

Summer 2006

"Doing the Right Thing": A Study of Cross-Generational Eldercare Decision-making in Community and Disease Context

Jeannie Baron-Yenerall

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***“Doing the Right Thing”: A Study of Cross-Generational Eldercare
Decision-Making in Community and Disease Context***

A Thesis

Presented to the

McAnulty College and Graduate School of Liberal Arts

Duquesne University

In Partial Fulfillment of the Requirements for the Degree of

Master of Arts

By

Jeannie Baron-Yenerall

July 24, 2006

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Abstract

Utilizing the sociology of knowledge perspective, as well as elements of structural-functional theory this study examined the decision-making process as it relates to eldercare. Specifically, how does the knowledge of available resources, community context, and caregiving beliefs affect the caregiving alternative one chooses? Furthermore, what role does family social milieu play in the decision-making process?

This research used a 20-item interview schedule developed specifically for this study; and the unit of analysis was the individual responsible for making decisions about the care received by an elder. The survey used both closed and open-ended questions, designed to capture data related to the cultural, socio-demographic, and social structural level of each respondent. Thirty-three (33) individuals responsible for eldercare decision-making completed an interview, which took anywhere from 45 minutes to 2 hours to complete. Data from closed ended questions were coded and entered into an SPSS file. The data from open-ended questions were summarized on a case-by-case basis and the content analyzed for particular themes or patterns that could be measured.

Finding from this study, as well as policy recommendations are discussed, concentrating on social service agencies, medical organizational resources, public education as it relates to social and medical agencies, and economic and medical dilemmas effecting decision-makers.

Acknowledgements

The road to completing this thesis has been long; with many bumps, turns, and detours along the way. I have many to thank and acknowledge for not only accompanying me on this journey, but also for supporting, guiding, and often times putting me back on the right path.

I am not sure that my interest in eldercare would have grown to where it is today had it not been for my mother, Dorothy, and my aunt, Nellie. It was their influence and example that taught me to respect and have a high regard for elders, particularly those who could no longer care for themselves. I wish they could have witnessed the completion of this work – I think they would have enjoyed it.

My interest and determination in attaining a college degree began as a way to set an example for my children, Jessica and Matthew. The three of us set out supporting one another on this quest, and in the end we have each earned a Master's degree. Without their love, support, and understanding I would have given up long ago. Jessie and Matthew...thank you so much for never doubting my abilities and for always, always, and always, being in my corner. I love you.

Then there is my husband, Joe. There are often times when I wonder if you had any idea what you were getting when you married me and came on board with this endeavor. Your patience and ability to know when to push and when to hold back has always been admired, and your insight and suggestions welcomed. My appreciation and love for you will always be forever and a day.

Norm Conti and Doug Harper, my committee members. Thank you for stepping to the plate when I need you most. You went beyond the call of duty and I will always

be indebted to you. Thank you.

To Linda Rendulic and Joan Lapyczak...my thanks is not enough. I will remember all of your help and support with great fondness and appreciation.

Finally, to those who took the time to share their story with me. I admire you and hold you in great esteem. You step into your role as decision-maker with grace, determination, and tenacity. Thank you. I am in awe of all that you do.

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Introduction

The focus of this study is to determine *how* individuals and families navigate the decision-making process concerning the care of an elderly family member. Specifically, it will investigate how the knowledge of available resources, community context, caregiving beliefs, and patient's disease affect the caregiving alternative chosen. In short, this is a research project on how families formulate their "native" health-care policies. In broader perspective, the study outlined is one seeking to know how "provincial" family health care cultures are created and with what consequences.

Families face the process of making decisions daily. Very often, with regard to health care, the decision is one that a family finds difficult, making it necessary to seek help from outside the family unit. Knowing where to look for assistance is essential when a family is faced with the decision of caring for an elderly member. Finding resources is time consuming and, once found, often difficult to understand. Utilizing those resources in the best possible manner is a challenge.

