table 6).

Table 6: Cohort 1998, 2000, 2002

	1998		2000		2002	
	Frequency	%	Frequency	%	Frequency	%
AHEAD	246	51.6	158	45.7	107	40.5%
CODA	74	15.5	56	16.2	52	19.7%
HRS	139	29.1	116	33.5	90	34.1%
WAR BABIES	18	3.8	16	4.6	15	5.7%
Total	477	100.0	346	100.0	264	100.0%

Descriptive demographic characteristics and functional status of the sample in the three waves of this study are presented in Tables 6-10. This sample of stroke survivors is similar to the national population of older Americans. According to the 2000 U.S. Census, 75 percent of older Americans (65+) were white and 12.3 percent were African American (U.S. Census Bureau, 2000a). In this study, approximately 75 percent of the respondents are white and 18 percent are African American. This higher percentage of African American stroke survivors in this sample is due to the oversampling of this group. The age distribution of stroke survivors is also very similar to the distribution of the general U.S. population. Thirty-two percent of Americans over 65 are between the age of 75 and 84 (Gist & Hetzel, 2004). This study has approximately 32 percent of respondents in this age range in the first and second waves of this study. The percentage of respondents in this age category increases in 2002 to 43 percent. This study does have a higher percentage of older Americans (over 85) due to the sampling from the AHEAD portion of the data set. Another similarity to the general population is that 14 percent of stroke survivors have another stroke within one year of the initial incident (American Heart Association, 2006). In this data, 18 percent of respondents had a second stroke during the study period.

Table 7: Demographic characteristics at Wave I -III

		1998		2000		2002	
		Frequency	Percent	Frequency	Percent	Frequency	Percent
Age	43-64	99	20.8	74	21.4	49	18.6
	65-74	135	28.3	98	28.3	62	23.6
	75-84	157	32.9	119	34.4	114	43.3
	85+	86	18.0	55	15.9	38	14.4
	Total	477	100.0	346	100.0	263	100.0
Gender	Male	217	45.5	158	45.7	113	44.0
	Female	260	54.5	188	54.3	144	56.0
	Total	464	100.0	346	100.0	257	100.0
Education	No formal through grade 11	220	46.5	165	47.8	117	44.3
	High School	142	30.0	102	29.6	81	30.7
	Some College	64	13.5	43	12.5	35	13.3
	College Graduate and Higher	47	9.9	35	10.1	31	11.7
	Total	473	100.0	345	100.0	264	100.0
Marital Status	Not married	238	50.1	176	50.9	147	55.7
	Married	237	49.9	170	49.1	117	44.3
	Total	475	100.0	346	100.0	264	100.0
Race	White	360	75.9	267	77.6	202	76.8
	African American	91	19.2	64	18.6	48	18.3
	Other	23	4.9	13	3.8	13	4.9
	Total	474	100.0	344	100.0	263	100.0

A large portion (60%) of the respondents report difficulties with specific activities of daily living (ADL) in the three waves of this study. Between 50 and 60 percent of respondents in the study period report difficulties with specific instrumental activities of daily living (IADL)[1].

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[1] The IADL survey question only queried about a limited number of IADL tasks. Other IADL tasks could include items such as housekeeping, laundry, or the ability to manage finances (Lawton & Brody, 1969).

Table 8: Mean number of ADL impairments

Year	Mean	sd	% with any impairment
1998	2.13	2.3	60.1
2000	1.88	2.2	56.2
2002	1.9	2.1	58.3

Table 9: 1998, 2000, 2002 ADL Difficulty due to Health or Memory Problem

		1998		2000		2002	
		Frequency	Percent	Frequency	Percent	Frequency	Percent
Dressing Difficulty	Yes	207	43.4	131	41.5	110	45.5
Walking Difficulty	Yes	173	36.3	124	42.6	83	38.1
Bathing Difficulty	Yes	196	41.1	129	44.2	105	47.9
Eating Difficulty	Yes	132	27.7	83	28.4	56	25.8
Difficulty getting in and out of bed	Yes	158	33.1	97	33.2	77	35.2
Toileting Difficulty	Yes	150	31.4	85	29.3	73	33.3

Table 10: Mean number of IADL impairments

Year	Mean	sd	% with any impairment
1998	1.37	1.5	53.7
2000	1.19	1.4	50
2002	1.29	1.5	51.1

Table 11: 1998, 2000, 2002 IADL Difficulty due to Health or Memory Problem

		1998		2000		2002	
		Frequency	Percent	Frequency	Percent	Frequency	Percent
Difficulty Preparing Meals	Yes	197	41.4	118	34.2	104	39.4
Difficulty Taking Medication	Yes	110	23.1	66	19.1	50	18.9
Difficulty Using the Phone	Yes	132	27.7	83	24.1	75	28.4
Difficulty Grocery Shopping	Yes	217	45.6	148	42.9	112	42.4

Variables

The primary dependent variable is caregiving status at each wave categorized as formal, informal, mixed, and no caregiving. Key variables from the HRS/AHEAD dataset included in the analyses corresponding to Andersen-Aday Model domains (predisposing, enabling, and need) were included in the analysis and are presented below. Fifteen variables were included in the analyses.

Dependent Variables

Caregiving Status. The dependent variables reflecting caregiving type at each wave (1998, 2000, 2002--identified here as careADL98, careADL00 and careADL02) were created from questions indicating type of care (formal or informal) reported by the respondent for help with ADL tasks (see Table 12). The variable measuring utilization of caregiving services (formal or informal) is constructed from six ADL questions indicating source of help which are coded as formal and informal depending on the answer indicated by the respondent. Any caregiving provided by an employee or institution is coded as formal care. All other care provided by family, friends, or household members was coded as informal. This variable is referred to as caregiving status which represents the four caregiving categories: formal only, informal only, mixed, or no caregiving. Detailed information about the original variables from the HRS/AHEAD data is available in Appendix A. For each wave the same categorical variable indicating source of help the following categories was created. The categories for the dependent variables were created by examining the primary and secondary caregiver from the following questions:

1. Who most often helps you with getting across a room, dressing, bathing, eating, getting in and out of bed, using the toilet?
2. What is that person's relationship to you?
3. Does anyone else help you with [this activity/these activities]?
4. What is that person's relationship to you?

Since most respondents only had only two different caregivers per ADL task this study will only focus on the primary and secondary caregivers which were then categorized into the four groups (formal, informal, mixed, and no caregiving). This classification was chosen based on previous research that utilized similar categories (Miller et al., 1994;

Norgard & Rodgers, 1997) and constraints in the data did not allow for a reasonable proportion of caregiving services.

Table 12: Dependent Variables

Concept	Variable Name	Operational definition
Caregiving Status	CareADL98 CareADL00 CareADL02	Four part categorical variables with the following categories: formal service use only, informal only, mixed, and no caregiving

Independent Variables

The predisposing, enabling, and need variables consistent with the Andersen-Aday Model domains which were described in Chapter two are operationalized and described in Table 13 for this study.

Table 13: Predisposing, Enabling and Need Variables

Domain	Concept	Operational definition	Categories	Reference Group
Predisposing	Age	Respondent age	less than 75, older than 75	less than 75
	Gender	Respondent gender	Male, Female	Male
	Marital Status	Respondents marital status	Married, Unmarried includes separated/divorced, never married,	Unmarried
	Educational Attainment	Respondent highest level of education attained	More than High School, Less than High School	More than High School
	Race/Ethnicity	Respondents race or ethnic background	White (includes other), Black	White
Enabling	Medicaid Status	Medicaid Status	Yes, No	No
	Long-term Care Insurance	LTC insurance	Yes, No	No
	Total Wealth	Total Wealth	<38,000 >38,000	>38,000
	Children within 10 Miles	Children within 10 miles	Yes, No	No
	Resident Children	Resident children	Yes, No	No
Need	Number of ADL deficiencies	Self-reported Activities of Daily Living	Count	N/A
	Number of IADL deficiencies	Self-reported Instrumental Activities of daily Living	Count	N/A
	Incontinence	Self-reported incontinence	Yes, No	No
	Memory Related Disease	Self-reported memory related disease	Yes, No	No
	CESD	CESD score	Score	N/A

Domain 1: Predisposing

Included in the predisposing domain are demographic characteristics and factors associated with social position. The demographic characteristics include age, gender, and marital status. Age is measured on a ratio scale and was dichotomized (<75,<75) for the multivariate models. Gender is included in this model with male as the reference group. Marital status is also dichotomized as married and not married. The reference group is unmarried. Measures of social structure included in this are educational attainment and race/ethnicity. Educational attainment is a categorical variable with college graduate as the reference group. Lastly, race/ethnicity is measured as White and African American. The White category includes a small number of other races that did not have enough cases to remain an individual category (n=23). The dichotomized variable is included in the analyses with White as the reference group.

Domain 2: Enabling

Enabling factors included in this study are: presence of children in the household, children within ten miles of care recipient, long-term care insurance, total wealth, and use of Medicaid. Total wealth includes the sum of assets such as: stocks, bonds, house, and checking/savings accounts less total debt. These variables, except total wealth, are measured dichotomously with the reference group as 'no'. The original total wealth variable was a continuous variable which is categorized in the multivariate analyses as less than $38,000 and greater than $38,000 to provide more information than would be provided by only including the median total wealth. The reference group is a total wealth of greater than $38,000. An indicator variable combining total wealth with Medicaid status was created to differentiate between respondents that were poor (total wealth <

$38,000) with Medicaid, poor (total wealth < $38,000) without Medicaid, and all other respondents.

Domain 3: Need

In this study need was measured using the functional status of the respondent as measured by self-reported ADL and IADL functioning, incontinence, and presence of a memory related disease. Both the ADL and IADL variables are counts of the number of impairments reported by each stroke survivor. Incontinence and the presence of a memory related disease are dichotomous questions (yes, no) with no as the reference group. The depression scale (CESD) is also a scored variable with eight items included in the score. Possible scores range from zero to eight with higher scores indicating higher levels of depression.

Missing Data and Sample Size Issues

Patterns of missing data were examined prior to data analysis. Participants that reported no difficulty with high level ADL functions (walking one block; sitting for two hours; climbing several flights of stairs; stooping, kneeling, and crouching; extending arms above shoulders; pushing large objects; carrying over ten pounds; picking up a dime) were not asked the lower functioning ADL skills such as dressing, walking, bathing, eating, and toileting and were therefore coded as missing in the original data set. These respondents were recoded as 0 (no difficulty). The most common missing variables were children residing within ten miles (CH10MILE), memory disease (MEMORY), and depression scale (CESD) variables. Since 20 - 30 percent of data points were missing all eight questions included in the CESD variable, the depression scale was not included in the bivariate or multivariate analyses. Imputation was not conducted due to the high number of missing responses in this variable.

Table 14: Missing Data by Variable: All Stroke Survivors

	1998	2000	2002
Variable	**# of cases with missing data (n=477)**	**# of cases with missing data (n=346)**	**# of cases with missing data (n=264)**
Age	0	0	0
GENDER	0	0	0
MARITAL	0	0	0
EDUCATION	0	0	0
RACE	0	0	0
LTC	2	1	0
INCOME	0	0	0
CH10MILE	69	71	31
RESCHILD	0	0	7
MCD	3	4	3
ADLCOUNT	1	1	0
IADLCOUNT	0	0	0
INCONT	1	2	4
MEMORY	1	42	11
CESD	144	97	75

Table 15 presents missing data by cases. Across the three waves, over half of the cases did not have any missing data and over 80 percent only had one missing data point.

Table 15: Missing Variables by Case

# of missing variables	1998 Frequency	1998 %	2000 Frequency	2000 %	2002 Frequency	2002 %
0	275	57.7	184	53.2	153	58.0
1	165	34.6	116	33.5	83	31.4
2	34	7.1	32	9.2	22	8.3
3	2	.4	11	3.2	5	1.9
4	1	.2	3	.9	1	.4

Outliers

To examine the influence of outliers among the independent variables frequencies and histograms were examined to identify out of range values and missing data. Examination of outliers of the only continuous predictor variable indicating total wealth was conducted using Mahalanobis Distance (Tabachnick & Fidell, 2001). As a result total wealth was categorized in the multivariate analyses as less than 38, 000; 38,000-139,000; and > 139, 000 to provide more information than would be provided by only dichotomizing at the median total wealth. This categorization of total wealth has been utilized in the past with HRS/AHEAD data (Hickenbottom et al., 2002; Langa, Fultz, Saint, Kabeto, & Herzog, 2002) and was chosen to provide more information than simply including the median total wealth.

Statistical Analysis Plan

Overview

This study explores the Andersen-Aday Model variables as predictors of formal and informal caregiving both cross-sectionally and longitudinally. Initial descriptive analyses include examination of univariate distributions of the independent variables (IVs) and dependent variables (DV) at each wave (1998, 2000, and 2002). Bivariate associations were evaluated to identify relevant predictors. Finally, research questions two and three were examined using multinomial logistic regression to examine cross-sectional relationships between the dependent variable and the independent variables. Finally, clustered multinomial logistic regression techniques were utilized to examine relationships between the predictor variables in the Andersen-Aday Model and caregiving type longitudinally in sub-questions 2B and 3B.

Descriptive Analyses

Research question 1: To examine characteristics of stroke survivors at 3 points in time post-stroke (up to 6 years) in terms of:

A. Utilization of formal and informal caregiving services
B. Predisposing, enabling, and need variables

To answer research question one univariate and bivariate cross-sectional analyses were performed at each wave (1998, 2000, and 2002). Descriptive analyses were conducted on all predisposing, enabling, and need variables in the Andersen-Aday Model domains as well as the dependent variables, caregiving type for the three waves. Measures of central tendency [measures of variation] (Means [sd] and Median [IQR) are presented in addition to measures of variation. Bivariate descriptive statistics were examined to assess relationships between the predictor variables in each domain and dependent variables 1998 (CAREADL98), 2000 (CAREADL00), and 2002 (CAREADL02) at each wave. Specific bivariate tests and measures of strength of relationships were selected as appropriate for the level of measurement of the variables under consideration.

Multivariate Analysis

Research question 2: To what extent does the Andersen-Aday Model (predisposing, enabling, and need variables) explain the receipt of formal and informal caregiving both cross-sectionally and longitudinally in terms of: 1) the strength of the association between caregiving use explained by the different Andersen model domains, and 2) identification of specific variables in each Andersen model domain which are more likely to be associated with caregiving type?

Specific sub-questions include:

A. To what extent do the predisposing, enabling, and need variables as cross-sectional predictors of caregiving type at each wave 1998 (CAREADL98), 2000 (CAREADL00), and 2002 (CAREADL02) describe the consistency of the variables within these domains?

B. To what extent do the Andersen-Aday Model domains (predisposing, enabling, and need) act as longitudinal predictors in caregiving type over time?

To answer question 2A and to test the Andersen-Aday Model, multinomial logistic regression was employed. At each wave (1998, 2000, and 2002) cross-sectional analyses were performed using multinomial logistic regression to determine if the variables in the Andersen-Aday Model domains predict caregiving status. For each wave, multinomial logistic regression was used to examine how well the Andersen-Aday Model domains predict use of caregiving, cross-sectionally.

Multinomial logistic regression is the proper technique when analyzing unordered categorical outcome measures for the following reasons (Cohen, Cohen, West, & Aiken, 2003; Tabachnick & Fidell, 2001):

- Multinomial logistic regression does not require the data to meet the strict requirements of linear regression: linearity, homoscedacity , or normally distributed independent variables.
- The outcome (dependent) variables can be nominal or ordinal with two or more categories.
- Independent variables can be of any measurement scale: nominal, ordinal, ratio, or interval.
- Multinomial logistic regression provides odds ratios to explain the relationship between the independent and dependent variables.
- This method allows the researcher to enter variables sequentially (hierarchical method) in the regression equation.

The multinomial logistic regression model will be calculated using the following equations (StataCorp, 2005a).

$$Pij = \Pr(Y_j = i) = \begin{cases} \dfrac{1}{1 + \sum\limits_{m=2} \exp(x_j \beta_m)}, if \ \mathrm{i} = 1 \end{cases} \qquad (1)$$

$$Pij = \Pr\left(Y_j = i\right) = \begin{cases} \dfrac{\exp\left(x_j \beta_i\right)}{1 + \sum_{m=2}^{k} \exp\left(x_j \beta_m\right)}, if \ \mathrm{i} > 1 \end{cases} \tag{2}$$

k=# of categorical outcomes

x_j= row vector of observed values of the independent variables for the jth observation

β_m=coefficient vector for outcome m

i=i$^{\text{th}}$ outcome

For each wave (1998, 2000, and 2002) a multinomial logistic regression model was computed. Multinomial logistic regression is based on maximum likelihood procedures which means this method attempts to estimate the regression coefficients that are most likely to model the observed data. The results of each model were interpreted by comparing the null or baseline model to the model with covariates to specifically examine the change in the -2 log likelihood from the null/baseline model and the model with covariates, predicted group membership, and the pseudo R^2. The reference category for all analyses is informal only caregiving.

The -2 log likelihood was examined first. The likelihood values range from 0 to positive infinity. A model with a -2 log likelihood (minus twice the log of the likelihood ratio) of 0 indicates a good model. The difference between the null model and the model with covariates will also be examined to determine how much error was reduced when adding covariates to the model. This will indicate how much the model improved and how much error was reduced by the variables included in each Andersen-Aday Model domain (predisposing, enabling, and need). Significance of the -2 log likelihood ratio between the null and the model with covariates were determined with the chi-square statistic. A significant chi-square test resulting in a *p* value less than .05 indicates whether the model improved with the addition of covariates (Pampel, 2000).

Multinomial logistic regression predicts the probabilities of a respondent answering in one of the four caregiving categories (formal use, informal, mixed, or no caregiving). The predicted group membership describes how accurate the model was when classifying respondents. Further examination of predicted group membership was used to determine the percentage of respondents that were correctly classified. This will give an idea of how well the model is able to predict group membership.

Several measures of the pseudo R^2 were calculated as one method of determining the goodness of fit of the multinomial regression models. A pseudo R^2 is an approximation, similar to linear regression, of the amount of variance accounted for in the logistic regression model based on log likelihoods (Tabachnick & Fidell, 2001). Typically, the pseudo R^2 is not reported since other methods described above describe goodnesss of fit. The pseudo R^2 shows the reduction of the model error of the null model and the model with the predictor variables (Tabachnick & Fidell, 2001).

Statistics for each independent variable included in the model were evaluated. The statistics evaluated for each covariate include: unstandarized regression coefficients, standard error, the Wald statistic, odds ratio [Exp(B)], and the 95% confidence interval.

1) The unstandarized regression coefficient (B) describes the effect the independent variables have on the dependent variable (caregiving status).

2) The standard error (S.E.) is the SE of the unstandarized regression coefficient (B). The SE of the odds ratio will also be presented.

3) The Wald statistic measures of the significance for B and represents whether or not each variable is a significant predictor and illustrates the significance of each variable in its ability to contribute to the model.

4) The odds ratio for each independent variable describes the change in the odds of being in a category when the predictor variable increases by 1 unit. The odds ratio describes the increase or decrease of the odds of being in one of the three caregiving categories with informal caregiving as the reference category.

5) The 95 percent confidence interval was computed for each odds ratio.