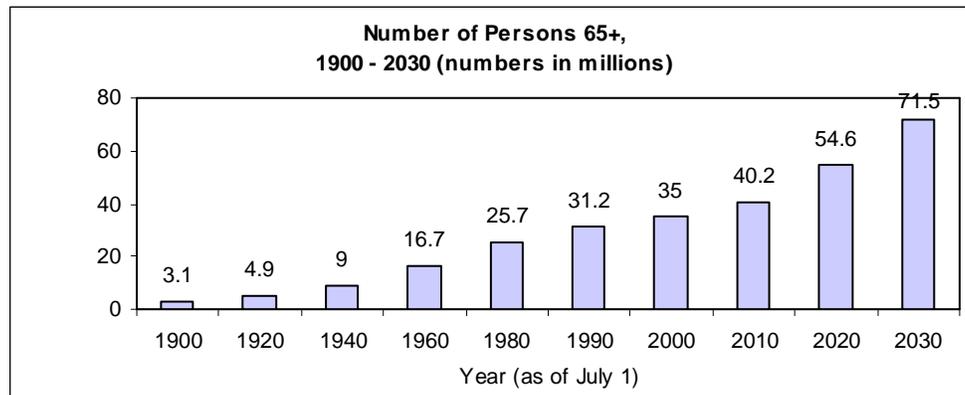
What type of care is in the best interest of their loved one? Will they care for their loved one at home? Will they place them in a nursing home, an assisted living facility, or a personal care facility? Will they themselves become the caregiver? If so, what adjustments will they have to make? How will the decision they make affect their daily life and routine? How will they know what is "best" for their loved one, as well as for themselves? Individuals and families struggle with these questions, as well as the ways and means in which to solve them successfully.

The elderly population continues to be the fastest growing segment of the United States. According to a report released by the Administration of Aging, U.S. Department

of Health and Human Services:

By 2030, there will be about 71.5 million older persons, more than twice their number in 2000. People 65+ represented 12.4% of the population in the year 2000 but are expected to grow to be 20% of the population by 2030. The 85+ population is projected to increase from 4.6 million in 2002 to 9.6 million in 2030.(Fowles and Greenberg, 2003:3) (see Figure 1)

Figure 1



If projections are accurate, the minority populations will represent 26.4% of the elderly population in 2030; up from 17.2% seen in 2002. Categorized via ethnicity, the impressive increases projected are seen in Table 1.

Table 1 – Projected Minority Population Increase: 2000 to 2030

Ethnicity	Percentage of Increase by 2030
White Population	77%
Hispanics	342%
African-Americans	164%
American Indians, Eskimos, Aleuts	207%
Asians, Pacific Islanders	302%

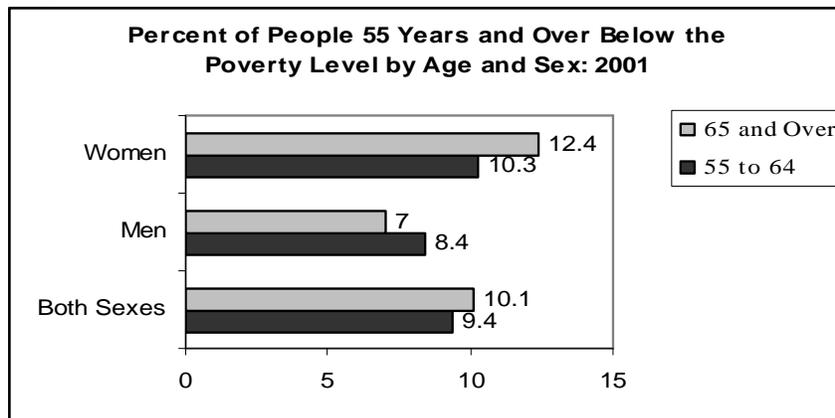
Source for Figure 1 and Table 1: *Projections of the Population by Age are taken from the January 2004 Census Internet Release. Historical data are taken from "65+ in the United States", Current Population Reports, Special Studies, P23-190 Data for 2000 are from the 2000 Census and 2002 data are taken from the Census estimates for 2002.*

Among other changes that will occur in our society, the marked increase to the elder and minority populations will have a significant effect on our economy. Generally

speaking, those populations 55 years of age and older and minority groups, represent a considerable percentage of society who fall below the national poverty level.

Of the 59.6 million people 55 years and over in 2002, 5.8 million (9.8 percent) were below the poverty level in 2001. The poverty rate was 9.4 for those 55 to 64 and 10.1 percent for those 65 years and over. Older women, in general, had a higher poverty rate than older men – 10.3 percent and 8.4 percent for those 55 to 64, compared with 12.4 percent and 7.0 percent among those 65 and over. (Smith, US Census Bureau, 2002) (See Figure 2)

Figure 2



Source: Denise Smith: *The Older Population in the United States: March 2002*. U.S. Census Bureau Current Population Reports, P20-546

Along with the increase of the elder and minority populations, it is reasonable to assume that the number and percentage of those elders in poverty will also increase, affecting available resources for their health care.