The Hierarchical Entry Strategy

The hierarchical entry strategy for each of the Andersen-Aday domains for the cross-sectional analyses is summarized in Table 15. Each domain (predisposing, enabling, and need) will be entered in sequence. Each domain corresponds to variables identified earlier in this chapter. The results of each step/block will be interpreted by examining the -2 log likelihood, the overall significance of the model indicated by χ^2, and the pseudo R^2. Additionally, the beta and odds ratio at each wave attributed to each Andersen-Aday Model domain are examined.

Table 16: Hierarchical Entry Strategy for Cross-sectional Analyses

Step/Block	Domain	Predictor Variables Added to Model at this Step	Interpretation of Results at Each Step
1	Predisposing	AGE, GENDER, MARITAL, EDUCATION, RACE	Significance of initial -2 log likelihood, overall significance of the model indicated by the χ^2, and the pseudo R2. Additionally significant B indicated by the Wald statistic, and Exp(B) at each wave attributable to predisposing variables were examined.
2	Enabling	LTC, TOTAL WEALTH , CH10MILE, RESCHILD, MCD	Change of initial -2 log likelihood, overall significance of the model indicated by the χ^2, and the pseudo R2. Additionally significant B indicated by the Wald statistic, and Exp(B) at each wave attributable to addition of enabling variables were examined.
3	Need	ADL_COUNT, IADL_COUNT, INCONT, MEMORY	Change of initial -2 log likelihood, overall significance of the model indicated by the χ^2, and the pseudo R2. Additionally significant B indicated by the Wald statistic, and Exp(B) at each wave attributable to addition of need variables were examined.

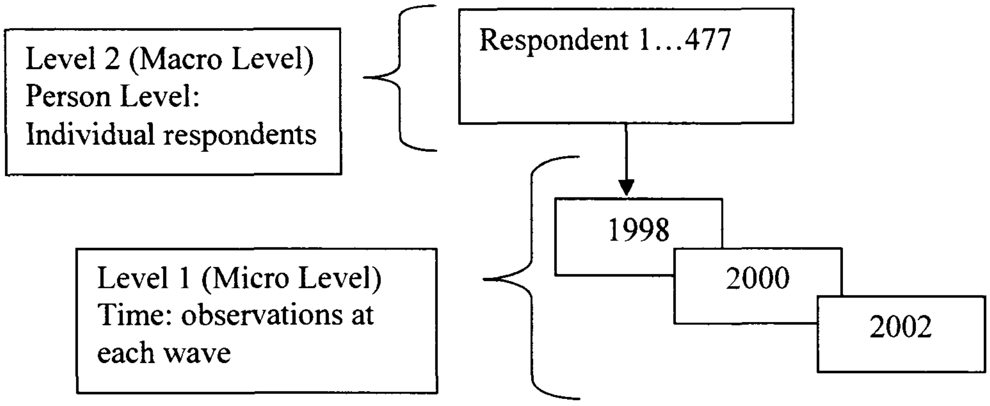
2B: Longitudinal Prediction of Caregiving Source

Question 2B: To what extent do the Andersen-Aday Model domains (predisposing, enabling, and need) act as longitudinal predictors of change in caregiving type over time?

Although the original purpose of the study was to evaluate the balance between caregiving types longitudinally among stroke survivors, the present analyses were constrained by limitations in the data, primarily small sample sizes and the limited number of transitions in caregiving type waves. Only 33% of the entire sample transitioned during the study period, creating only a small sample to evaluate the concept of change. This sample does not provide enough transitions to use a multi-level model to determine whether the Andersen-Aday Model domains predict changes in caregiving status. Because of these limitations the original research question was changed. The new question looks at how the Andersen-Aday Model domains affect caregiving across waves, holding time constant, using a clustered multinomial logistic regression analysis (mlogit with the cluster command in Stata) (StataCorp, 2005b) to obtain robust standard errors to examine the longitudinal relationships between the categorical (unordered) dependent variable, predictor variables, and time in this study. Clustered analyses adjust for the dependency (intragroup correlation) between participants over time in the logistic regression model as a result of the three repeated measures on the same participants. This procedure is a type of multilevel modeling, which is used in health services research due to the nested/clustered nature of many health-related problems (Muramatsu & Campbell, 2002; Zhu et al., 2006).

This type of data essentially has a two-level structure; the respondents are nested within the three observations (1998, 2000, and 2002). Level 1 (micro level) represents time and level 2 (macro level) represents individual respondents at each wave of the study period (Figure 3) (Twisk, 2003).

Figure 3: Two-level Structure



The repeated measures of the study participants at equal intervals (years) are a hierarchical or clustered structure that inherently creates correlated data issues. Since the responses between years are from the same person, one would expect that the data are not independent. There are several ways to handle this correlated data structure such as multilevel modeling (also known as hierarchical modeling, mixed models, or random coefficient models). Repeated Measures ANOVA is also commonly used in longitudinal analyses, but cannot accommodate a categorical dependent variable. The dependency between observations can be accounted for by adjusting for the correlation among individual respondents across the waves of the study using a cluster function available as a command in Stata (Stansbury et al., 2005). In binary or continuous models this adjustment is usually obtained by including a random effect term in the model (Hosmer & Lemeshow, 2000). The cluster option for multinomial logistic regression was chosen in this instance even though this adjustment for correlated data with a categorical (unordered) dependent variable is not documented well in the literature (Williams, 2000). The cluster function provides easy to interpret results while still accounting for the dependency between time periods, but does not include a random effect term. The data in this study have only three clusters representing the waves (1998, 2000, and 2002) during the period of interest in this study. Multilevel models are more efficient when dealing with an unbalanced data set. Although a multilevel model can handle unbalanced data more efficiently, clustering using Huber-White standard errors was chosen in this situation as the most efficient and elegant model to handle the correlated responses in this longitudinal data.

The focus of this part of the analyses was to delineate the association between time and the outcome and predictor variables in this study. In order to analyze these longitudinal relationships, the data were transformed into a person-period (long data) format. The multinomial logistic regression analyses were completed in Stata version 9 (StataCorp, 2005b).

This analysis technique utilizes the Huber-White sandwich estimator to obtain the robust standard errors. The Huber-White sandwich estimator provides a distribution free estimate of the variance of the regression coefficient. This estimate adjusts the standard errors to account for the dependency within groups (Carlin, Wolfe, Coffey, & Patton, 1999). The sandwich estimator provides estimates the variance of $\hat{\beta}$ by approximating the covariance matrix and then including a correction factor based on the observed data. The general specification of the Huber-White sandwich estimator is as follows:

$$\left(\frac{1}{\sum N_{i=1} x_i^2}\right) \sum_{i=1}^{N} x_i \left(Y_i - \hat{\beta} x_i\right)\left(Y_i - \hat{\beta} x_i\right) x_i \left(\frac{1}{\sum N_{i=1} x_i^2}\right) \qquad (3)$$

The sandwich estimator will also provide an estimate of the covariance matrix to model the actual covariance of the clusters (years) (Agresti, 2002). The standard errors resulting from this analysis are robust to model assumptions and result in accurate standard errors (Carlin et al., 1999; Fitzmaurice, Laird, & Ware, 2004).

The result of these analyses are examined using the same criterion that was utilized for the cross-sectional models with the except of using McFaddens R^2 which is a type of pseudo R^2 that is a transformed likelihood ratio statistic to act as an R^2 (Tabachnick & Fidell, 2001). Table 17 presents the hierarchical entry strategy that was utilized to enter the Andersen-Aday Model predictors in this regression model. Predictors with $p<.05$ were considered significant.

Table 17: Hierarchical Entry Strategy for Longitudinal Analyses

Step/Block	Andersen Domain Entered	Predictor Variables Added to Model at this Step	Interpretation of Results at Each Step
1	Predisposing	AGE GENDER MARITAL EDU RACE	Significance of Exp(B), standard error of the regression coefficient, log likelihood at each wave attributable to predisposing variables.
2	Enabling	CH10MILE RESCHILD TOTAL WEALTH	Significance of Exp(B), standard error of the regression coefficient, log likelihood at each wave attributable to significant predisposing variables and enabling variables.
3	Need	ADLCOUNT IADLCOUNT INCONT MEMORY	Significance of Exp(B), standard error of the regression coefficient, log likelihood at each wave attributable to significant predisposing, enabling, and need variables.

Research Question 3

To explore possible differences between non-Hispanic Whites and minority (African Americans and Hispanics) stroke survivors in terms of the predictive role of the specific Andersen-Aday Model domains (predisposing, enabling, and need) that influence caregiving choices, sub-group analyses was undertaken to answer this research question. Previous analyses to answer research question two (2A and 2B) were replicated to determine if the models differ by race/ethnicity. Specifically, bivariate and multivariate procedures were utilized to examine differences between these groups.

Bivariate, cross-sectional analyses were performed at each wave (1998, 2000, and 2002). Descriptive analyses were performed on all predisposing, enabling, and need variables in the Andersen-Aday Model domains as well as the dependent variable, caregiving type for the three waves. Specific attention was paid to the relationship between race/ethnicity and the Andersen-Aday Model domains and caregiving type. Bivariate descriptive statistics were examined to assess relationships between the predictor variables in each domain and dependent variables 1998 (CAREADL98), 2000 (CAREADL00), and 2002 (CAREADL02) at each wave. Bivariate tests and measures of strength of relationships were selected as appropriate for the level of measurement of the variables under consideration.

Multivariate analyses were conducted to examine the relationship between race/ethnicity in terms of the Andersen-Aday Model domains and whether race/ethnicity was a predictor of caregiving type. To test the Andersen-Aday Model, separate multinomial logistic regressions were conducted to obtain contrasts of odds ratios with informal caregiving as the reference category in order to examine the differences between White and African American stroke survivors. At each wave (1998, 2000, and 2002) cross- sectional analysis was performed to determine if the Andersen-Aday Model domains determined the probability of the stroke survivor receiving care in one of the mutually exclusive caregiving categories. The same hierarchical entry strategy was used to answer question 2A and 2B for each of these domains for the cross-sectional analyses are summarized in Table 16 and Table 17.

Lastly, the separate multinomial logistic regression analyses were performed and interpreted to illustrate the differences in race/ethnicity and caregiving type, and time. In all analyses, at each step/block, variables corresponding to the Andersen-Aday Model domains were entered into the model to examine the contribution of time and the "between subjects" and "within subjects" associations. The same hierarchical entry strategy was employed that was described earlier in this chapter.

Statistical Power Analysis

Estimates of statistical power were computed for this study using SamplePower 2.0, which is a product developed by SPSS to calculate power estimates for the multinomial logistic regression (SPSS, 2000). Statistical power for logistic regression models take into consideration the sample size and number of events per covariate (Hosmer & Lemeshow, 2000).

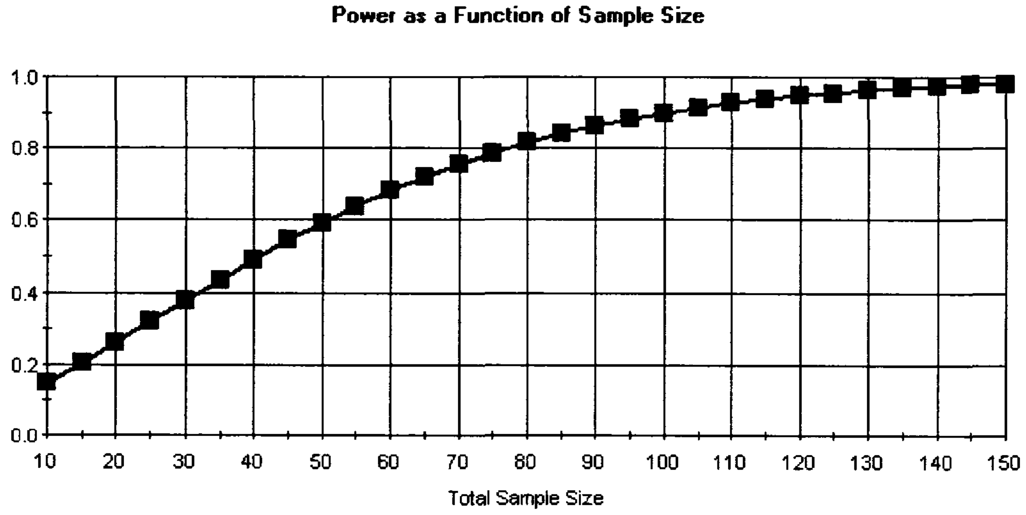
SamplePower 2.0 requires the user to select the significance level, event rate, and proportion of respondents in each category (informal only, formal only, mixed, and no caregiving). For the analyses predicting caregiving at each wave (1998, 2000, 2002), alpha was set at .05, 2-tailed test, and the corresponding event rates are presented in Table 18. Event rates are based upon the actual percentage of respondents in each caregiving category. For example in 1998, 24 percent of respondents reported receiving informal only caregiving which equates to an event rate of .24 for the power analysis. Results of this analysis indicate that the number of cases available for analyses at each time period (N = 477, 346, and 264), respectively yield power to detect statistically significant effect 100 percent of the time, rejecting the null hypothesis that the event rates between the four groups are identical. The power for the three waves is 1.0. The minimum number of participants required for a power of .80 is n=78, 67, 73 for each wave (1998, 2000, and 2002) of the study, respectively. The sample available in the HRS/AHEAD data exceeds this requirement.

Table 18: Statistical Power Analysis Calculated by SamplePower 2.0

Wave (Year)	Category	Event Rate	Power
1998 (n=477)	Informal Only	.24	1.0
	Formal Only	.11	
	Mixed	.07	
	No Caregiving	.58	
2000 (n=346)	Informal Only	.21	1.0
	Formal Only	.10	
	Mixed	.09	
	No Caregiving	.60	
2002 (n=264)	Informal Only	.24	1.0
	Formal Only	.11	
	Mixed	.06	
	No Caregiving	.60	

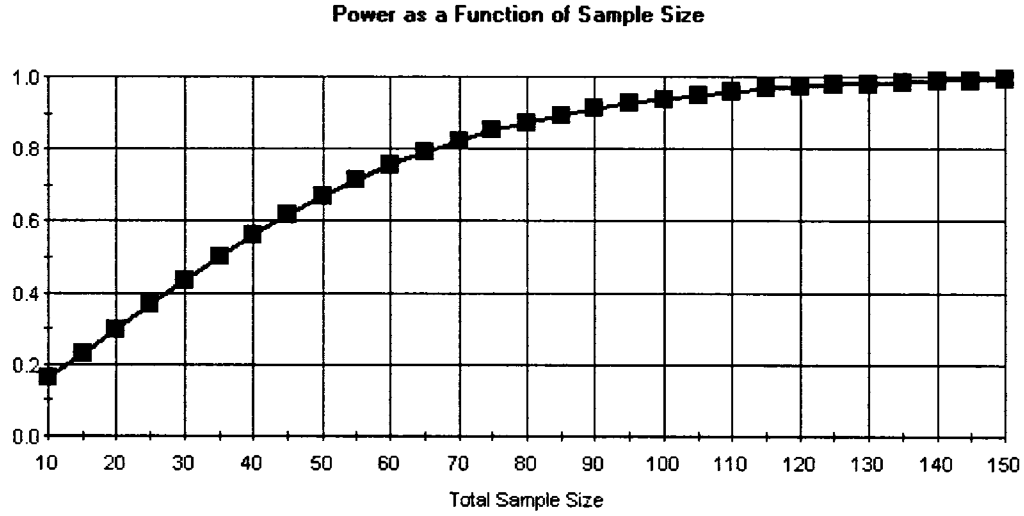
Figures 4 through 6 present a graphical display of the power at each wave. In 1998, Figure 4 presents the total sample size needed to reach a corresponding level of power. As the sample reaches 150 participants, the power reaches 1.0.

Figure 4: Sample Size Required in 1998



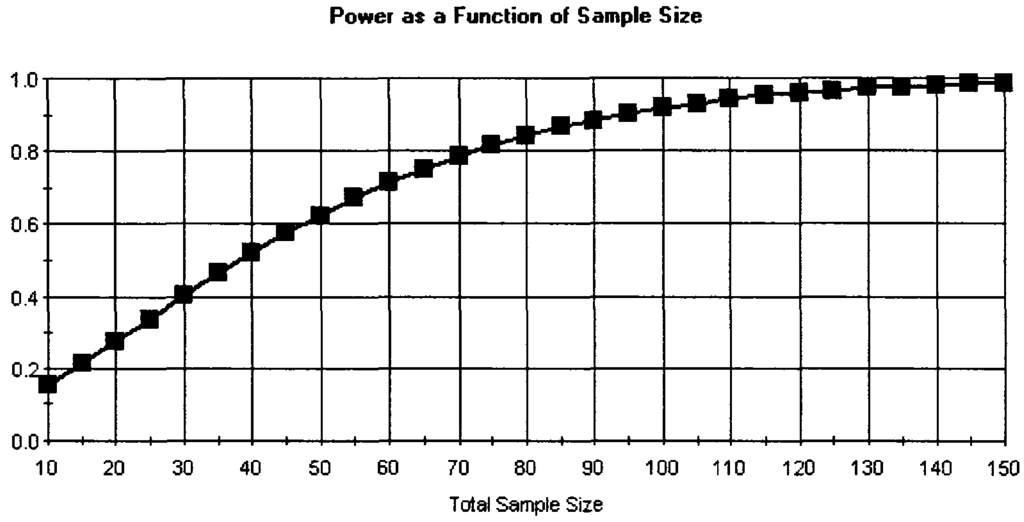
Similar to the previous wave, the sample size required in 2000, presented in Figure 5, also shows the power reaching 1.0 as the sample size reaches 150 participants.

Figure 5: Sample Size Required in 2000



Similar to the previous two waves, the sample size required in 2002, presented in Figure 6, also shows the power reaching 1.0 as the sample size reaches 150 participants.

Figure 6: Sample Size Required in 2002



Estimation of power for longitudinal (correlated data) analyses is more complex as the outcome variables are correlated with (and will share variance) with initial values of these variables. Conventional power calculators have not been created to estimate power for a categorical (unordered) study that contains correlated data such as this longitudinal study. Cross-sectional power calculations use a closed-form expression to compute statistical power (Fitzmaurice et al., 2004). These expressions cannot be used for this more complicated calculation. This calculation also becomes more complicated due to the non-linear link function (mlogit) and the dependence between responses over time (Fitzmaurice et al., 2004). Existing power calculators will accommodate continuous or dichotomous predictor variables, but not an unordered categorical variable. It is acknowledged that sample size and power should be evaluated looking at both level 1 and level 2 effects (Cohen et al., 2003). Since these estimates cannot be obtained through conventional methods, the models are examined to ensure the estimates from these models are within a reasonable range and examine the overall fit of the longitudinal model.

CHAPTER IV

Results

Bivariate Analysis

Research Question 1

What are the characteristics of stroke survivors at 3 points in time post-stroke (up to 6 years) in terms of: utilization of formal and informal caregiving services and predisposing, enabling, and need variables?

Caregiving Status

Caregiving status is described in Table 19 and Figure 7. In all waves, the majority of respondents received no caregiving (58.3%, 60.1%, 59.5%), followed by informal caregiving (24.3%, 21.1%, 23.5%), formal caregiving (10.5%, 9.5%, 11%), and mixed (6.9%, 9.2%, 6.1%).

Figure 7: Caregiving Status at Each Wave

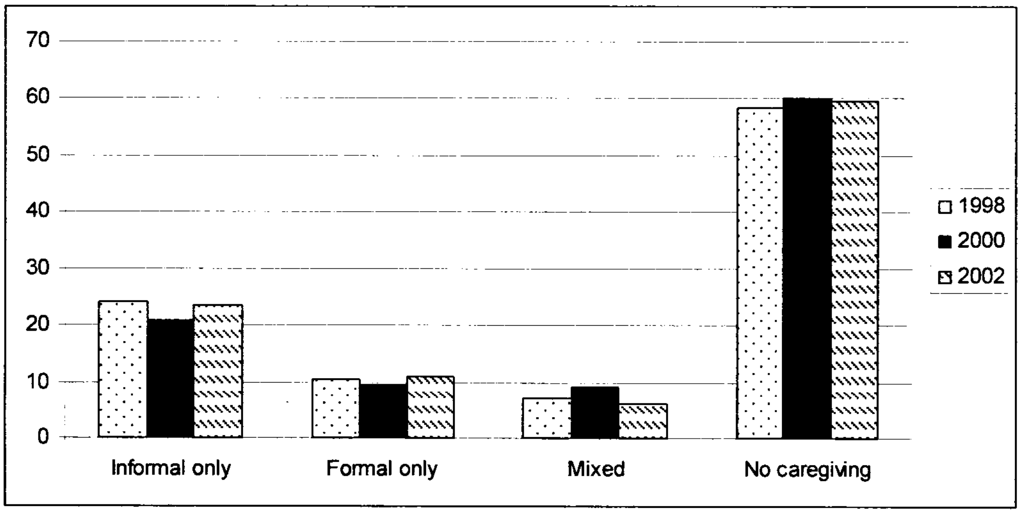


Table 19: Caregiving Status 1998, 2000, 2002

	1998		2000		2002	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Informal	116	24.3	73	21.1	62	23.5
Formal	50	10.5	33	9.5	29	11.0
Mixed	33	6.9	32	9.2	16	6.1
No caregiving	278	58.3	208	60.1	157	59.5
Total	477	100.0%	346	100.0%	264	100.0%

The percentage of respondents that used each type of care is presented in Table 19. Over the three waves, the percentage of respondents that continued to use each type of care is described in Table 20. Between 1998 and 2000, 62.9% continued to use informal only caregiving in 2000 and 53.4% continued to use informal only caregiving by 2002.

Table 20: Percentage of Respondents Using Type of Care at Each Transition

	1998-2000	2000-2002	1998-2002
	%	%	%
Informal	62.9%	53.4%	53.4%
Formal	66.0%	87.9%	58.0%
Mixed	74.8%	56.5%	48.5%
No Caregiving	74.8%	75.5%	56.5%

Across the three waves, 33% of respondents changed the source of caregiving between 1998 and 2002 (see Table 21). Twenty-eight percent changed between 1998 and 2000 and 28% changed between 2000 and 2002.

Table 21: Caregiving Transitions Between 1998-2002

	ADL Transition 1998 to 2000		ADL Transition 2000 to 2002		ADL Transition 1998 to 2002	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
No transition - Informal only	38	11.0	28	10.9	28	10.6
No transition - Formal only	17	4.9	10	3.9	9	3.4
No transition - Mixed	8	2.3	6	2.3	4	1.5
No Transition - No caregivers	186	53.8	139	54.1	136	51.5
Informal to Formal	5	1.4	9	3.5	6	2.3
Informal to Mixed	13	3.8	3	1.2	5	1.9
Informal to No Caregivers	19	5.5	12	4.7	19	7.2
Formal to Informal	3	0.9	2	0.8	3	1.1
Formal to Mixed	6	1.7	2	0.8	2	0.8
Formal to No Caregivers	1	0.3	2	0.8	1	0.4
Mixed to Informal Only	3	0.9	6	2.3	2	0.8
Mixed to Formal Only	3	0.9	4	1.6	1	0.4
Mixed to No Caregivers	2	0.6	0	0.0	1	0.4
No Caregivers to Informal Only	29	8.4	24	9.3	29	11.0
No Caregivers to Formal Only	8	2.3	6	2.3	13	4.9
No Caregivers to Mixed	5	1.4	4	1.6	5	1.9
Total	346	100.0	257	100.0	264	100.0
Known Dead	108		82		190	
Lost to Follow Up	23		17		23	

Domain 1: Predisposing Characteristics

The predisposing characteristics included demographics (age, gender, race, and education) and each of these was analyzed for a bivariate relationship with caregiving status. Respondents receiving any form of caregiving were older than those that did not receive any caregiving ($p<.001$). A closer examination of age indicated that older respondents in the AHEAD cohort were more likely to use formal and mixed care ($p<.001$). At baseline (1998), more female respondents utilized formal or mixed caregiving compared to men ($p=.047$). However, the relationship between gender and caregiving status was not statistically significant in the next two waves (2000 and 2002). Respondents that were unmarried consistently utilized more formal caregiving across the three waves than married respondents.

Age

Age is measured as a continuous variable which indicated the age of the respondent at each wave. The age of stroke survivors ranged from 43 years to 101 years old. Stroke survivors who utilized formal and mixed caregiving were older than those who used informal and no caregiving. A one-way ANOVA was calculated comparing the average age among the four caregiving status categories: formal, informal, mixed, and no caregiving. A significant effect was found [1988 ($F(3)=15.343, p=.000$; 2000 ($F(3)=9.110, p=.000$; 2002 ($F(3)=9.257, p=.000$)].

Table 22: Age by Caregiving Status

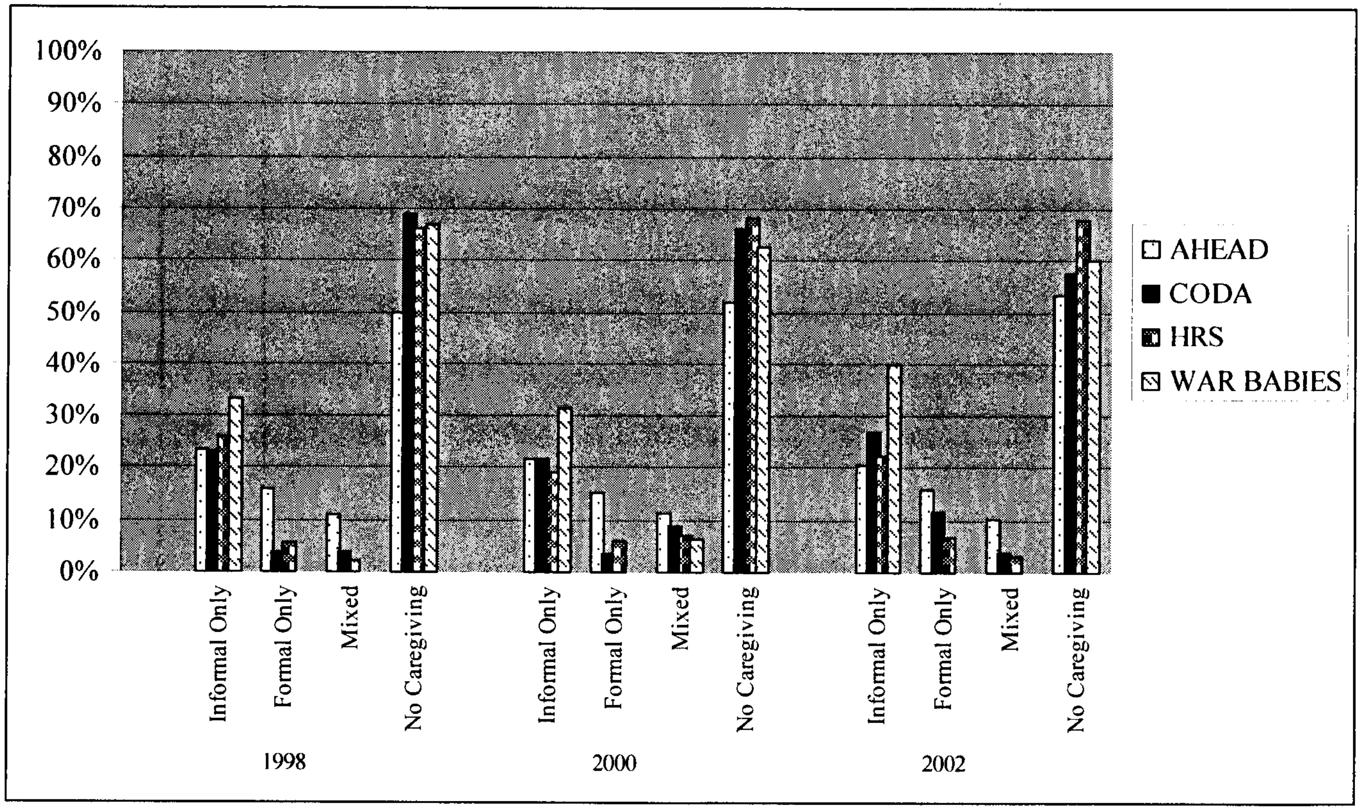
	1998		2000		2002	
	Mean	sd	Mean	sd	Mean	sd
Informal only	73.3	12.2	73.5	10.7	73.4	11.0
Formal only	80.9	9.6	81.6	10.3	82.4	8.7
Mixed	80.4	8.2	75.5	11.0	80.7	7.5
No caregiving	71.9	10.0	72.1	9.9	73.2	9.7

The distribution of caregiving status and age was also examined by cohort of the study sample. In the sample of stroke survivors four age cohorts exist: AHEAD, HRS, CODA, and War Babies. Table 23 and Figure 8 show that in 1998 there was a significant relationship between caregiving status and birth cohort (chi-square (9) = 34.039, *p*=.000). Consistently in the three waves, the oldest cohort (AHEAD) used a higher percentage of formal care when compared to the younger age cohorts.

Table 23: Cohort by Caregiving Status

	1998					2000					2002				
	n	Informal Only	Formal Only	Mixed	No Caregiving	n	Informal Only	Formal Only	Mixed	No Caregiving	n	Informal Only	Formal Only	Mixed	No Caregiving
AHEAD	246	23.2%	15.9%	11.0%	50.0%	158	21.5%	15.2%	11.4%	51.9%	107	20.6%	15.9%	10.3%	53.3%
CODA	74	23.0%	4.1%	4.1%	68.9%	56	21.4%	3.6%	8.9%	66.1%	52	26.9%	11.5%	3.8%	57.7%
HRS	139	25.9%	5.8%	2.2%	66.2%	116	19.0%	6.0%	6.9%	68.1%	90	22.2%	6.7%	3.3%	67.8%
WAR BABIES	18	33.3%	0.0%	0.0%	66.7%	16	31.3%	0.0%	6.3%	62.5%	15	40.0%	0.0%	0.0%	60.0%

Figure 8: Cohort by Caregiving Status



Gender

Table 24 presents caregiving status by gender. At baseline, there was a significant relationship between caregiving status and gender (chi-square (3) = 7.93, p=.047). Males were significantly less likely to receive caregiving (62.7%) than females (54.6%). Female stroke survivors were more likely to receive formal (11.5% versus 8.2%) or mixed care (9.6% versus 3.7%) than males. However, this relationship was not statistically significant in 2000 and 2002.

Table 24: Caregiving Status by Gender

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	p
1998	Male (n=217)	24.4%	8.2%	3.7%	62.7%	7.93	3	.047
	Female (n=260)	24.2%	11.5%	9.6%	54.6%			
2000	Male (n=158)	22.2%	8.9%	8.2%	60.8%	.640	3	.887
	Female (n=188)	20.2%	10.1%	10.1%	59.6%			
2002	Male (n=113)	21.2%	9.7%	6.2%	62.8%	1.226	3	.747
	Female (n=144)	25.0%	12.5%	5.6%	56.9%			

Educational Attainment

Level of educational attainment was not significantly related to caregiving status in any of the three waves (see Table 25).

Table 25: Caregiving Status by Educational Attainment

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	p
1998	No formal – Grade 11 (n=220)	28.2%	10.5%	9.1%	52.3%	15.89	9	.069
	High School Graduate (n=142)	19.0%	14.1%	5.6%	61.3%			
	Some College (n=64)	26.6%	1.6%	4.7%	67.2%			
	College Graduate – Post College (n=47)	19.1%	12.8%	4.3%	63.8%			
2000	No formal – Grade 11 (n=165)	21.8%	8.5%	10.9%	58.8%	7.033	9	.634
	High School Graduate (n=102)	17.6%	13.7%	9.8%	58.8%			
	Some College (n=43)	20.9%	7.0%	7.0%	65.1%			
	College Graduate – Post College (n=35)	28.6%	5.7%	2.9%	62.9%			
2002	No formal – Grade 11 (n=117)	26.5%	9.4%	5.1%	59.0%	9.228	9	.411
	High School Graduate (n=81)	18.5%	16.0%	6.2%	59.3%			
	Some College (n=35)	28.6%	0%	8.6%	62.9%			
	College Graduate – Post College (n=31)	19.4%	16.1%	6.5%	58.1%			

Ethnicity

In 1998 and 2000 there was not a significant relationship between caregiving status and ethnicity (see Table 26). However, in 2002 there was a significant association between caregiving status and ethnicity. White stroke survivors were more likely than African American stroke survivors to receive formal care (12.6% versus 4.2%), while African American respondents were more likely than white respondents to receive informal care (37.5% versus 20.5%).

Table 26: Caregiving Status by Ethnicity

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	White & Other (n=383)	22.5%	10.4%	7.0%	60.1%	3.045	3	.385
	African American (n=91)	30.8%	11.0%	6.6%	51.6%			
2000	White & Other(n=280)	20.4%	10.0%	9.3%	60.4%	.505	3	.918
	African American (n=64)	23.4%	7.8%	9.4%	59.4%			
2002	White & Other (n=215)	20.5%	12.6%	5.6%	61.4%	8.684	3	.034
	African American (n=48)	37.5%	4.2%	8.3%	50.0%			

Domain 2: Enabling Characteristics

The enabling characteristics were resources that assist in obtaining health services. Enabling characteristics included were: total wealth, long-term care insurance, marital status, children within ten miles, co-resident children, and Medicaid.

Respondents who reported using formal care reported a lower median income than those who reported using informal, mixed sources, or no caregiving. Respondents with co-resident children reported more informal caregiving than those who did not have children in the household. The presence of co-resident children was significant across the three waves, while having children within ten miles of the care receiver was not significantly related to caregiving. Medicaid coverage was statistically significantly related to use of formal and mixed caregiving consistently across all three waves.

Total Wealth

Table 27 presents caregiving status by total wealth category. In all waves a significant association was found. Stroke survivors with a total wealth less than $37,000 were more likely than those in higher wealth categories to receive any form of caregiving (formal, informal, and mixed caregiving). Consistent with this finding, stroke survivors with a total wealth greater than $139,001 were more likely to report no caregiving. For example in 1998 among respondents who were in the lowest total category, 17.5% received formal care as compared to 4.3% of respondents in the highest total wealth category. These patterns were consistent in each caregiving category and throughout the three waves of this study.

Table 27: Total Wealth Categorized

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
	Less than 37,999 (n=211)	28.4%	17.5%	10.0%	44.1%			
1998	38,000 - 139,000 (n=126)	26.2%	5.6%	4.0%	64.3%	42.672	6	.000
	139,001 or greater (n=140)	16.4%	4.3%	5.0%	74.3%			
	Less than 37,999 (n=143)	24.5%	14.7%	12.6%	48.3%			
2000	38,000 - 139,000 (n=89)	19.1%	10.1%	4.5%	66.3%	20.792	6	.002
	139,001 or greater (n=114)	18.4%	2.6%	8.8%	70.2%			
	Less than 37,999 (n=116)	31.9%	17.2%	6.9%	44.0%			
2002	38,000 - 139,000 (n=66)	21.2%	3.0%	7.6%	68.2%	25.329	6	.000
	139,001 or greater (n=82)	13.4%	8.5%	3.7%	74.4%			

Long-Term Care Insurance

Few respondents (7.8%, n=36) reported having long-term care (LTC) insurance in any of the three waves. There was not a significant relationship between caregiving status and LTC insurance (see Table 28). In 2000, 7.1% (n=17) had LTC insurance and in 2002, 7.3% (n=19) had LTC insurance. However, due to the small number of respondents having LTC insurance this could reflect a lack of power.

Table 28: Long-Term Care Insurance by Caregiving Status

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	No LTC Insurance (n=425)	24.9%	10.6%	7.3%	57.2%	2.233	3	.525
	Has LTC Insurance (n=36)	19.4%	5.6%	5.6%	69.4%			
2000	No LTC Insurance (n=316)	21.8%	9.2%	8.9%	60.1%	4.446	3	.217
	Has LTC Insurance (n=24)	8.3%	4.2%	16.7%	70.8%			
2002	No LTC Insurance (n=240)	23.8%	11.3%	5.8%	59.2%	2.818	3	.421
	Has LTC Insurance (n=19)	21.1%	0.0%	5.3%	73.7%			

Marital Status

Table 29 shows a significant relationship between caregiving and marital status at each wave. The percentage of unmarried stroke survivors who received formal (18.9%) and mixed (8.8%) caregiving was much greater than among married stroke survivors (2.1% versus 5.1%), respectively. Differences by marital status were much larger in the formal and mixed categories, than in the informal caregiving category. Throughout the three waves, approximately half of the sample remained unmarried, and these relationships were consistent at all years.

Table 29: Caregiving Status by Marital Status

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	p
1998	Not Married (n=238)	20.6%	18.9%	8.8%	51.7%	40.50	3	.000
	Married (n=237)	28.3%	2.1%	5.1%	64.6%			
2000	Not Married (n=176)	20.5%	15.9%	8.0%	55.7%	17.137	3	.001
	Married (n=170)	21.8%	2.9%	10.6%	64.7%			
2002	Not Married (n=147)	25.9%	16.3%	6.1%	51.7%	12.775	3	.005
	Married (n=117)	20.5%	4.3%	6.0%	69.2%			

Proximity to Children

Table 30 presents the crosstabulation of caregiving status and children within 10 miles. No significant relationship between caregiving status and children within 10 miles was found in any wave.

Table 30: Proximity to Children

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	No Children Within 10 Miles (n=207)	22.2%	11.6%	6.8%	59.4%	1.378	3	.711
	Has Children Within 10 Miles (n=263)	26.6%	9.9%	6.8%	56.7%			
2000	No Children Within 10 Miles (n=144)	23.6%	11.1%	6.9%	58.3%	2.363	3	.501
	Has Children Within 10 Miles (n=174)	19.0%	9.8%	10.9%	60.3%			
2002	No Children Within 10 Miles (n=114)	22.8%	13.2%	6.1%	57.9%	1.266	3	.737
	Has Children Within 10 Miles (n=147)	24.5%	8.8%	6.1%	60.5%			

Resident Children

Table 31 presents caregiving status by presence of resident children. In all waves a significant relationship was found. Stroke survivors with resident children in the household consistently received more informal caregiving than those who reported no resident children (37.5% versus 19.5%). Conversely those with no resident children reported more formal caregiving than those who reported resident children (13.2% versus 3.1%). These findings were consistent in all of the waves.