Another trend occurring is the geographic distributions that these changing populations are manifesting, particularly in states such as California, Florida, and Nevada. (See Table 2) As changes amplify in various affected states, policies relating to the economy, health-care, and insurance, just to name a few, will need to be addressed.

Table 2: Marked Population Changes by State Documentation in 2002

52% of Persons 65+ Lived in 9 States		Persons 65+ Constituted \geq14% of Total Population		Population Increased by \geq20% between 1992-2002	
State	Number of Persons	State	Percent of All Ages	State	Percent of Increase
California	3,716,836	Florida	17.1%	Nevada	63.8%
Florida	2,854,838	Pennsylvania	15.5%	Alaska	53.6%
New York	2,473,510	West Virginia	15.3%	Arizona	35.2%
Texas	2,152,896	North Dakota	14.8%	New Mexico	28.4%
Pennsylvania	1,908,962	Iowa	14.7%	Colorado	24.3%
Ohio	1,513,372	Maine	14.4%	Hawaii	24.0%
Illinois	1,499,249	Rhode Island	14.2%	Delaware	24.0%
Michigan	1,231,920	South Dakota	14.2%	Utah	23.7%
New Jersey	1,121,197	Arkansas	14.0%	So. Carolina	20.7%

Source: *Census Bureau Population Estimates 2002*

With these projections and given the greater prevalence of chronic illnesses among those 65 years old and over, the number of individuals and families faced with the task of seeking reasonable and satisfying solutions to the questions relating to elder care will also increase. The decisions made related to eldercare, such as choosing in home care or institutionalization for our elder loved ones, will contribute to how our society copes in the coming years with issues affecting the economy and policies addressing long-term health care and insurance.

Further complicating eldercare decision-making is the matter noted in the publication *CareGuide, Care for Caregivers: A Profile of Informal and Family Caregivers*, by the American Society on Aging. They suggest that:

Five social trends may affect the supply of caregivers in the future: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility; (3) decreasing family size; (4) delayed childbearing; and (5) more women workplace. (1998-2003:3)

As we address these projections and prepare for the rapid of growth of the elderly populace, understanding the process of the eldercare decision-making process is essential to the formulation of enlightened social and public policy in the years ahead.

Rationale

The responsibility of caring for an older member or members of one's family is not new. Traditionally it has been the responsibility of families to care for their loved one at home for as long as possible. Michael Katz gives an example of this in his book, *In the Shadow of the Poorhouse: A Social History of Welfare in America*:

[t]he best recent research estimates that in the nineteenth century most old people with adult children lived with them. More than any other factor, a lack of family distinguished the old people in poorhouses from those who escaped confinement. (1996:208)

Another example of caregiving responsibility is noted in *The Realities of Aging: An Introduction to Gerontology*:

Before World War II, among many ethnic groups, the expectation was for the youngest daughter to remain at home and to postpone or give up marriage in order to ensure support for parents into old age. (Kart & Kinney, 2001:263)

In today's society, this type of care-giving responsibility has become increasingly difficult due the geographic dispersion of adult family members. In addition, women, who in the past have been the caregivers, increasingly need, or desire, work outside the home. Nevertheless, “[n]early 1 in 4 US households (an estimated 22.4 million) are caring for elderly family members...” (Rachor 1998) and “nearly three out of four (72%) caregivers are female, mostly wives and adult daughters” (American Society on Aging, 2003).

A decision to “institutionalize” the ill elder may be made. With regard to those individuals residing in nursing homes, the most recent U.S. Census Bureau statistics is seen in Table 3:

Table 3: Population 65 Years and Over in Nursing Homes by Age

Age	Percent of Age Group		2000
	1990	2000	
65 years and over	5.1	4.5	1,557,800
65 to 74 years	1.4	1.1	210,159
75 to 84 years	6.1	4.7	574,908
85 years and over	24.5	18.2	772,733

Source: U.S. Census Bureau, *Census 2000 special tabulation; 1990 Census of Population, Nursing Home Population: 1990 (CPH-L-137)*

Note there was a decrease in nursing home residence, which affected all age groups between 65 years old and over. However, those 85 years and over experienced the largest growth in percentage of those residing in nursing homes. When comparing the overall age percentage change between 1990 and 2000, those in the age groups 85 to 89 and 90 to 94 had the largest change in increase, as is seen below.

Table 4: Overall Percent Change in Nursing Home Populations by Age

<u>Percent Change by Age: 1990 – 2000</u>	
65 to 69 years	-5.7
70 to 74 years	10.8
75 to 79 years	21.1
80 to 84 years	25.7
85 to 89 years	35.4
90 to 94 years	44.6
95 years and over	34.7

Source: U.S. Census Bureau, *Census 2000 Summary File 1; 1990 Census of Population General Population Characteristics, United States (1990 CP-1-1)*

With the exception of those folks representing the age group 65 to 69, all other age groups had a considerable increase. As the “baby boomers” age, individuals over the age of 65 will increase; and decisions made by individuals and families regarding the care of their elders will surely affect the number of patients who will reside in more formal institutions, such as nursing homes. It is appropriate to state here that the trends

described suggest that age of the elder influences the decision whether or not to institutionalize.

In their publication *Choosing Long-Term Care, Your Guide to Choosing Quality Health Care*, the Agency for Healthcare Research and Quality defines other forms of long-term eldercare options as follows:

- **Assisted Living** – provides 24-hour supervision, assistance, meals, and health care services in a home-like setting. Services include help with eating, bathing, dressing, toileting, taking medicine, transportation, laundry, and housekeeping. Social and recreational activities are also provided.
- **Home Care** – can be given in your own home by family members, friends, volunteers, and/or paid professionals. This type of care can range from help with shopping to nursing care. Some short-term, skilled home care (provided by a nurse or therapist) is covered by Medicare and is called “home health care”. Another type of care than can be given at home is hospice care for terminally ill people.
- **Community Services** – are support services that can include adult day care, meal programs, senior centers, transportation, and other services. These can help people who are cared for at home, and their families.
- **Supportive Housing Programs** – low-cost housing offered to older people with low to moderate incomes. The Federal Department of Housing and Urban Development (HUD) and State or local governments often develops such housing programs. A number of these facilities offer help with meals and tasks such as housekeeping, shopping, and laundry. Residents generally live in their own apartments.
- **Continuing Care Retirement Communities** – provide a full range of services and care based on what each resident needs over time. Care usually is provided in one of three main stages: independent living, assisted living, and skilled nursing. (2001: 1-2)

The extraordinary strains experienced by adult children, (the sandwich generation), in coping with the care needs of their elderly parents is documented in sociological literature (Matcha, 1996). However, literatures relating to the specific nature

of how those responsible for eldercare go about making decisions to do “the right thing” for their loved one is sparse.

The inflated number of elderly individuals leaving the work-force, becoming ill, or incapable of caring for themselves will have a dramatic effect on society, and thus on policy making in areas such as employment, health care, public assistance, housing, as well as community, state, and federal based agencies. The caregiving decisions families make will have marked consequences, not only on their family as a whole, but on the community work place and the nation’s financial health, as well.

In his article *The Consequences of Living Longer*, Dan Johnson states:

A sobering near-term fact-of-life looms ahead: the burden that will be created when 76 million U.S. baby boomers retire in the next half-century. As boomers retire in huge numbers, beginning in 2011, healthcare costs are expected to climb, while the ratio of potential workers to potential retirees will be cut in half between 2010 and 2030. (*The Futurist*, 1998, p.8)

As his article continues, Johnson quotes William Styring III and Thomas Duesterberg, policy analysts from the Hudson Institute, from their report *The Cost Effectiveness of Home Health Care* (1997):

This mass exodus from the work force will be the single most important social policy challenge facing the country during the next three decades. (p. 9)

“These grim figures should motivate us to find new ways of controlling the costs of care for the elderly, Styring and Duesterberg conclude in their report”. (Johnson, p. 9)

Furthermore, related to caregiving and the workplace, a national study conducted by the National Alliance for Caregiving and the National Center on Women and Aging at Brandeis University suggest:

The total number of employed caregivers in the United States is expected to increase to between 11 and 15.6 million working Americans – roughly one in ten employed workers.” (Wagner, 1999:2)

This prediction provides another window to the future that supports the significant consequence associated with the decisions we make regarding the care of our elders.

My Personal Experiences with Eldercare

My socialization to eldercare began at a young age. First, my mother, and aunt worked for a county nursing home; a common term in those days for a skilled nursing facility. A few years later, they started their own skilled nursing facility, which was separate from our home. Finally, during my teenage years, they cared for elders in our home who required more care than an assisted living environment could provide, but less care than a skilled nursing facility would offer.