Table 31: Resident Children

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	No Resident Children (n=349)	19.5%	13.2%	8.0%	59.3%	24.06	3	.000
	Has Resident Children (n=128)	37.5%	3.1%	3.9%	55.5%			
2000	No Resident Children (n=263)	19.0%	12.2%	9.9%	58.9%	10.948	3	.012
	Has Resident Children (n=83)	27.7%	1.2%	7.2%	63.9%			
2002	No Resident Children (n=189)	18.5%	14.3%	5.8%	61.4%	13.242	3	.004
	Has Resident Children (n=68)	36.8%	2.9%	5.9%	54.4%			

Medicaid Coverage Since Previous Wave

Table 32 presents the crosstabulation of caregiving status by Medicaid where a significant association was found in all three waves. Stroke survivors who reported no Medicaid coverage in 1998 received less formal care than stroke survivors who reported Medicaid coverage (5.8% versus 26.4%). A similar result was found for mixed caregiving. This finding is reasonable since the primary payer of community and institutional long-term care is Medicaid. Stroke survivors who reported Medicaid coverage consistently reported higher percentages of receiving any of the three types of caregiving than stroke survivors who reported no Medicaid coverage throughout the three waves of this study.

Table 32: Medicaid Coverage

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	No Medicaid Coverage Since Previous Wave (n=364)	24.5%	5.8%	4.7%	65.1%	59.39	3	.000
	Medicaid Coverage Since Previous Wave (n=110)	24.5%	26.4%	14.5%	34.5%			
2000	No Medicaid Coverage Since Previous Wave (n=262)	21.0%	4.2%	5.7%	69.1%	56.111	3	.000
	Medicaid Coverage Since Previous Wave (n=80)	22.5%	23.8%	21.3%	32.5%			
2002	No Medicaid Coverage Since Previous Wave (n=205)	20.5%	5.9%	4.9%	68.8%	39.982	3	.000
	Medicaid Coverage Since Previous Wave (n=56)	33.9%	28.6%	10.7%	26.8%			

Interaction between Medicaid and Total Wealth

Table 33 presents the interaction between Medicaid and total wealth and the relationship to caregiving source. This variable was created because the use of Medicaid and total wealth were highly correlated. The relationship between Medicaid status and total wealth was tested using Spearman's correlation and were found to have a moderate positive correlation (r=.461; p=.001). An indicator variable was created to explain the close relationship between Medicaid use and total wealth during each wave.

A chi-square test of independence was conducted to determine the relationship between reported caregiving status and the new variable representing Medicaid status and Total Wealth. A significant result was found at each wave of the study. However, due to small cell sizes the results should be interpreted with caution. At baseline, among respondents who reported a total wealth less than $37,999 and did have Medicaid, 7.9% received formal care, while respondents who reported a total wealth less than $37,999 and had Medicaid, 29.8% received formal care. Across the three waves, stroke survivors who reported a total wealth less than $37,000 and had Medicaid consistently reported receiving formal or mixed caregiving as compared to the other total wealth/Medicaid categories. These results are not surprising since Medicaid is the primary payer of long-term care and in order to qualify for this program the recipient must have a low level of income/assets. These results were similar in the 2000 and 2002 waves.

Table 33: Interaction between Medicaid and Total Wealth

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	<37,999, No Medicaid (n=114)	32.5%	7.9%	5.3%	54.4%	82.952	12	.000
	38,000-139,000, No Medicaid (n=115)	26.1%	5.2%	3.5%	65.2%			
	>139,000, No Medicaid (n=135)	16.3%	4.4%	5.2%	74.1%			
	<37,999, Medicaid (n=94)	24.5%	29.8%	16.0%	29.8%			
	>38,000, Medicaid (n=16)	25.0%	6.3%	6.3%	62.5%			
2000	<37,999, No Medicaid (n=74)	25.7%	2.7%	6.8%	64.9%	67.133	12	.000
	38,000-139,000, No Medicaid (n=78)	19.2 %	7.7%	2.6%	70.5%			
	>139,000, No Medicaid (n=110)	19.1%	2.7%	7.3%	70.9%			
	<37,999, Medicaid (n=67)	23.9%	26.9%	19.4%	29.9%			
	>38,000, Medicaid (n=13)	15.4%	7.7%	30.8%	46.2%			
2002	<37,999, No Medicaid (n=62)	30.6%	8.1%	3.2%	58.1%	51.039	12	.000
	38,000-139,000, No Medicaid (n=62)	19.4%	1.6%	8.1%	71.0%			
	>139,000, No Medicaid (n=81)	13.6%	7.4%	3.7%	75.3%			
	<37,999, Medicaid (n=51)	33.3%	37.5%	11.8%	27.5%			
	>38,000, Medicaid (n=5)	40.0%	40.0%	0%	20.0%			

Domain 3: Need Characteristics

The need domain included characteristics of the stroke survivor such as activities of daily living, instrumental activities of daily living, incontinence, and presence of a memory related disease. All of the variables included in the need domain were statistically significant across the three waves (1998, 2000, and 2002) in this study. In 2000 and 2002 more respondents became incontinent and required more care in all three categories (formal, informal, and mixed). The relationship between incontinence and caregiving status was statistically significant. Respondents who indicated no caregiving (93.5%) were more likely to also report not having a memory related disease. In 2000, there was a smaller difference between caregiving status and presence of a memory related disease, but the difference was still significant (p=.013).

Activities of Daily Living

A Kruskal-Wallis test was conducted comparing the average number of activities of daily living (ADL) between the four caregiving categories. In all three waves (1998, 2000, and 2002) a significant result was found [1998 (H(3)=286.678, p=.000)], [2000 (H(3)=240.069, p=.000)], [2002 (H(3)=157.163, p=.000). Across the three waves respondents who reported a higher median number ADL utilized formal and mixed caregiving (see Table 34). Since the caregiving categories were based upon needing assistance with ADL activities, a significant result was expected.

Table 34: Caregiving Status by Number of ADL functions with assistance

	1998		2000		2002	
	Median	IQR	Median	IQR	Median	IQR
Informal	4.0	4.0	3.0	3.0	3.0	3.0
Formal	5.5	3.0	5.0	2.5	4.0	4.0
Mixed	6.0	2.0	5.0	3.0	5.0	2.8
No Caregiving	0.0	1.0	0.0	1.0	0.0	1.0

Instrumental Activities of Daily Living

A Kruskal-Wallis test was conducted comparing the average number of instrumental activities of daily living (IADL) between the four caregiving categories. In all three waves (1998, 2000, and 2002) a significant result was found [1998 (H(3)=153.141, p=.000)], [2000 (H(3)=103.730, p=.000)], [2002 (H(3)=110.351, p=.000) (see Table 35). Across the three waves respondents who reported a higher median number IADL utilized formal and mixed caregiving.

Table 35: Caregiving Status by Number of IADL functions with assistance

	1998		2000		2002	
	Median	IQR	Median	IQR	Median	IQR
Informal	2.5	2.0	2.0	2.0	3.0	3.0
Formal	3.0	2.0	2.0	2.0	2.0	2.0
Mixed	4.0	1.5	3.0	2.0	3.0	2.0
No Caregiving	0.0	1.0	0.0	1.0	0.0	1.0

Urinary Incontinence

Table 36 presents the crosstabulation of caregiving status and urinary incontinence (UI). Among respondents who were not UI 6.6% received formal care, while respondents who were UI 14.9% received formal care. Additionally, stroke survivors who were UI (12.2%) received a higher percentage of mixed caregiving as compared to stroke survivors who were not UI (3.5%). Stroke survivors who were not UI (71.7%) were also more likely to receive no caregiving than stroke survivors who were UI (38.8%). Similar results were found in 2000 and 2002.

Table 36: Urinary Incontinence

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	Not Incontinent (n=286)	18.2%	6.6%	3.5%	71.7%	52.756	3	.000
	Incontinent (n=188)	34.0%	14.9%	12.2%	38.8%			
2000	Not Incontinent (n=204)	18.1%	4.4%	5.4%	72.1%	34.138	3	.000
	Incontinent (n=140)	25.0%	16.4%	15.0%	43.6%			
2002	Not Incontinent (n=169)	21.9%	7.1%	3.6%	67.5%	13.265	3	.004
	Incontinent (n=91)	27.5%	14.3%	11.0%	47.3%			

Memory Related Disease

Table 37 presents the results of the crosstabulation of caregiving status and presence of a memory related disease. A significant relationship was found between caregiving status and presence of a memory related disease at each wave. Stroke survivors who reported a memory related disease received more care in all categories than stroke survivors without a memory related disease. Stroke survivors who reported no memory related disease were more likely than stroke survivors with a memory related disease to receive no caregiving (64.4% versus 25%). Similar results were found in 2000 and 2002.

Table 37: Memory Related Disease

Year	Category	Informal Only	Formal Only	Mixed	No Caregiving	χ^2	df	P
1998	No memory related disease (n=404)	20.5%	8.7%	6.4%	64.4%	40.223	3	.000
	Memory related disease (n=72)	44.4%	20.8%	9.7%	25.0%			
2000	No memory related disease (n=404)	18.9%	7.7%	6.3%	67.0%	10.838	3	.013
	Memory related disease (n=72)	10.5%	10.5%	26.3%	52.6%			
2002	No memory related disease (n=404)	21.5%	9.0%	4.5%	65.0%	18.783	3	.000
	Memory related disease (n=404)	36.7%	20.0%	16.7%	26.7%			

Summary of Bivariate Results

Across the three waves, approximately 40% of stroke survivors required caregiving either informally, formally, or mixed sources of care. Over the three waves of the study, 56% of respondents did not use any caregiving services. Caregiving status remained fairly consistent across the three waves of this study with 33% of respondents transitioning to a different source care between 1998 and 2002. The 33% of respondents who transitioned to different sources of care did not fit any clear pattern. A summary of the bivariate analyses is presented in Table 38 in terms of the Andersen-Aday Model domains.

Table 38: Summary of Significant Bivariate Relationships

Andersen-Aday Domain	Variable	1998	2000	2002
Predisposing	Birth Year	p=.000	-	-
	Gender	p=.047	NS	NS
	Marital Status	p=.000	p=.001	p=.005
	Education	NS	NS	NS
	Ethnicity	NS	NS	p=.001
Enabling	Total Wealth	p=.000	p=.000	p=.000
	LTC Insurance	NS	NS	NS
	Proximity to Children	NS	NS	NS
	Resident Children	p=.000	p=.012	p=.004
	Medicaid	p=.000	p=.000	p=.000
	Total Wealth and Medicaid	p=.000	p=.000	p=.000
Need	ADL	p=.000	p=.000	p=.000
	IADL	p=.000	p=.000	p=.000
	Incontinence	p=.000	p=.000	p=.004
	Memory Disease	p=.000	p=.013	p=.000

In the bivariate analyses all predictors except educational attainment, race, long-term care (LTC) insurance and proximity to children were significantly related to caregiving status in the first wave (1998) of the study. At the second wave (2000), in addition to the predictors that were not significant in 1998, gender was not related to caregiving status. In 2002, the findings remained consistent with the exception of race, which was significantly related to caregiving status.

Multivariate Analyses

Research Question 2

To what extent does the Andersen-Aday Model (predisposing, enabling, and need variables) explain the receipt of formal and informal caregiving both cross-sectionally and longitudinally in terms of: 1) The relative amount of variance accounted for in caregiving use explained by the different Andersen model domains, and 2) Identification of specific variables in each Andersen model domain which are more likely to be associated with caregiving type?

Multinomial Logistic Regression

To answer the cross-sectional component of the second research question, multinomial logistic regression was applied to the variables of interest corresponding to the Andersen-Aday Model domains in each wave of this study (1998, 2000, and 2002). For each cross-sectional analyses corresponding to each wave of the study, all stroke survivors in the four caregiving categories were included in the multivariate models. Due to small sample sizes in the mixed caregiving category there were empty cells. In order to limit the number of empty cells, age was dichotomized into younger than 75 years and older than 75 years of age for the multinomial logistic regression. The empty cells did not appear to negatively influence the results for the following reasons: 1) the model is not saturated, 2) the models did not have difficulty converging, and 3) the estimates and standard errors are stable and within a reasonable range (Agresti, 1996). Overall, the models at each wave are statistically significant.

Cross-Sectional Multinomial Models

The models for each year were statistically significant at each step/block and after the inclusion of the three Andersen-Aday Model domains (predisposing, enabling, and need).

Wave I: 1998 Cross-Sectional Model

The results of the regression models for the first wave (1998) are presented in Table 40. At each step/block of the final 1998 model there was significant improvement in the -2 Log Likelihood of the full model compared to the null model. This indicates how much the model improved due to the entry of the variables included in each Andersen-Aday Model domain (predisposing, enabling, and need) (chi-square (21) =474.312, p=.000). The Nagelkerke pseudo R^2 explained the amount of variance accounted after entry of the variables in each Andersen-Aday Model domain into the model. After the inclusion of each domain there was improvement in the pseudo R^2. The Nagelkerke pseudo R^2 of the final 1998 model was .716. The predicted group membership described how accurate the model was when classifying respondents. Further examination of predicted group membership in the final 1998 model found that 75.4% of the cases were correctly classified into the correct caregiving category (see Table 39). The 1998 model was able to correctly classify 91.6% of respondents that had no caregiving, 61.2% of respondents with informal, and 64% of respondents with formal caregiving. This model did not do well in classifying respondents with mixed caregiving; only 9.1% of respondents were correctly classified. This is not surprising because the mixed category was the smallest caregiving category. Also, because it is a mixture of the two outcome categories, it is not unexpected that it was difficult to distinguish.

Table 39: Percentage Correctly Classified 1998

Category	Percent Correct
Informal	61.2%
Formal	64.0%
Mixed	9.1%
No Caregiving	91.6%
Total Correct	75.4%

Figure 9 presents a visual depiction of the number of cases that were classified in the correct category. Approximately, 25% were not classified correctly, mainly those in the mixed category.

Figure 9: Scatter Diagram of Actual and Predicted Frequencies in 1998

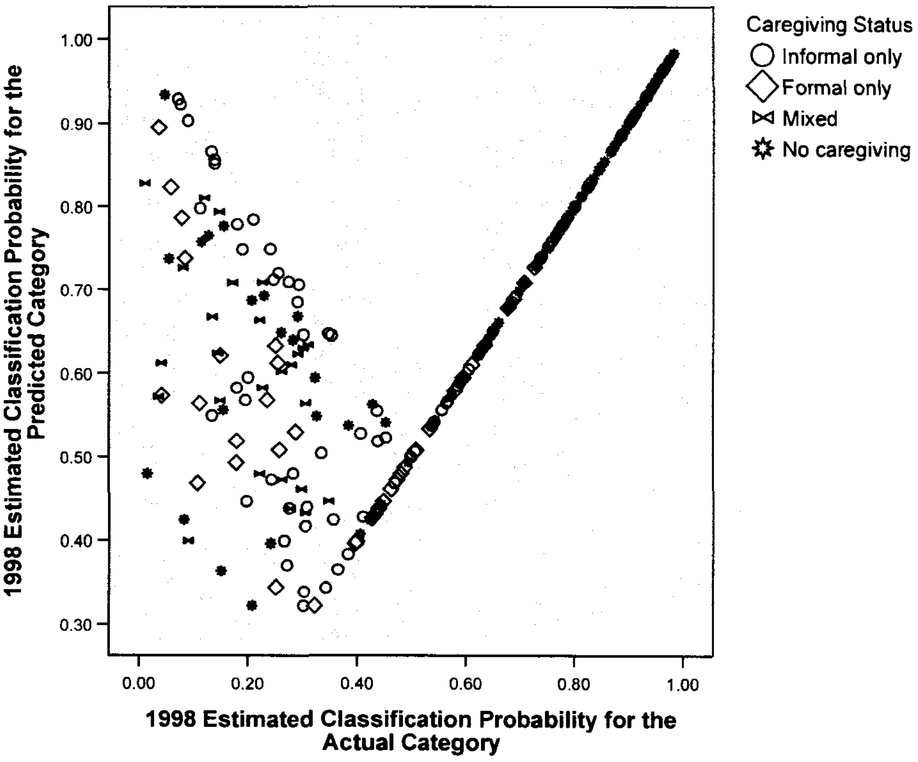


Table 40: Multinomial Logistic Regression 1998

	Domain 1	Domain 1, 2	Domain 1, 2, 3	Final Model
-2 Log Likelihood Null	187.845	526.205	965.775	937.425
-2 Log Likelihood Model	134.394	369.720	490.616	463.112
p of Model	.001	.001	.001	.001
Nagelkerke R^2	.121	.333	.721	.716
Δ in R^2	N/A	+.212	+.388	N/A
Significant Coefficients $p \leq .05$	Age Race	Age Marital Status Resident Children Poor with Medicaid Poor without Medicaid	Age Marital Status Resident Children Poor with Medicaid IADL ADL	Age Marital Status Resident Children Poor with Medicaid IADL ADL
# of cases	471	448	468	472

Significant predictors of the final 1998 wave model are presented in Table 41. In the 1998 model each construct of the Andersen-Aday Model was significantly related to the three sources of caregiving (formal, mixed, and no caregiving) with informal caregiving as the reference category.

In 1998, the only significant predictor in the predisposing domain was age of the stroke survivor. Older (75+) stroke survivors were more likely (OR=3.1) than younger stroke survivors to receive formal care as opposed to informal caregiving. Older (75+) stroke survivors were also more likely (OR=2.8) than younger stroke survivors to receive mixed caregiving as opposed to informal caregiving. The variable indicating race of the stroke survivor was no longer significantly related to caregiving source in the final 1998 model. In fact, after the entry of the enabling and need domains there was no relationship between race and caregiving source.

Significant predictors in the enabling domain included: marital status, resident children, and poor with Medicaid. Stroke survivors who had another person in the household either a spouse or resident child were less likely to receive formal, mixed, or no caregiving as opposed to informal caregiving. Specifically, married stroke survivors were less likely than unmarried stroke survivors to receive formal (OR=.102) and no caregiving (OR=.362) as opposed to informal caregiving. Similarly, stroke survivors with resident children were less likely than stroke survivors without resident to receive formal (OR=.050) and mixed care (OR=.122) as opposed to informal caregiving. Consistent with the bivariate results, stroke survivors who were poor (>38,000 total wealth) and had Medicaid were more likely than stroke survivors that were not poor and did not have Medicaid to receive formal (OR=5.2) and mixed caregiving (OR=3.3) as opposed to informal caregiving.

The variables in the need domain significantly related to caregiving status were ADL and IADL impairments. Each additional IADL impairment increased the odds of receiving mixed care by 60% as opposed to informal caregiving. Also, for each additional IADL impairment, stroke survivors were 54% less likely to receive no caregiving as opposed to informal caregiving. For each additional ADL impairment stroke survivors were 49% less likely to receive no caregiving as opposed to informal caregiving. Interestingly, neither ADL nor IADL impairments were significantly related to formal caregiving.

Table 41: 1998 Significant Predictors of Type of Caregiving [1]

	Formal Only				Mixed				No Caregiving			
	OR	**SE**	**P**	**95% CI**	**OR**	**SE**	**P**	**95% CI**	**OR**	**SE**	**P**	**95% CI**
Predisposing												
Age (75+)	3.1	1.58	0.026	1.1-8.5	2.8	1.51	0.057	.031-.562	0.827	0.42	0.574	.426-1.605
Enabling												
Poor with Medicaid[2]	5.2	2.70	0.001	1.9-14.4	3.3	1.78	0.028	3.1-33.0	0.513	0.24	0.155	.280-1.31
Poor No Medicaid[2]	0.872	0.50	0.058	.285-2.67	0.725	0.44	0.592	.223-2.35	0.605	0.24	0.203	.280-1.31
Married	0.102	0.06	0.001	.033-.318	0.503	0.26	0.181	.184-1.38	0.362	0.14	0.008	.172-.764
Has Resident Children	0.05	0.03	0.001	.014-.182	0.122	0.07	0.001	.023-.378	0.643	0.23	0.211	.322-1.28
Need												
ADL[3]	1.22	0.15	0.12	.951-1.57	1.25	0.18	0.13	.940-1.66	0.504	0.05	0.00	.411-.618
IADL[3]	1.17	0.24	0.44	.786-1.73	1.6	0.37	0.03	1.6-3.9	0.459	0.067	0.00	.344-.612

[1] Reference Category=Informal Only

[2] Reference Category=Not poor, no Medicaid

[3] Number of ADL (range 0-6) and IADL (range 0-4) impairments (high scores denote more impairment)

Wave II: 2000 Cross-Sectional Model

The results of the regression models for the second wave (2000) are presented in Table 43. At each step/block there was significant improvement in the -2 Log Likelihood of the full model compared to the null model, this indicated how much the model improved after entering the variables included in each Andersen-Aday Model domain (predisposing, enabling, and need) (chi-square (12) =253.095, p=.001). The Nagelkerke pseudo R^2 explained the amount of variance reduced after entry of the variables in each Andersen-Aday Model domain into the model. After the inclusion of each domain there were statistically significant increases in the pseudo R^2 values. The Nagelkerke pseudo R^2 of the final 2000 model was .715. The predicted group membership described how accurate the model was when classifying respondents. Further examination of predicted group membership in the final 2000 model found that 77.7% of the cases were correctly classified (see Table 42). The 2000 model was able to correctly classify 95.7% of respondents that had no caregiving, 58.9% of respondents with informal, and 60.6% of respondents with formal caregiving. This model did not correctly classify respondents with mixed caregiving. Only 21.9% of respondents were correctly classified in this category.

Table 42: Percentage Correctly Classified 2000

Category	Percent Correct
Informal	58.9%
Formal	60.6%
Mixed	21.9%
No Caregiving	95.7%
Total Correct	77.7%

Figure 10 presents a visual depiction of the number of cases that were classified in the correct category. Approximately, 23% were not classified correctly. As in the previous wave, the mixed caregiving category was not classified correctly.

Figure 10: Scatter Diagram of Actual and Predicted Frequency in 2000

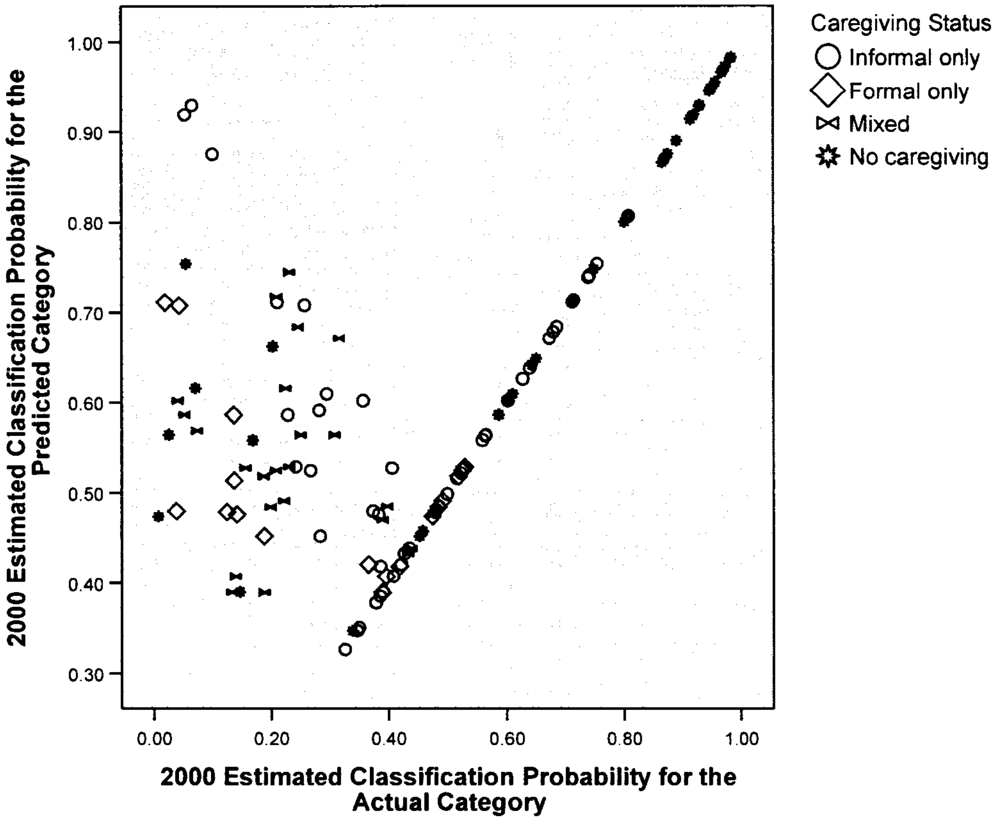


Table 43: Multinomial Logistic Regression 2000

	Domain 1	Domain 1, 2	Domain 1, 2, 3	Final Model
-2 Log Likelihood Null	145.185	296.557	561.027	598.282
-2 Log Likelihood Model	123.057	209.226	275.354	253.095
p of Model	.036	.001	.001	.001
Nagelkerke R^2	.071	.274	.715	.715
Δ in R^2	N/A	+.203	+.441	N/A
Significant Coefficients $p \leq .05$	Age	Age Marital Status Poor with Medicaid Resident Children	Marital Status Resident Children ADL IADL	Marital Status Resident Children ADL IADL
# of cases	343	314	301	345

Significant predictors for the final model for the second wave (2000) are presented in Table 44. In the 2000 final model only the enabling and need domains were significantly related to caregiving status.

In the final 2000 model none of the predisposing characteristics were significantly related to caregiving status.

The significant predictors in the enabling domain were marital status and resident children. Similar to the previous wave, stroke survivors who reported another person in the household (either spouse or child) were less likely than stroke survivors with someone else in the household to receive formal caregiving as opposed to informal caregiving. Married stroke survivors were less likely than unmarried stroke survivors to receive formal care (OR=.168) as opposed to informal care. Additionally, stroke survivors who had resident children (OR=.057) were less likely than stroke survivors who did not have resident children to receive formal as opposed to informal caregiving.

The factors in the need domain that were significantly related to no caregiving were ADL and IADL impairments. In this wave, for each additional ADL and IADL impairment stroke survivors were 80% and 40%, respectively less likely to receive no caregiving as opposed to informal caregiving. Similar to the previous wave (1998) ADL and IADL impairments were not significantly related to formal only caregiving and IADL impairments that were related to mixed caregiving in the previous were no longer significant.

Table 44: 2000 Significant Predictors of Type of Caregiving [1]

	Formal Only				Mixed				No Caregiving			
	OR	**SE**	**P**	**95% CI**	**OR**	**SE**	**P**	**95% CI**	**OR**	**SE**	**P**	**95% CI**
Predisposing												
None												
Enabling												
Married	0.168	0.029	0.001	.056-.505	1.300	0.576	0.549	.547-3.11	0.498	0.228	0.128	.203-1.22
Has Resident Children	0.057	0.061	0.007	.007-.462	0.463	0.250	0.154	.161-1.33	0.814	0.361	0.681	.306-2.17
Need												
ADL[2]	1.3	0.224	0.163	.906-1.80	1.2	0.197	0.192	.900-1.69	0.2	0.045	0.001	.161-.341
IADL[2]	1.1	0.237	0.606	.737-1.70	1.230	0.239	0.296	.837-1.80	0.6	0.122	0.015	.422-.910

[1] Reference Category=Informal Only

[2] Number of ADL (range 0-6) and IADL (range 0-4) impairments (high scores denote more impairment)

Wave II: 2002 Cross-Sectional Model

The results of the 2002 regression models for the third wave are presented in Table 46. At each step/block there was significant improvement in the -2 Log Likelihood of the full model compared to the null model, this indicates how much the model improved and how much error was reduced by the variables included in each Andersen-Aday Model domains (predisposing, enabling, and need) (chi-square (21)=224.867, p=.001). The Nagelkerke pseudo R^2 explained the amount of variance reduced after entry of the variables in each Andersen-Aday Model domain into the model. After the inclusion of each domain there was improvement in the pseudo R^2. The Nagelkerke pseudo R^2 of the final 2002 model was .669. The predicted group membership described how accurate the model was when classifying respondents. Further examination of predicted group membership in the final 2002 model found that 78.3% of the cases were correctly classified (see Table 45). The 2002 model was able to correctly classify 93.4% of respondents that had no caregiving. This model was able to correctly classify respondents with informal (66.1%). This model was not able to correctly classify respondents with formal caregiving (57.1%) or mixed caregiving (13.3%) better than chance.

Table 45: Percentage Correctly Classified 2002

Category	Percent Correct
Informal	66.1%
Formal	57.1%
Mixed	13.3%
No Caregiving	93.4%
Total Correct	78.3%

Figure 11 presents a visual depiction of the number of cases that were classified in the correct category. Approximately, 22% were not classified correctly.

Figure 11: Scatter Diagram of Actual and Predicted Frequencies 2002

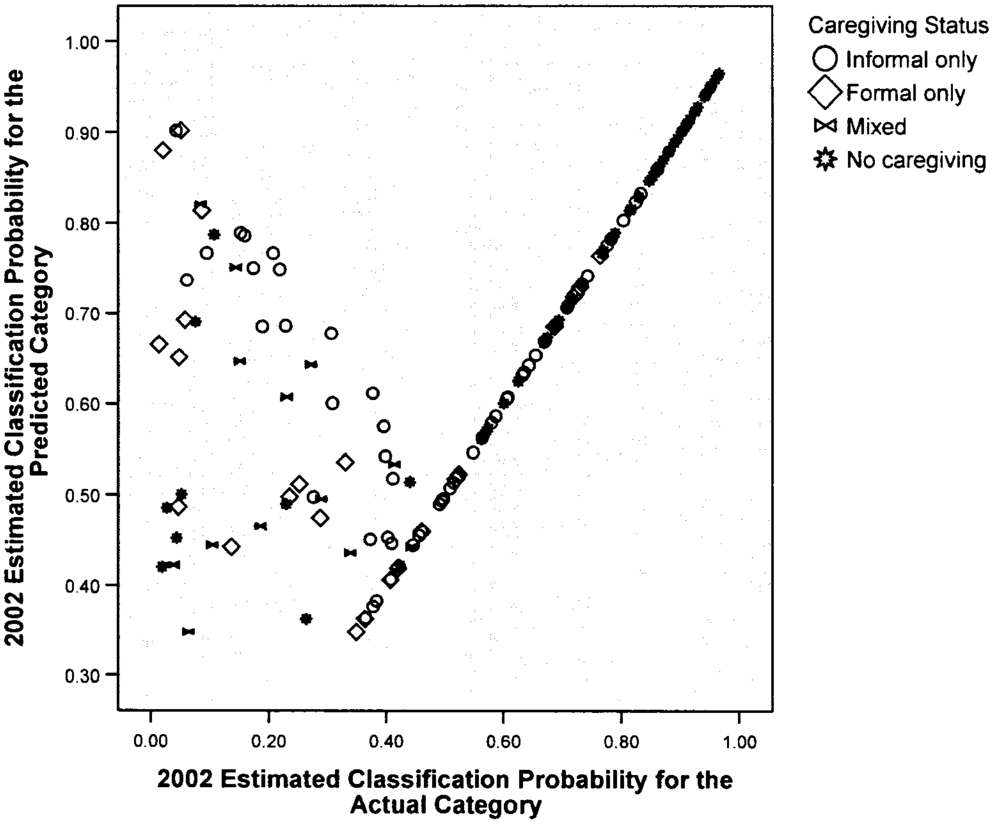


Table 46: Multinomial Logistic Regression 2002

	Domain 1	Domain 1, 2	Domain 1, 2, 3	Full Model
-2 Log Likelihood Null	127.399	252.266	473.685	505.653
-2 Log Likelihood Model	104.216	182.429	270.321	280.786
p of Model	.026	.001	.001	.001
Nagelkerke R^2	.099	.276	.661	.669
Δ in R^2	N/A	+.177	+.385	N/A
Significant Coefficients $p \leq .05$	Race	Race	Race	Race
		Marital Status	Marital Status	Marital Status
		Resident Children	Resident Children	Resident Children
		Poor No Medicaid	ADL	ADL
		Poor with Medicaid	IADL	IADL
# of cases	255	227	238	253

Significant predictors in the final 2002 model are presented in Table 47. In the 2002 model each construct of the Andersen-Aday Model was significantly related to the three sources of caregiving with informal caregiving as the reference category. Significant predictors included: race, marital status, resident children, ADL, and IADL.

The only predisposing factor significantly related to formal caregiving, race, was not significant in the previous two waves. African American stroke survivors (OR=.114) were less likely than white stroke survivors to receive formal care as opposed to informal caregiving.

The only enabling factors that were significantly related to caregiving was marital status and resident children. Married stroke survivors were less likely than unmarried stroke survivors to receive formal care (OR=.217) as opposed to informal caregiving. Stroke survivors who had resident children (OR=.064) were less likely than stroke survivors without resident children to receive formal caregiving as opposed to informal caregiving. Unlike previous waves the total wealth/Medicaid variable was not associated with caregiving which may indicate the presence of potential caregivers was much more predictive of use of caregiving among stroke survivors.

The only factors in the need domain that continued to be significantly related to no caregiving were ADL and IADL impairments. For each additional IADL and ADL impairment stroke survivors were 39% and 62%, respectively less likely to receive no caregiving as opposed to informal caregiving. ADL and IADL impairments were not significantly related to formal or mixed caregiving.

Table 47: 2002 Significant Predictors of Type of Caregiving[1]

	Formal Only				Mixed				No Caregiving			
	OR	SE	P	95% CI	OR	SE	P	95% CI	OR	SE	P	95% CI
Predisposing												
African American	0.114	0.100	0.013	.020-.631	1.23	0.963	0.794	.264-5.70	0.401	0.222	0.087	.141-1.14
Enabling												
Married	0.217	0.135	0.014	.064-.738	1.00	0.377	0.998	.271-3.67	0.647	0.296	0.342	.264-1.59
Has Resident Children	0.064	0.055	0.001	.012-.340	0.44	0.334	0.280	.101-1.94	0.462	0.229	0.119	.175-1.22
Poor with Medicaid	2.70	1.78	0.132	.742-9.79	0.80	0.599	0.764	.183-3.48	0.574	0.284	0.384	.164-2.00
Poor No Medicaid	0.837	0.599	0.804	.206-3.41	0.40	0.380	0.334	.062-2.57	0.677	0.335	0.453	.245-1.87
Need												
ADL[2]	1.13	0.205	0.514	.790-1.60	1.35	0.302	0.178	.872-2.10	0.385	0.069	0.001	.272-.547
IADL[2]	0.916	0.234	0.732	.556-1.51	1.36	0.456	0.365	.702-2.61	0.607	0.115	0.008	.419-.879

[1] Reference Category=Informal Only

[2] Number of ADL (range 0-6) and IADL (range 0-4) impairments (high scores denote more impairment)

Summary of Cross-Sectional Results

A summary of the results of the final cross-sectional models at each wave are summarized in Table 48. Overall the cross-sectional models correctly classified over 70 percent of the respondents in the correct caregiving category. Respondents with no caregiving were classified correctly over 90 percent of the time across the three waves of the study followed by formal caregiving where 60 percent were correctly classified in the first wave (1998). These models could not correctly classify mixed caregiving.

The results of the cross-sectional models indicated that all three domains in the Andersen-Aday Model were predictive of formal caregiving in 1998. However, in the second wave (2000) fewer enabling and need variables were significant and no variables in the predisposing domain were significant. In 2002 all three domains were significantly related to caregiving status. The results indicated that stroke survivors who were white, unmarried, and did not have resident children are more likely to receive formal than informal caregiving. The no caregiving category was significantly related to the need domain. As expected the results indicated that those who reported less impairment were more likely to receive no caregiving than informal caregiving. Across the three waves consistent predictors of caregiving status included ADL and IADL impairments, marital status, and resident children. Variables such as race, age, and total wealth/Medicaid were not consistently significant across the three waves.

Table 48: Summary of Statistically Significant Predictors in Final Models

Model Construct		1998				2000				2002			
		R^2	Formal	Mixed	No Caregiving	R^2	Formal	Mixed	No Caregiving	R^2	Formal	Mixed	No Caregiving
Predisposing	Age	.121	X	X	NS	.071	NS	NS	NS	.099	NS	X	NS
	Gender		NS	NS	NS		NS	NS	NS		NS	NS	NS
	Race		NS	NS	NS		X	NS	NS		NS	NS	NS
	Education		NS	NS	NS		NS	NS	NS		NS	NS	NS
	Martial Status		X	NS	X		X	NS	NS		X	NS	NS
Enabling	Poor with Medicaid	.212	NS	X	X	.274	NS	NS	NS	.177	NS	NS	NS
	Children 10 Mile		NS	NS	NS		NS	NS	NS		NS	NS	NS
	Resident Children		X	X	NS		X	NS	NS		X	NS	NS
Need	ADL	.388	NS	NS	X	.441	NS	NS	X	.385	NS	NS	X
	IADL		NS	X	X		NS	NS	X		NS	NS	X
	Incontinence		NS	NS	NS		NS	NS	NS		NS	NS	NS
	Memory		NS	NS	NS		NS	NS	NS		NS	NS	NS

Longitudinal Models

To answer the longitudinal component of the second research question (Question 2b), a clustered multinomial logistic regression model with robust standard errors was applied to the variables of interest corresponding to the Andersen-Aday Model domains in each wave of this study (1998, 2000, and 2002). All of the models at each step/block converged and improved as factors in each domain were added to the model.

Although the original purpose of the study was to evaluate the balance between caregiving types longitudinally among stroke survivors, the present analyses were constrained by limitations in the data, primarily small sample sizes and the limited number of transitions in caregiving type waves. Since this sample does not provide enough transitions to use a multi-level model to determine whether the Andersen-Aday Model domains predict changes in caregiving status the research question was changed to look at caregiving across all three waves holding time constant. In order to adjust the variances for the correlated nature of the observations the cluster option for multinomial logistic regression was chosen in this instance even though this adjustment for correlated data with a categorical (unordered) dependent variable is not documented well in the literature (Williams, 2000). The results of this analysis were similar, but have more power than the cross-sectional models and controled for the dependency/correlation between observations.

In the final model, which included the significant predictors in all three domains, type of caregiving (formal, mixed, and no caregiving) compared to informal only caregiving were statistically related to at least one predictor in each of the Andersen-Aday Model domains (see Table 49). The regression coefficients were transformed into odds ratios to describe the relationship between caregiving status and the Andersen-Aday Model domains. Results were reported for each caregiving type: formal, mixed, and no caregiving with informal only as the reference category. Significance of individual variables in the model were evaluated with the z-value and corresponding p-value (95% CI). Predictors with $p<=.05$ were considered significant.