During those years, when my mother and aunt provided elder care in our home, I witnessed how difficult it was for some families to leave their loved one, while for others it seemed to be a relief. Looking back, I realize I did not know the various factors decision-makers had to consider before deciding to place their loved one in the care of a facility or to keep them in their home environment. Additionally, if they did decide to keep them in a home environment was that decision due to their “family culture”? Did they believe that caring for a loved-one was a responsibility they needed to meet? Furthermore, was their caregiving experience “positive” (Roff, 2004:185) or more of “a burden” (Morgan and Kunkel, 2001:242); and how successful were they in finding and accessing resources that may have lessened their caregiving concerns?

I have since met many people who have had to make decisions regarding elder care. Several of these folks experienced difficulty finding, understanding, and utilizing

the resources available. In addition to making their decision-making process more complex, the added weight of uncertainty contributed to the likelihood they would, and in some situations did, experience “caregiver stress”...a social problem of great magnitude for an increasing number of Americans (Zarit, 1980).

In 1999, I accepted the role of decision-maker and caregiver. Even though I had been around caregiving most of my life there were many areas of this responsibility that felt unfamiliar to me. I learned how hard it is to make decisions that are in the best interest of everyone while feeling I had limited knowledge about so many eldercare issues. I struggled to find the best resources available to assist my loved ones, as well as me, during a time when I was also managing the responsibilities of a household, full time employment, college, and taking care of my family, while trying to make ends meet financially.

On the positive side, I believe that making the decision to provide in-home care for my family members was “the right thing to do”, and one with which I am able to look back upon without regret. While providing in-home care for my mother and aunt, I also saved the state a very large of money. The reality of how significant the savings were can be seen in a study funded by the Retirement Research Foundation, Janssen Pharmaceutical, Inc., AARP, and the American Red Cross for the National Family Caregivers Association and the National Alliance for Caregiving. Their report, *Self-Awareness in Family Caregiving: A Report on the Communications Environment*, notes that:

America’s health care system is heavily dependent on the direct care family caregivers provide, especially to the aged and people with chronic diseases and disabilities. According to a study published in *Health*

Affairs, (Levine and Memmot, 1999) caregivers' contribution to the nation's health care system has enormous economic value, estimated at \$196 billion annually, compared to \$32 billion for paid home care and \$83 billion spent on nursing home care. Their services significantly reduce costs to Medicare, Medicaid, and private payers. Without this immense unpaid work force, our fragile health care financing system would be even more strained. (Hoffmann, 2002:1)

On the negative side, my decision affected my employment and *every aspect* of my life. It was necessary for me to compromise my living space and to give up some personal freedoms – from simply getting a good night's rest, or socializing with friends, to not going to the store spontaneously. Finally, because of my commitment to elder caregiving at home, I lost my employment of fifteen years and thus, considerable financial resources.

The family members I cared for died about a year after in-home care commenced, as a result, my life returned somewhat to a state of normalcy. The decision-making and caregiving experience afforded me the opportunity to realize that our society lacks a definite, clear culture on these matters and that absence is harmful to individuals and families making elder caregiving decisions.

As was my experience, one of the problems facing the caregiver(s) who are designated to be the eldercare decision-maker is the difficulty in learning about and locating resources; and then, once found, utilizing those resources effectively. A fact sheet on Alzheimer's disease, published by The Administration on Aging emphasizes:

The type of assistance available for individuals and their families varies considerable from community to community. Consequently, locating the right services requires persistence and oftentimes several calls and conversations with different agencies. (1999:2)

The process can be long, frustrating, and very time consuming. Consequently, there are times when decisions are made quickly in order to comply with the need for the decision maker to continue with their daily responsibilities; or, an individual may choose to put other responsibilities aside while in the midst of making the necessary decisions.

More often than not, when I was immersed within the decision-making role, and would discuss the matter of eldercare with others, many seemed reluctant at the prospect of becoming decision-makers or caregivers simply because they believed themselves to be without knowledge regarding the subject. Statements such as, “I know I will be in this situation someday and I have no idea where to go or what to do”, or, “I’m not looking forward to the responsibility of caregiver” were common. Even when speaking with someone already in the decision-making role the uncertainties came through in statements such as, “I hope I’m doing the right thing...” or “I hope I made the right decision...”