Table 49 presents a summary of the results of the final longitudinal model. Chi-square statistics to describe model fit were not available in the longitudinal models. This may be due to the small sample size, the limited number of clusters (years), or unbalanced data. However, the following model fit statistics were reported below: log likelihood, McFaddens R^2, and percentage correctly classified. McFaddens R^2 is a type of pseudo R^2 that is a transformed likelihood ratio statistic to act as an R^2 (Tabachnick & Fidell, 2001). Overall, in the longitudinal models there were improvement in the -2 log likelihood and the percentage of respondents correctly classified in the model were high in the informal and formal categories.

Table 49: Summary of Model Fit of Longitudinal Models

	Domain 1 Clustered SE	Domain 1, 2 Clustered SE	Domain 1, 2, 3 Clustered SE	Final Model Clustered SE
-2 Log Likelihood Null	-1160.017	-1103.012	-1033.068	-1137.504
-2 Log Likelihood Model	-1100.783	-937.125	-571.724	-573.663
p of Model	--	--	--	--
McFaddens R^2	.05	.15	.447	.447
Δ in R^2	N/A	+.10	+.297	N/A
Significant Coefficients $p \leq .05$	Age Race Gender Education	Age Race Marital Status Gender Education Poor without Medicaid Poor with Medicaid Resident Children	Age Race Marital Status Gender Education Poor without Medicaid Poor with Medicaid Resident Children Incontinence Memory ADL count IADL count	Age Race Education Marital Status Poor No Medicaid Poor with Medicaid Resident Children Incontinence Memory ADL count IADL count

Table 50 presents how well the final model was classified. Three comparisons were made to evaluate how well the clustered multinomial logistic regression model classified the respondents. The three comparisons were: informal and formal; informal and mixed; and formal and mixed. In the first comparison, 80% of informal caregiving was correctly classified and 41% of the formal caregiving was classified. In the second comparison (informal and mixed), 78% of the informal caregiving was correctly classified and only 44% of mixed caregiving was classified correctly in the model. In the last comparison (formal and mixed), 70% of the formal was correctly classified and only 35% of the mixed caregiving was correctly classified. Overall, the final longitudinal model was able to correctly classify both informal and formal caregiving, but consistently failed to correctly classify mixed caregiving.

Table 50: Classification of Longitudinal Model

Comparison	Caregiving Status	Classification			
		Classified Correctly	Ambiguous	Not Classified Correctly	Total
1	Informal	80.08%	17.13%	2.79%	100.00%
	Formal	41.07%	26.79%	32.14%	100.00%
2	Informal	78.49%	20.72%	0.80%	100.00%
	Mixed	44.44%	48.15%	7.41%	100.00%
3	Formal	69.64%	24.11%	6.25%	100.00%
	Mixed	34.57%	33.33%	32.10%	100.00%

The results from the first step/block in the multinomial logistic regression are presented in Table 51. At the first step/block the predisposing characteristics were entered into the model. There was improvement in the -2 Log Likelihood of the full model compared to the null model.

At the first step/block the predisposing characteristics were significantly related to the three types of caregiving. Results from this step suggest that when time was held constant age, race, gender, and education were significant predictors of caregiving status. Older (75+) stroke survivors were more likely than younger stroke survivors to receive formal (OR=1.09) and mixed (OR=1.05) as opposed to informal caregiving. African American stroke survivors were less likely than white stroke survivors to receive no caregiving (OR=.576) as opposed to informal caregiving. Female stroke survivors were less likely than male stroke survivors to receive formal caregiving (OR=.93) as opposed to informal caregiving. Lastly, stroke survivors who had less than a high school education were more likely than stroke survivors with more than a high school education to receive formal (OR=2.02) as opposed to informal caregiving.

Table 51: Longitudinal Multinomial Logistic Regression – Predisposing[1]

	Formal Only vs Informal Only			Mixed vs Informal Only			No Caregiving vs Informal Only		
Variable	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI
Age	1.09**	0.007	1.08-1.11	1.05**	0.022	1.01-1.10	0.985**	0.001	.980-.990
African American	0.88	0.257	.496-1.56	0.956	0.099	.780-1.17	.576**	0.081	.436-.759
Female	0.93**	0.005	.920-.940	1.31	0.347	.782-2.20	0.943	0.053	.845-1.05
Less than HS	2.02**	0.153	1.74-2.34	1.62	0.494	.887-2.94	0.995	0.103	.812-1.22

* p<=.05, **p<=.01

[1] Reference Category=Informal Only

Table 52 presents the results from the second step/block in the multinomial logistic regression. In this step only the significant predisposing variables and all of the enabling variables were included in the model. Results from this step suggest that when time was held constant age, race, gender, and education continued to be significant predictors of caregiving status once the enabling domain was entered into the model. Significant enabling variables included: marital status, poor no Medicaid, poor with Medicaid, and resident children.

In addition to the results reported in the first step, older stroke survivors were less likely than younger stroke survivors to receive no caregiving (OR=.977) as opposed to informal caregiving. All of the enabling characteristics were significantly related to all three types of caregiving except having children within ten miles of the care receiver. Results from this step suggest that holding time constant, factors such as having another person in the household and being poor with Medicaid were significantly related to receiving caregiving. Stroke survivors who were married were less likely than unmarried stroke survivors to receive formal (OR=.156) as opposed to informal caregiving. Also, stroke survivors who reported having resident children were less likely than stroke survivors without resident children to receive formal (OR=.087), mixed (OR=.352), or no caregiving (OR=.528) as opposed to informal care. Respondents who reported being poor with Medicaid were more likely than stroke survivors who were not poor and did not have Medicaid to receive formal (OR=4.26) or mixed (OR=2.56) caregiving as opposed to informal caregiving. Since the odds of receiving formal or mixed caregiving were so high it would make sense that stroke survivors who were poor and had Medicaid were less likely than stroke survivors who were not poor and did not have Medicaid to receive no caregiving (OR=.278) as opposed to informal caregiving. Interestingly, stroke survivors who were poor (<$38,000) but do not have Medicaid were less likely than stroke survivors who were not poor and did not have Medicaid to receive mixed (OR=.673) and no caregiving (OR=.532) as opposed to informal caregiving. These findings point to the fact that formal (paid) caregiving was dependent upon the care receiver having Medicaid, which is the primary payer of long-term care in the US.

Table 52: Longitudinal Multinomial Logistic Regression - Predisposing & Enabling[1]

	Formal Only vs Informal Only			Mixed vs Informal Only			No Caregiving vs Informal Only		
Variable	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI
Age	1.08**	0.009	1.07-1.10	1.06*	0.021	1.02-1.10	.977**	0.005	.968-.986
African American	0.654	0.19	.370-1.15	0.972	0.167	.695-1.36	.753*	0.096	.586-.968
Female	.466**	0.065	.353-.613	1.57	0.481	.859-2.86	0.946	0.139	.709-1.26
Less than HS	1.84**	0.161	1.56-2.19	2	0.863	.862-4.66	1.32	0.204	.972-1.79
Married	.156**	0.089	.051-.479	1.41	0.474	.729-2.72	0.697	0.186	.413-1.17
Poor no Medicaid	0.79	0.111	.600-1.04	.673**	0.076	.539-.840	.532**	0.041	.457-.619
Poor with Medicaid	4.26**	0.349	3.63-5.01	2.56**	0.487	1.77-3.72	.278**	0.045	.203-.381
Has Child 10 Miles	0.776	0.203	.465-1.30	1.02	0.211	.683-1.53	0.931	0.103	.749-1.16
Has Resident Children	.087**	0.007	.075-.101	.352*	0.135	0.683-1.53	.528**	0.064	.417-.669

* $p<=.05$, ** $p<=.01$

[1] Reference Category=Informal Only

Table 53 presents the results from the third step/block in the multinomial logistic regression. The third step/block in the model included only the significant predisposing and enabling variables and all of the need variables. Results from this step suggest that when time was held constant age, gender, education, marital status, poor no Medicaid, poor with Medicaid, resident children continued to be significant predictors of caregiving status once the need domain was entered into the model. Significant need variables included: memory, incontinence, ADL, and IADL.

At this step/block the predisposing and enabling characteristics were significantly related to the three types of caregiving. Once need variables were entered into the model several relationships between the predisposing variables and caregiving status changed. In addition to the results reported in the previous step, stroke survivors who reported being poor with no Medicaid were less likely than stroke survivors who were not poor and did not have Medicaid to receive formal caregiving (OR=.670) as opposed informal care. This finding is interesting and makes sense because stroke survivors who report being poor with Medicaid were more likely to receive formal only care (OR=3.02).

The need characteristics were significantly related to all three types of caregiving in this step/block. Results from this step/block suggest that holding time constant, stroke survivors who reported memory related disease were more likely than stroke survivors who did not report a memory related disease to receive formal (OR=1.90) as opposed to informal caregiving. Stroke survivors who reported UI were more likely than stroke survivors who did not report UI to receive no caregiving (OR=1.18) as opposed to informal caregiving. This finding is barely significant and may not provide enough information to understand the relationship between UI and caregiving status.

Additionally, this finding may point to younger and/or healthier group of stroke survivors or these stroke survivors may have been able to manage their incontinence on their own without assistance from care providers. For each additional ADL impairment stroke survivors were 23% less likely to receive mixed caregiving as opposed to informal caregiving. Moreover, for each additional ADL and IADL impairment stroke survivors were 60% and 46% less likely to receive no caregiving as opposed to informal caregiving.

Table 53: Longitudinal Multinomial Logistic Regression - Predisposing, Enabling, & Need[1]

	Formal Only vs Informal Only			Mixed vs Informal Only			No Caregiving vs Informal Only		
Variable	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI
Age	1.07**	0.004	1.06-1.08	1.05**	0.008	1.04-1.07	0.998	0.012	.974-1.02
African American	0.774	0.338	.326-1.82	0.894	0.228	.542-1.47	1.05	0.361	.538-2.06
Female	.450**	0.064	.341-.595	1.45	0.546	.693-3.04	0.884	0.137	.653-1.20
Less than HS	2.19**	0.256	1.75-2.76	1.99	0.914	.807-4.90	1.49**	0.094	1.31-1.68
Married	.092**	0.068	.021-.396	1.45	0.385	.860-2.44	.492*	0.112	.315-.767
Poor no Medicaid	.670**	0.034	.606-.740	.520**	0.094	.365-.740	.653*	0.13	.442-.963
Poor with Medicaid	3.02**	0.627	2.01-4.54	2.36**	0.58	1.46-3.82	.573*	0.109	.395-.830
Has Resident Child	.086**	0.036	.038-.197	.270*	0.173	.077-.948	.556**	0.041	.481-.643
Has memory disease	1.90**	0.113	1.70-2.14	0.906	0.464	.332-2.47	1.28	0.207	.941-1.77
Urinary Incontinence	0.999	0.393	.462-2.16	1.17	0.16	.896-1.53	1.18*	0.06	1.06-1.30
ADL[2]	1.12	0.09	.961-1.32	1.23**	0.03	1.18-1.29	.396**	0.08	.266-.589
IADL[2]	0.95	0.087	.794-1.14	1.33	0.23	.948-1.87	.540**	0.072	.416-.700

* p<=.05, **p<=.01

[1] Reference Category=Informal Only

[2] Number of ADL (range 0-6) and IADL (range 0-4) impairments (high scores denote more impairments)

Table 54 presents the results of the final clustered multinomial logistic regression model. This model included only the variables in each Andersen-Aday Model domain that were significantly associated with caregiving status in previous steps. This model excluded race, which was not significantly related to caregiving status in the previous step/block. Results were similar to the previous step and included the following significant variables: age, education, marital status, poor no Medicaid, poor with Medicaid, resident children, UI, memory related disease, ADL, and IADL. In addition to the results reported in the previous step, gender was no longer significantly related to caregiving status in the final model.

Two of the <u>predisposing</u> characteristics were significantly related to caregiving status. Results from this step suggest that holding time constant, age and education were significant predictors. Stroke survivors who were older were more likely than younger stroke survivors to receive formal (OR=1.07) and mixed (OR=1.05) caregiving when compared to informal caregiving. This relationship while statistically significant was moderate at best. A much stronger relationship was found with the second significant predisposing variable, educational attainment. Respondents who reported less than a high school education were more likely than stroke survivors with more than a high school education to receive formal (OR=2.15) and no caregiving (OR=1.51) as opposed to informal caregiving.

<u>Enabling</u> characteristics that were significantly related to all three types of caregiving in the final model included: marital status, resident children, poor no Medicaid, and poor with Medicaid. Results from this step suggest that holding time constant, the enabling variables that have continued to be significantly related to

caregiving status in previous models remained significant in this model. Stroke survivors with resident children were less likely than stroke survivors without resident children to receive formal (OR=.086), mixed (OR=.267), or no caregiving (OR=.579) as opposed to informal caregiving. Married stroke survivors were less likely than unmarried stroke survivors to receive formal (OR=.095) or no caregiving (OR=.513) as opposed to informal caregiving. As with previous models, having a spouse or child in the household may have created a situation where the care receiver was less likely than stroke survivors who do not have family in the household to receive formal or no caregiving as opposed to informal caregiving. Stroke survivors who report being poor with no Medicaid were less likely than stroke survivors who were not poor and did not have Medicaid to receive formal (OR=.654) and mixed (OR=.509) as opposed to informal caregiving. Conversely, stroke survivors who report being poor with Medicaid were more likely to receive formal (OR=2.93) and mixed (OR=2.32) as opposed to informal caregiving. Additionally, stroke survivors who reported being poor with Medicaid were less likely to receive no caregiving (OR=.572) when compared to informal caregiving. These results suggest that being poor with Medicaid provides the means to pay for long-term care.

The need characteristics were significantly related to all three types of caregiving in the final model. Results suggest that holding time constant, stroke survivors who reported a memory related disease were more likely than stroke survivors who did not report a memory related disease to receive formal (OR=1.87) as opposed to informal caregiving. Additionally, stroke survivors who reported UI were more likely than stroke survivors who did not report UI to receive no caregiving (OR=1.14) as opposed to informal caregiving. Unlike the cross-sectional models, controlling for the dependency of responses between waves revealed that memory related disease might be a factor in receiving caregiving services. Other need factors such as ADL and IADL impairments were significantly related to caregiving status. For each additional ADL impairment stroke survivors were 23% less likely to receive mixed caregiving as opposed to informal caregiving. Moreover, for each additional ADL and IADL impairment stroke survivors were 60% and 46% less likely to receive no caregiving as opposed to informal caregiving. For each additional ADL and IADL impairment stroke survivors were 60% and 46% less likely to receive no caregiving as opposed to informal caregiving.

Table 54: Longitudinal Multinomial Logistic Regression - Final Model[1]

	Formal Only vs Informal Only			Mixed vs Informal Only			No Caregiving vs Informal Only		
Variable	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI	Exp(B)	SE	95% CI
Age	1.07**	0.009	1.05-1.09	1.05**	0.005	1.04-1.06	0.998	0.014	.971-1.03
Female	0.452	0.06	.348-.587	1.47	0.515	.736-2.91	0.914	0.142	.673-1.24
Less than HS	2.15**	0.32	1.61-2.88	1.99	0.932	.798-4.98	1.51**	0.106	1.32-1.73
Married	.095*	0.073	.021-.432	1.47	0.392	.869-2.48	.513*	0.124	.319-.825
Poor no Medicaid	.654**	0.047	.569-.752	.509**	0.076	.380-.681	0.673	0.157	.426-1.06
Poor with Medicaid	2.93**	0.752	1.78-4.85	2.32**	0.471	1.56-3.46	.572*	0.12	.380-.863
Has Resident Child	0.086**	0.038	.037-.203	.267*	0.168	.078-.918	.579**	0.052	.486-.691
Urinary Incontinence	0.998	0.402	.453-2.20	1.17	0.172	.878-1.56	1.14*	0.072	1.01-1.29
Has memory disease	1.87**	0.11	1.67-2.10	0.897	0.476	.317-2.54	1.25	0.201	.909-1.71
ADL[2]	1.12	0.097	.946-1.33	1.23**	0.031	1.17-1.29	.397**	0.079	.268-.587
IADL[2]	0.958	0.077	.819-1.12	1.33	0.243	.929-1.90	.543**	0.07	.422-.699

* p<=.05, **p<=.01

[1] Reference Category=Informal Only

[2] Number of ADL (range 0-6) and IADL (range 0-4) impairments (high scores denote more impairment)

Summary of Longitudinal Results

The clustered multinomial logistic regression models which accounted for the longitudinal nature of the data provided more information about the characteristics of the stroke survivors over the study period. The results of the longitudinal models indicated that, holding time constant, there were several characteristics within the Andersen-Aday Model that may influence the type of caregiving used over time among survivors of stroke. Significant variables included age, education, marital status, wealth, and Medicaid status, resident children, urinary incontinence, memory related disease, ADL, and IADL limitations.

Results suggest that holding time constant, the predisposing variables age and education were consistently predictive of type of caregiving status. Stroke survivors who were older and reported less than a high school education were more likely to receive formal caregiving when compared to informal caregiving. Interestingly, education continued to be significant after the entry of wealth and Medicaid were entered into the model which may indicate an effect beyond that of wealth. Race was not statistically associated with caregiving status in the final model. Once the variables in the enabling domain were entered into the model, race was no longer significant. Enabling factors were strongly associated with caregiving status include marital status, poor with Medicaid, poor no Medicaid, and resident children. The need factors that were significantly associated with caregiving status include urinary incontinence, memory related disease, ADL, and IADL impairments.

Research Question 3

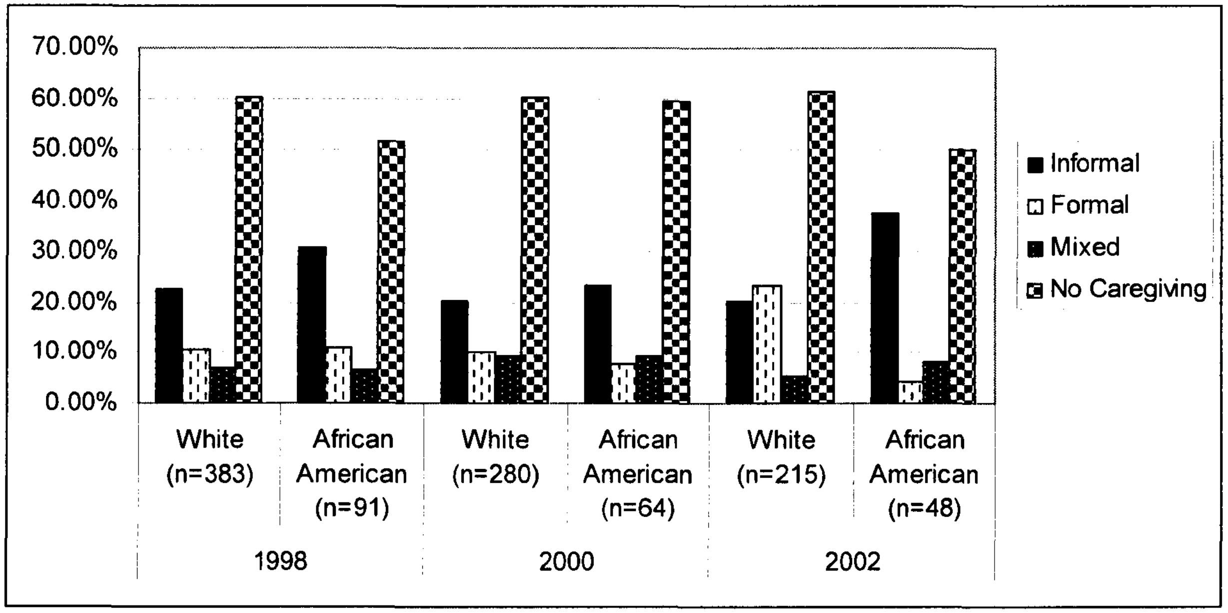
Are there differences between non-Hispanic Whites and minorities (African Americans and Hispanics) in terms of the specific Andersen-Aday Model domains (predisposing, enabling, and need) that influence utilization of formal service use and informal caregiving?

At each wave differences between non-Hispanic White and non-Hispanic Black/African American stroke survivors were examined to determine the type of caregiving utilized during the study period. Interpretation of the results of the following bivariate analyses should be used cautiously as they do not adjust for other differences that are known to exist between African American and white Americans. Table 55 presents results of the chi-square analyses comparing race and caregiving status at each wave. While the chi-square test was only significant in 2002, there were suggestive, but not significant differences in the previous two waves. The results show more African American stroke survivors used informal caregiving at each wave compared to white stroke survivors. Conversely, more white stroke survivors reported using formal care compared to African American respondents (see Figure 12).

Table 55: Caregiving Type by Race at Each Wave

		Informal	Formal	Mixed	No Caregiving	Chi-square	df	p-value
1998	White (n=383)	22.50%	10.40%	7.00%	60.10%	3.045	3	0.385
	African American (n=91)	30.80%	11.00%	6.60%	51.60%			
2000	White (n=280)	20.40%	10.00%	9.30%	60.40%	0.505	3	0.918
	African American (n=64)	23.40%	7.80%	9.40%	59.40%			
2002	White (n=215)	20.50%	23.60%	5.60%	61.40%	8.684	3	0.034
	African American (n=48)	37.50%	4.20%	8.30%	50.00%			

Figure 12: Caregiving Type by Race at Each Wave



There were also differences between White and African American stroke survivors in use of Medicaid since the last wave. The use of Medicaid was examined further because long-term care is often financed through this system and may explain use of formal (paid) services. Over the three waves, more African American stroke survivors report having had Medicaid since the previous wave (see Table 56). This finding was significant in 1998 and 2002 and reflects the overall lower wealth of African Americans in this sample.

Table 56: Use of Medicaid and Race/Ethnicity

		No Medicaid	Medicaid	Chi-square	df	p-value
1998	White (n=381)	80.10%	19.90%	12.93	1	0.001
	African American (n=90)	62.20%	37.80%			
2000	White (n=277)	78.00%	22.00%	1.234	1	0.321
	African American (n=63)	71.40%	28.60%			
2002	White (n=215)	81.20%	18.80%	5.308	1	0.03
	African American (n=47)	66.00%	34.00%			

In addition to differences in the use of Medicaid, there were significant differences in total wealth (see Table 57). More African American stroke survivors reported less than $37,999 total wealth compared to White respondents. These differences were statistically significant over the three waves.

Table 57: Total Wealth by Race/Ethnicity

		Less than $37,999	More than $38,000	Chi-square	df	p-value
1998	White (n=381)	38.40%	61.60%	26.401	1	0.000
	African American (n=90)	68.10%	31.90%			
2000	White (n=280)	34.60%	65.40%	25.054	1	0.000
	African American (n=64)	68.80%	31.30%			
2002	White (n=215)	38.10%	61.90%	14.942	1	0.000
	African American (n=48)	68.80%	31.30%			

The presence of children residing in the household also differed between white and African American stroke survivors in 1998 (see Table 58). During the first wave of this study, more African American survivors (36.3%) had resident children compared to 24% of white survivors (Chi-square=5.676 (1), p=.024). The last two waves of the study did not show any significant differences between African American and white stroke survivors in the presence of children residing in the household.

Table 58: Resident Children by Race/Ethnicity

		No Resident Children	Resident Children	Chi-square	df	p-value
1998	White (n=381)	76%	24%	5.676	1	.024
	African American (n=90)	63.7%	36.3%			
2000	White (n=280)	77.5%	22.5%	.916	1	.332
	African American (n=64)	71.9%	28.1%			
2002	White (n=215)	74.6%	25.4%	.389	1	.582
	African American (n=48)	70.2%	29.85			

The level of functioning measured by ADL and IADL impairments were only significantly different in 1998. African American stroke survivors reported significantly more ADL impairments compared to white stroke survivors. The remaining variables included in this study were not significantly different between white and African American stroke survivors.

Multivariate analyses were conducted to examine the relationship between race/ethnicity in terms of the Andersen-Aday Model domains and whether race/ethnicity is a predictor of caregiving type. To test the Andersen-Aday Model, separate multinomial logistic regression models were conducted to explore whether differences in models exist between white and African American stroke survivors. At each wave (1998, 2000, and 2002) cross-sectional analyses were performed to determine if the Andersen-Aday Model domains were associated with the stroke survivor receiving care in one of the mutually exclusive caregiving categories. Cross-sectionally, the separate sub-group analyses did not produce valid models for the African American group due to both attrition in the sample and few African American stroke survivors receiving formal or mixed caregiving services. However, in the final cross-sectional models presented earlier, being African American was not significantly related to informal caregiving in 1998, 2000, and 2002.

Separate clustered multinomial logistic regression analyses were performed to illustrate the differences in race/ethnicity and caregiving type, and holding time constant. As with the cross-sectional models, separate subgroup analyses did not produce models that would converge, meaning that Stata was unable to produce estimates of the variance components. This was due to sparse cells.

Summary of Results

Across the three waves, approximately forty percent of stroke survivors required caregiving either informally, formally, or mixed sources of care. The source of caregiving of stroke survivors did not change for the majority of respondents over time. Approximately 33% of respondents transitioned from one source of caregiving to another over the six-year period. The transitions varied considerably among the respondents and did not present any consistent pattern. A summary of the bivariate analyses and whether or not the proposed hypotheses were supported are presented in Table 59.

Table 59: Summary of Support for Bivariate Hypotheses

	Hypotheses	Supported (Yes/No)
Domain 1: Predisposing Characteristics	Older stroke survivors (>75) will be more likely than younger (<75) stroke survivors to receive formal or mixed services than informal services, and will be less likely to receive no caregiving.	Yes
	African American stroke survivors will be more likely than white stroke survivors to receive informal care, while white stroke survivors will be more likely to receive formal, mixed, or no caregiving.	Yes (2002 only)
	Male stroke survivors will be more likely than female stroke survivors to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes (1998 only)
	Stroke survivors with at least a high school education will be more likely than stroke survivors with more than a high school education to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	No
Domain 2: Enabling Characteristics	Stroke survivors with Medicaid will be more likely than stroke survivors without Medicaid to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes
	Stroke survivors with long-term care insurance will be more likely than stroke survivors without long-term care insurance to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	No
	Stroke survivors who have children residing within ten miles will be less likely than stroke survivors who do not have children residing within ten miles to receive formal or no caregiving than informal caregiving, and more likely to receive mixed caregiving.	No
	Stroke survivors with resident children will be less likely than stroke survivors without resident children to use formal or no caregiving than informal caregiving, and more likely to receive mixed caregiving.	Yes
	Unmarried stroke survivors will be less likely than married stroke survivors to receive formal, mixed, or no caregiving than informal caregiving.	Yes
	Stroke survivors who have a smaller total wealth (less than $38,000) will be less likely than stroke survivors who have a larger total wealth (greater than $38,000) to use formal or mixed caregiving than informal caregiving, and more likely to receive no caregiving.	No
	Stroke survivors who are poor (total wealth < $38,000) and have Medicaid will be more likely than stroke survivors who are not poor and do not have Medicaid to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes
	Stroke survivors who are poor (total wealth <$38,000) and do not have Medicaid will be less likely than stroke survivors who are not poor and do not have Medicaid to receive formal, mixed, or no caregiving than informal caregiving.	Yes

Table 59 Continued

Domain 3: Need Characteristics	Stroke survivors who have more ADL impairments will be more likely than stroke survivors with fewer ADL impairments to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes
	Stroke survivors who have more IADL impairments will be more likely than stroke survivors with fewer IADL impairments to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes
	Stroke survivors who report urinary incontinence will be more likely than stroke survivors who do not report urinary incontinence to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes
	Stroke survivors who report a memory related disease will be more likely than stroke survivors who do not report a memory related disease to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Yes
	Stroke survivors who have a higher Center for Epidemiologic Studies Depression Score (CESD) score will be more likely than stroke survivors who have a lower CESD score to receive formal or mixed caregiving than informal caregiving, and less likely to receive no caregiving.	Not Tested

A summary of the hypotheses for the multivariate analyses is presented in Table 60. The results of the cross-sectional models indicated that all three domains in the Andersen-Aday Model were predictive of formal caregiving in 1998. However, in the second wave only the enabling and need domains were significantly associated with caregiving status. The results indicated that stroke survivors who were white, unmarried, and did not have resident children, were more likely to receive formal caregiving than informal care. The level of need was strongly related to whether or not an individual fell into the no caregiving group. The results indicate that less impairment was associated with no caregiving as opposed to informal caregiving.

The longitudinal models indicated there were several characteristics of stroke survivors that may influence the type of caregiving when the dependency between the waves was accounted for, which essentially holds time as a constant. Results suggest that holding time constant, the predisposing variables age and education were consistently predictive of type of caregiving status. Stroke survivors who were older and reported less than a high school education were more likely to receive formal only as opposed to informal only caregiving. Race was not statistically associated with caregiving status in the final model. Once the variables in the enabling domain were entered into the model race was no longer significant. Enabling factors were strongly associated with caregiving status include marital status, poor with Medicaid, poor no Medicaid, and resident children. The need factors that were significantly associated with caregiving status include urinary incontinence, memory related disease, ADL, and IADL impairments.

The sub-group analyses suggest that there may be some differences between white and African American stroke survivors; however, the results should be interpreted with caution because they do not adjust for other differences. The results show more African American stroke survivors used informal caregiving at each wave compared to white stroke survivors. In the bivariate analyses, the only variables that were significantly related to race/ethnicity were Medicaid, total wealth, and resident children. The remaining variables were not significantly different between white and African American stroke survivors. Separate multivariate analyses to examine differences between white and African American stroke survivors did not produce valid models or did not converge. Therefore, estimates were not presented.

Table 60: Summary of Support for Multivariate Hypotheses

		Direction of OR Compared to Informal Caregiving					
Domain	Variable	Odds of Formal	Hypothesis Supported (Cross-sectional/Longitudinal)	Odds of Mixed	Hypothesis Supported (Cross-sectional/Longitudinal)	Odds of No Caregiving	Hypothesis Supported (Cross-sectional/Longitudinal)
Predisposing	Age 75+	Increase	(- / +)	Increase	(- / +)	Decrease	(- / -)
	Female	Increase	(- / -)	Increase	(- / -)	Decrease	(- / -)
	Less than high school	Increase	(- / +)	Increase	(- / -)	Decrease	(- / -)
	African American	Decrease	(+ / -)	Decrease	(- / -)	Increase	(- / -)
Enabling	>$38,000 total wealth	Increase	Not Tested	Increase	Not Tested	Decrease	Not Tested
	Has Medicaid	Increase	Not Tested	Increase	Not Tested	Decrease	Not Tested
	Poor with Medicaid	Increase	(+ / +)	Increase	(+ / +)	Decrease	(- / +)
	Poor without Medicaid	Decrease	(- / +)	Decrease	(- / +)	Increase	(- / -)
	Has children within 10 miles	Decrease	(- / -)	Decrease	(- / -)	Decrease	(- / -)
	Has resident children	Decrease	(+ / +)	Increase	(- / -)	Decrease	(- / +)
	Married	Decrease	(+ / +)	Increase	(- / -)	Decrease	(+ / +)

Table 60 Continued

Enabling	Has LTC insurance	Increase	(- / -)	Increase	(- / -)	Decrease	(- / -)
	ADL impairments	Increase	(- / -)	Increase	(- / +)	Decrease	(+ / -)
	IADL impairments	Increase	(- / -)	Increase	(+ / -)	Decrease	(- / +)
Need	Reports UI	Increase	(- / -)	Increase	(- / -)	Decrease	(- / -)
	Reports memory related disease	Increase	(- / +)	Increase	(- / -)	Decrease	(- / -)
	Depression	Increase	Not Tested	Increase	Not Tested	Decrease	Not Tested

* Hypothesis not supported (-) Hypothesis supported (+)

CHAPTER V

Discussion

The purpose of this study is to determine the utility of the Andersen and Aday Model of Health Services Use (Andersen-Aday Model) in describing cross-sectional differences and changes in the caregiving source between formal and informal caregiving among stroke survivors over a six-year period. This study involved analyses, both cross-sectional and longitudinal, of data from the Health and Retirement Study/Assets and Health Dynamics Among the Oldest Old (HRS/AHEAD) to address the following three research questions:

1) What is the pattern of formal and informal caregiving among elderly stroke survivors over a six-year period?

2) To what extent does the Andersen-Aday Model (predisposing, enabling, and need variables) explain the receipt of formal and informal caregiving both cross-sectionally and longitudinally?

3) Are there differences between non-Hispanic Whites and minorities (African Americans and Hispanics) in terms of the specific Andersen-Aday model domains (predisposing, enabling, and need) that influence utilization of formal service use and informal caregiving?

Importance of Andersen-Aday Model Domains

The Andersen-Aday Model was utilized to guide the inclusion of predictors focusing on population characteristics consisting of the predisposing, enabling, and need factors of each stroke survivor. The implications of using health care utilization measured by the actual use and defined by type of caregiving received are discussed.

Additionally, the importance of each of the Andersen-Aday Model domains in the regression models constructed for this study are discussed cross-sectionally and longitudinally.

This study does increase our understanding about the type of caregiving utilized by stroke survivors over many years and does find, at least preliminarily, that some factors in the Andersen-Aday Model were predictive of receiving some types of caregiving. These results are all the more important given past research indicating that using a categorical variable to measure health care utilization (i.e. caregiving) does not provide the best measure of caregiving no describe the relationships adequately. These results can be used to guide future studies to understand caregiving source, which may attempt to capture the amount of care received by stroke survivors. Previous research by Norgard and Rodgers (1997) utilized a similar methodology and found somewhat similar results in a larger group of older Americans, which affirms the results of this study. However, other methods that utilize hours or days (Hanley et al., 1991; Pezzin et al., 1996) of caregiving by type are a much more informative methodology to really understand how much and what type of caregiving is being utilized. Future studies should be cognizant of the group sampled and be wary of using biased sample from care providers. Future research to evaluate caregiving of stroke survivors needs to consider not only the type of caregiving received by stroke survivors, but amount of care provided.

Presented in Table 61 is the contribution at each step of the cross-sectional analyses. The pseudo R^2 values and the changes in those values after the inclusion of each domain are also presented. Overall, the Andersen-Aday Model was able to successfully predict the caregiving source of stroke survivors.

Table 61: Influence of Andersen-Aday Model of Health Services Use Domains in the Cross-Sectional Models

Domain	1998 Model R^2 (% Δ)	2000 Model R^2 (% Δ)	2002 Model R^2 (% Δ)
Predisposing	.121	.071	.099
Enabling	.212 (+9.1)	.274 (+20.3)	.177 (+7.8)
Need	.388 (+17.6)	.441 (+16.7)	.385 (+7.8)

Table 62 presents the proportion of the total explained variance by each Andersen-Aday Model domain from the cross-sectional analyses. Across the three waves the need domain accounted for on average 40% of the explained variance. The predisposing (7-12%) and enabling (7-20%) domains accounted for approximately equivalent amounts of the explained variance across the three waves. At each wave the need domain accounts for the largest proportion of the explained variance followed by the enabling domain. This finding is not surprising since previous research has found the need factors typically drive the explained use of caregiving services among the frail elderly. The use of caregiving services (paid and unpaid) among stroke survivors appears to be no different. Receiving caregiving services based upon functional impairments was shown in the results of this study and helps to explain the significance of the need domain in this model. Additionally, the enabling domain accounted for a large portion of the total explained variance with the variables indicating presence of resident children and being poor with Medicaid consistently showing significant relationships to caregiving status.

Table 62: Proportion of Total Explained Variance by Domains for Cross-Sectional Models

Domain	1998	2000	2002
Predisposing	16.8%	9.9%	15%
Enabling	29.4%	38.3%	26.8%
Need	53.8%	61.6%	58.2%

Importance of Individual Predictors

The population characteristics identified by the Andersen-Aday Model domains examine the individual traits that influence the utilization of caregiving services and consist of predisposing, enabling, and need factors. The importance of these factors and implications of these results are discussed.

Need Domain

As was expected, the variables in the need domain consistently remained significant in the cross-sectional and longitudinal models and accounted for a large percentage of the total explained variance. Within the cross-sectional and longitudinal models several variables stood out as the most influential and displayed stronger relationships with caregiving source.

In the cross-sectional models activities of daily living (ADL) and instrumental activities of daily living (IADL) impairments were significantly related to caregiving source. These findings are supported in previous studies about caregiving, where ADL and IADL assistance in all five areas was found to be related to an increased probability of using informal care (Kemper, 1992; Norgard & Rodgers, 1997).

Other need factors such as memory related disease and urinary incontinence (UI) were not significantly related to caregiving type in the cross-sectional models. However, in the longitudinal model, when the dependency of the waves was controlled for, memory related disease was significantly related to formal only caregiving. Across time the increased disability of an elder has been found to be associated with the use of formal care services (Liu et al., 2000) and this finding may be an indication that increased disability in the form of a memory related disease is predictive of formal caregiving utilization among stroke survivors. The third need significant factor measured in the need domain was UI. Only in the longitudinal model was this variable barely a significant predictor of caregiving source and not in the predicted direction. At least in this study this finding may indicate that urinary incontinence is not necessarily a good predictor of caregiving utilization.

Even though the need domain explained a great deal of the variance and was significant in all of the models, the predisposing and enabling factors were important predictors of caregiving status. However, once enabling and need variables were entered in the cross-sectional and longitudinal models; some of the predisposing factors became less significant and two fell out all together. In the cross-sectional models many variables fell out at the 2000 wave, but became significant again in the 2002 wave. This could have possibly been due to older, less healthy stroke survivors dying before the second wave (2000) interview and could also be due to the remaining strokes survivors growing older and sicker by the third wave (2002).

Predisposing Domain

The predisposing factors that were significant include age of the stroke survivor and education. Age was significantly related to the use of formal only and mixed caregiving in the 1998 cross-sectional model and the final longitudinal model when compared to informal only. This finding is consistent with previous research that concluded older individuals are more likely to use paid services (Crets, 1996; Mui & Burnette, 1994; Muramatsu & Campbell, 2002). Age can be one of the most influential predictors in the predisposing domain since it is related to increased frailty of an older person (Kadushin, 2004).

Education was associated with formal only and no caregiving in the longitudinal model. Stroke survivors who reported a high school education or less were more likely to receive either paid services or no long-term care services. This finding may need further investigation as only a few previous studies measuring type of caregiving have included the educational level of the care receiver (Miller et al., 1994; Norgard & Rodgers, 1997). Studies that included educational level found that it is negatively associated with the use of formal only and mixed caregiving (Norgard & Rodgers, 1997), which is a similar finding in this study. However, Miller, McFall, and Campbell (1994) found that education increased the likelihood of receiving ($OR=1.04$; $p<.05$) mixed caregiving.

Race/ethnicity did not continue to be significantly related to any of the caregiving types after the entry of enabling and need factors in the 1998 or 2000 cross-sectional or longitudinal models in this sample. The findings from this study are noteworthy because race was marginally significant in the 2002 cross-sectional model and may point to some differences not detected in this study. Results from the bivariate analyses did not find statistically significant results in 1998 or 2000, but African American stroke survivors did use a higher percentage of informal only caregiving and white stroke survivors used a higher percentage of formal only caregiving. It is also interesting to note that after enabling and need variables were entered into the model, race was no longer significantly related to type of caregiving received. Previous research has found that race is negatively associated with informal help (Norgard & Rodgers, 1997). Further research on this area should be conducted, but these preliminary results suggest that enabling and need factors are more important and predict caregiving utilization.

Enabling Domain

Enabling factors in the cross-sectional and longitudinal models were consistently associated with use of caregiving services. These findings suggest these variables may in fact be some of the most important predictors of long-term care use. Variables that were significantly related to caregiving such as being poor without Medicaid, having resident children in the household and marital status were important predictors of decreased use of formal only services.

The living situation either with <u>resident children</u> or <u>spouse</u> is predictive of utilization of informal or mixed caregiving. Prior research has found similar results in other samples where having family (spouse or child) in the household decreases the likelihood of receiving paid services (Kemper, 1992).

The availability of <u>Medicaid</u> dollars is an important factor when considering utilization of long-term care services (Muramatsu & Campbell, 2002). Since only a few insurance products pay for long-term care (formal care) it was expected that having Medicaid would be predictive of formal or mixed care among stroke survivors. Additionally, income or total wealth of the stroke survivor was related to the utilization of caregiving services. This finding is similar to previous research (Norgard & Rodgers, 1997). In this study enabling factors accounted for slightly more of the variance, but overall the results of this study are consistent with previous findings in different populations.

Limitations

While the original purpose of the study was to evaluate the balance between caregiving types longitudinally among stroke survivors, the present analyses were constrained by limitations in the data, primarily small sample sizes and the limited number of transitions in caregiving type waves. Only 33% of the entire sample transitioned during the study period, creating only a small sample to evaluate the concept of change. This sample does not provide enough transitions to use a multi-level model to determine whether the Andersen-Aday Model domains predict changes in caregiving status. These problems changed the nature of the study and the methodology for the longitudinal analyses. Instead of examining how time influences the receipt of caregiving services, time was held as a constant to determine if the Andersen-Aday domain would predict caregiving status.

Over half of the sample of the 477 stroke survivors across the three waves of this study in the HRS/AHEAD data did not utilize any caregiving services. This may indicate the HRS/AHEAD data does not provide a representative sample of stroke survivors. Respondents who participated in multiple waves of this survey were generally a healthier group of older Americans and could be healthier than the general population of stroke survivors. The potential for differences between the general population of survivors of stroke and survey respondents warrant additional investigation.

At the other extreme, the mortality of the stroke survivors also poses limitations on the findings presented here. Those stroke survivors that died during the course of the study may have utilized and transitioned between the three caregiving categories, but due to the severity of their illness they either dropped out of the study or died before this transition could be measured in the next wave of study interviews.

The data for this study are based upon self-report interviews that have been conducted every two years since 1993. This may have resulted in some test-retest bias with elderly participants who completed multiple interviews (Miller & Whicker, 1999). This study may also have omitted respondents who indicated no need for assistance with ADL or IADL functions, but who in fact needed assistance, due to the way these questions were asked during the interview process.

Utilization of caregiving services across the three waves of this study resulted in an unbalanced data set. Since there was a great deal of attrition and this was not equal across each caregiving type, the results of this study should be used cautiously. Unbalanced data is typical in longitudinal studies. The primary reason for missing data in this study is participants' mortality over the course of the study period, which was to be expected given the health status and age of participants. However, the unequal distribution across the groups was not due to respondents dying after the first wave (1998). Problems that occur due to unbalanced data include inaccurate estimates of the standard errors and variance. The Huber-White standard errors may also be underestimated due to the unbalanced data (Fitzmaurice et al., 2004). Variance depends on the frequency distribution of the variable. The small sample size in some of the groups may lead to unreliable estimates of the standard error due to asymptotic approximations (Fitzmaurice et al., 2004).

Lastly, this study does not attempt to make statements about preferences or values associated with utilization of formal or informal caregiving. This study can only determine which long-term care choice was made, not why or how the selection was derived. Future research should investigate the receipt of caregiving services further to determine if there are other reasons why these services were utilized beyond the individual characteristics of the stroke survivor.

Although the data did not allow for the examination of longitudinal changes, this study provides more information than was previously available about the resultant caregiving post-stroke and insight into the nature of future research needed to understand the dynamics of formal and informal caregiving in this population. While some of the original aims of this study were not met, this study does add to the overall body of literature about caregiving, particularly for stroke survivors. Past research about caregiving has typically used a sample of respondents from different types of long-term care providers and collapsed participants into one category regardless of disease state. Much of the previous work on this subject matter utilized samples from care providers (Greene, 1983; Moscovice et al., 1988; Pezzin et al., 1996) which by definition do not capture people who do not use formal services. This study attempted to obtain more complete information about stroke survivors by avoiding this source of potential selection bias. Evaluating stroke survivors from a national panel study about older Americans reduced the chances of excluding people who used no services or used only informal care. Additionally, instead of increasing the sample size by including several different disease states, this study focused on one condition, stroke, as those who survive a CVA may have unique caregiving needs. Past research that did not use samples limited to subjects obtained from care providers did include a variety of disease states, which does not provide information specifically applicable to survivors of stroke (Muramatsu & Campbell, 2002; Tennstedt et al., 1996).

Policy Implications

The demographic changes in the proportions of elders, workers, and informal caregivers have pushed policy makers to reconsider the current delivery system of long-term care services and to consider providing more support services aimed at family caregivers. The result has been numerous legislative endeavors to enhance supportive services for family caregivers providing services for America's aging population. Nationally, the most recent federal provisions included within the Older Americans Act is the National Family Caregiver Support Program which provides funding to the State Units on Aging (SUA) for caregiver support services for those in most economic and social need ("National Family Caregiver Support Program," 1965). In addition to this program, individual states are establishing or expanding services such as respite and adult day services to family caregivers that are typically funded through home and community based (HCBS) waivers via state Medicaid programs (Link, Dize, Folkemer, & Curran, 2006).

This study provides more information about the individual predictors of caregiving services use among stroke survivors and therefore has important policy implications for the organization of long-term care, caregiving support initiatives, and discharge planning. Meeting the needs of survivors of stroke often entail an abrupt initiation into a myriad of service providers after the acute event has left the survivor with lasting impairments. It can require informal caregivers to balance competing responsibilities for family, such as spouses or adult children and work with this new role. This study provides information about the caregiving situation post inpatient or sub acute rehabilitation, which is often the last formal care services survivors will receive. The transitions of caregiving source take place during the last contact with in patient services, in unison with disease progression, and while families tackle new roles (Levine et al., 2006). The results of this study have two primary health policy implications for survivors of stroke. First, the limited number of transitions between different types of caregiving services indicates the length of commitment required of informal caregivers. The lack of transitions during the study period suggests providing care for an older stroke survivor is a long-term commitment and that the source of care may not change dramatically over the lifetime of the stroke survivor. Those survivors of stroke who receive informal (unpaid) sources of assistance will utilize these sources of care for many years after the stroke incident. Heavy reliance on the informal care system, either as the sole source of care or with supplemental paid services, is important to note in relation to the level of frailty of the stroke survivors. Study participants who survived a stroke were older and became more functionally impaired. Knowing that the source of care may not change over a six year period provides an opportunity upon discharge of these types of patients to offer more comprehensive options counseling these patient and families as well as more information related to successful informal caregiving.

Discharge planning in the hospital or acute rehabilitation provides a 'teachable' moment or the key moment for intervention where realistic options for long-term care could be discussed and planned, knowing that whatever is chosen will be the arrangement for the caregiver and care receiver for a considerable amount of time. The rehabilitation period post stroke presents a serviceable opportunity to provide caregiving support services to make better decisions for the stroke survivor that will require long-term care assistance. Services could include more information about long-term care in general and provide options for the potential informal caregiver. This would also be an ideal opportunity to provide service management in terms of how to most effectively utilize both informal care and formal (paid) services. This enhanced information would also make patients and caregivers more aware of the type and amount of care paid for by insurance agencies.

Beyond individual and provider implications these findings pose serious questions and opportunities for national and state long-term care policy. Understanding the dynamic process of caregiving will inform federal and state policymakers on the type and amount of care desired by older Americans. Ultimately the question is not what type of care is used, but how will the cost of care be distributed and in the long run how can the federal government in partnership with the states and individuals plan for this type of care while creating a sustainable system. There is not an easy answer to this question and no one solution will fix the current system. Studies about the continuum of care, like this one, provide details about long-term care such as the use of formal and informal caregiving that can be utilized by policymakers to design systems to enhance both formal and informal caregiving. As this study illustrates a tremendous amount of caregiving of stroke survivors is provided by informal care providers such as spouses or adult children. While family members are providing care to these stroke survivors the cost of this care is not free and needs to be considered in any long-term care policy. The mixed caregiving group has the most potential to prevent the utilization of more expensive paid services by understanding the dynamics within this caregiving situation. Programs to start addressing the financing of long-term care are being developed and may provide preliminary answers to this question.

One such answer is partnership programs with Medicaid and private insurance companies to support the long-term care needs of Americans that need paid services (McCall, 2001). Secondarily, state Medicaid offices are integrating caregiver support programs and assessments in order to target limited services to those who need them most. Continued research about caregiving and the development of alternative programs for long-term care will lead to a long-term care system that will be coordinated, comprehensive, and meet the desires of individuals needing this type of care.

In the long run, being able to plan services effectively will ultimately lead to stroke survivors receiving the most comprehensive services possible and could potentially reduce the financial burden on public and private payers of services since a plan would be in place.

Future Research

The findings from this study underscore questions that remain unanswered and opportunities for future research about caregiving use among survivors of stroke and others with chronic illnesses and disabilities. Elderly stroke survivors present unique caregiving preferences and needs since this may not be the first encounter with formal or informal caregiving services. Existing support systems may be confronted with the new challenges that stroke survivors face and may or may not be prepared to handle these needs. There are three main areas that future research should address:

1. investigate the reason for choosing a particular type of care and when are these decisions are ultimately made;
2. further explore potential differences among racial/ethnic groups and their cargiving use; and
3. describe the caregivers of survivors of stroke to understand the caregiver(s) structure and needs and how these change over time.

The preferences for paid or unpaid caregiving among stroke survivors should be evaluated more closely to determine why particular sources were utilized. This study was only able to report which choices were made and not the reasoning or circumstances behind the decision. Understanding this decision-making process is crucial to being able to provide the necessary and proper support to informal caregivers. It may also provide insight into the decision to use paid home care versus institutional nursing care. This study found a great deal of informal only caregiving. Additional data about these choices would provide detailed information on which legislators and health services researchers could base meaningful suggestions for change that would support these informal caregivers over a longer period of time. This type of research about the caregiver(s) and the situation of a stroke survivor would provide another layer of detail that is not currently available. This would also move the research beyond the individual characteristics of the stroke survivor described in the Andersen-Aday Model to a broader perspective that could more effectively guide future practices and decisions.

Future studies should also re-examine the potential differences in the use of caregiving sources among white and non-white stroke survivors. Additional research is warranted due to the prevalence of stroke in the African American population. Overall, this study suggests that there may be some differences in the use of different types of caregiving associated with racial/ethnic identity. However, sample size limitations prevented further analyses at this level. Since this study was unable to definitively describe potential differences in service use future research should examine the caregiving sources of stroke survivors after the rehabilitation phase.

Studies should also collect more information about the informal caregiver of a survivor of stroke. These caregivers provide a vital service to these patients and are an important component of the caregiving decision. Further examination of variation according to which household member cares for a stroke survivor and differences in their needs during the caregiving period would provide information to policy makers about the unique challenges faced by different subgroups caregivers.

Conclusions

Examination of the receipt of caregiving services over multiple years enhances the understanding of the dynamic process of elder care among stroke survivors. Since caregiving can be a hidden phenomenon, understanding the individual predictors of source of care provides a depth of information not previously available. Individual characteristics contribute to the dynamics which influence the type caregiving used and provides a piece of the overall picture of how long-term care is utilized over an extended period of time. Understanding the type of caregiving utilized will help public policy makers, health care providers, and families make better decisions about appropriate assistance as they make key decisions regarding the organization of care for an impaired elder.

The results of this study support prior research, which found significant relationships between individual characteristics and type of caregiving utilized. This study confirmed that in stroke survivors as with other types of diseases such as dementia, the need factors consistently drive use of all caregiving types. This study evaluated the transitions between types of care over an extended period of time among stroke survivors. The finding that many stroke survivors are not experiencing changes in caregiving source may indicate that once a decision is made about caregiving source, that decision is comparatively permanent. Future research should move beyond the individual characteristics of stroke survivors to understand who the caregivers are and the decision-making process involved in these types of choices.

Policy makers and health professionals need to be aware of the permanent or at least long-term nature of the caregiving decisions that are made after an elderly person has a stroke. The period following a stroke presents an opportunity to provide caregiving support services and to assist patients and families to make better choices about long-term care.

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Appendix A

Original Health and Retirement (HRS/AHEAD)/ Assets and Health Dynamics Among the Oldest Old

Year	Variable Name	Description	Attributes
1998	F1014	Age	25-106 actual value
2000	G1101		
2002	HA019		
1998	F686	Gender	1=Male 2=Female
2000	G757		
2002			
1998	F1071	Marital Status	0= DK 1=Married 3=Separated 4=Divorced 5=Widowed 6=Never Married
2000	G1158		
2002	HMARITAL		
1998	F987a	Education	0=No Formal Education 1-11=Grades 12=High School 13-15=Some College 16=College Grad 17=Post College 97=Other 98=DK 99=RF
2000	G1074a		
2002	HB014a		
1998	F1005a	Race / Ethnicity	1=White / Caucasian 2=Black / African American 7=Other 8=DK 9=RF
2000	G10952a		
2002	HB031a		
1998	F5999	Long-Term Care Insurance	1= Yes 5=No 8=DK
2000	G6393		
2002	HN071		
1998	F1764	Proximity to Children	1= Yes 5=No 8=DK
2000	G1980		
2002	HE012		
1998	F809	Resident Children	1= Yes 5=No 8=DK
2000	G886		
2002	HA099		
1998	H4ATOTA	Total Wealth*	-1000000 through 9860000
2000	H5ATOTA		
2002	H6ATOTA		
1998	F5868	Medicaid	1= Yes 5=No 8=DK
2000	G6241		
2002	HN005		

Year	Variable Name	Description	Attributes
1998	F2425 F2427 F2444 F2454 F2464 F2477	ADL	1=Yes 5=No 6=Can't do 7=Don't do
2000	G2723 G2725 G2742 G2752 G2762 G2775		
2002	HG041 HG042 HG044 HG045 HG047 HG048 HG050 HG051 HG052		
1998	F2562 F2564 F2567 F2569 F2572 F2574 F2577 F2579	IADL	1=Yes 5=No 6=Can't do 7=Don't do
2000	G2860 G2862 G2865 G2867 G2870 G2872 G2875 G2876		
2002	HG041 HG042 HG044 HG045 HG047 HG048 HG050 HG051 HG052		
1998	F1193	Memory Related Disease	1= Yes 5=No 8=DK
2000	G1326		
2002	HC069		
1998	F1120	Incontinence	1= Yes 5=No 8=DK
2000	G1353		
2002	HC087		
1998	f2502 f2508 f2516 f2517 f2524 f2525 f2526 f2528 f2529 f2530 f2532 f2533 f2534 f2630_1 f2635 f2540 f2541 f2542	ADL Caregiving	1=Yes 5=No then corresponding question identified relationship to stroke survivor

Year	Variable Name	Description	Attributes
2000	G2800 G2806 G2808 G2814 G2815 G2822 G2823 G2824 G2826 G2827 G2828 G2830 G2831 G2832 G2834 G2835 G2836 G2838 G2839 G2840		
2002	HG031 HG032_1 HG032_2 HG033_2 HG032_3 HG033_3 HG032_4 HG033_4 HG032_5 HG033_5 HG032_6 HG033_6 HG032_7 HG033_7		

Appendix B

Litwak's Task Specifc Model

Litwak's Task Specific Model emphasizes the importance of matching the structural components of the task with the characteristics of the caregiver (formal/informal) (Litwak, 1985). This model asserts that each caregiving task (including activities of daily living (ADL) and instrumental activities of daily living (IADL) responsibilities) corresponds to the structural characteristics of the care source (e.g. spouse, neighbor, or formal paid source). Structural components of the task are further differentiated on seven dimensions: proximity, length of commitment, size, motivation, division of labor, social roles, and technical knowledge (Litwak, 1985; Messeri, Silverstein, & Litwak, 1993). The formal care system is incorporated on the dimensions of technical knowledge, division of labor, and economic incentives (Litwak, 1985). Litwak also allows for potential substitution and concluded that while substitution between formal services and informal caregiving does occur, the result will be gaps in service to the older person (Litwak, 1985).

Hierarchical-Compensatory Model

Alternatively, the Hierarchical-Compensatory Model suggests that there is a structured hierarchical order by which caregiving preferences are guided. For instance, spouses are more often selected as caregivers than other relatives. Formal care is the last preference in the ordered structure. Elders must compensate with another source of care (e.g. formal paid care) in the structured order when the preferred caregiver is not obtainable, which may result in substitution of care sources (Cantor & Brennan, 2000). Support for this model has been illustrated in an early caregiving study that found that a network of informal caregivers assume the responsibility for elder care and that there is an order to the use of different informal caregivers as illustrated in this model (Tennstedt, Crawford, & McKinlay, 1993a).

VITA

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Bachelor of Arts, Business Administration, Saint Leo University, Saint Leo, FL, 1999.

WORK EXPERIENCE

2007-Present	Center for the Study of Aging, Boise State University, Boise, Idaho Director Assistant Research Professor

Developed interdisciplinary aging research and educational programming through the creation of training opportunities and the procurement of external grants and contracts. Served as the principal or co-investigator on multiple projects that directly impact local and state social and health policy.

PUBLICATIONS

Jackson, M.Y., Beard, H. (2005). Nutrition Related Health Concerns for American Indian and Alaska Native Elders. *Journal of Native Aging and Health,* 1 (1), 15-19.

Beard, H., Payne, B.K. (2005). The Portrayal of Elder Abuse in the National Media. *American Journal of Criminal Justice,* 29(2), 269-284.

HONORS AND AWARDS

University Graduate Fellowship, Old Dominion University	2006- 2007
Air Force Aid Society General H. Arnold Education Grant	1997-1999