Eldercare providers must often rely on “informal” provincial cultures – often constructed in situations of distress and haste. This method of decision-making frequently contributes to existing stress, causing the decision-maker/caregiver to question their choice(s); thus never being content and satisfied that they have made the “right choice” for their loved-one, or themselves, as expressed above. The *Senior Citizen Information and Assistance Line*, provided by the Administration on Aging (AOA), (2000) receives about three million calls per year from caregivers anxious about a relative’s well being.

In her article, *Adults Spending More Time Caring for Elderly Parents*, Kathleen Schucked quoted the noted geriatrician and author Vivian Greensberg as stating, “12% of

working women have quit jobs to care for elderly parents, and with anticipated cuts in government spending, that figure is likely to rise”. (Houston Chronicle, Oct. 1996)

The American Society on Aging concurs with this statistic stating that; “An estimated 9 percent of care-givers quit their jobs to provide care. For adult daughters, this number rises to 12 percent.” (1998-2003) Neither article specifies whether the individuals quit work due to their personal desire to care for their parent(s) or if they resign from their employment due to their inability to find appropriate resources that would provide in-home care for their parent(s); thereby, allowing them to continue in their place of employment while still providing in-home care. Gail Hunt, of the National Alliance for Caregiving, found that many individuals are simply not aware of their options, such as adult day care and related programs. (*American Demographics*, Sept. 1998)

The gravity of how prevalent this lack of caregiving knowledge is underscored in the *Family Caregiving in the U.S.* report released by the National Alliance for Caregiving and the American Association of Retired Persons (NAC/AARP). The authors note that the number of individuals caring for an individual, friend, or relative in 1996 tripled in number since 1988. Furthermore, many of these people attempt eldercare-giving decisions **without knowledge** of available resources and care-giving options. (1997)

As was stated in the introduction to this study, I strive to measure if experiencing a lack of knowledge of available resources makes a difference in the process of eldercare decision-making. Do those individuals who have more knowledge of available resources utilize them in a way that affects their decisions relating to eldercare? I also seek to

discover the impact of other social and cultural factors on the process of eldercare decision-making; particularly community context and disease type.

Review of the Literature

The goal of this research was to unravel the decision making process experienced by various individuals and families concerning what type of eldercare actions are “the right choice” for those for whom they have eldercare responsibilities. This study utilizes both the sociology of knowledge perspective and elements of structural-functional theory toward a better understanding of the efforts of those overseeing eldercare to “do the right thing”.

We ask the sociological literature: “What factors affect the decision-making process, generally?” A review of this literature reveals several theoretical and empirical perspectives.

The Knowledge of Resources Factor and Stratification Issues

The importance of having knowledge of eldercare resources was noted earlier from reports of geriatricians. In the article *Caregivers to Dementia Patients: The Utilization of Community Services*, Caserta et al (1987) comment:

Elder caregivers must have knowledge of community supports if they are to maintain their caregiving. Particularly valuable for families caring for dementia patients are respite, adult daycare, and in-home services that give needed time out from and, also, compliment the care such families provide. (*The Gerontologist*, p. 290)

Knowledge of such eldercare resources may well depend on the presence of the services in the community in which the eldercare provider exists. Different community types are likely to produce different levels of health and human services for their populations. Urban communities, it is expected, would have a proliferation and variety of

health and social service resources that could be applied to eldercare. They should be more resource rich with regard to services and programs to assist the work of the eldercare giver. By contrast, communities that are more rural are likely to have a smaller number of formal services located in the small villages or open farm country for eldercare, and limited diversity in such services (Wilson, 1984; Yenerall, 1999). As is suggested here, eldercare support services are stratified by community type across the landscape of U.S. society. Thus, it is reasonable to suggest that eldercare decision-makers are not on a level playing field with regard to the knowledge of resources to assist their work and, in turn, eldercare decision-making.

The Administration on Aging (1992) has noted that the type of assistance available for individuals and their families varies considerably from community to community. Consequently, depending where an individual eldercare decision-maker resides, more knowledge of resources, (or less knowledge) become critical variables in the eldercare decision outcome. The argument here is that critical knowledge bearing on the actor's action for eldercare is filtered through community of residence. In this research, caregiver's community of residence was differentiated along with his/her knowledge levels regarding resources to assist the work of eldercare giving.

Using the telephone in an attempt to locate resources or agencies illustrates the example of how an individual's residence, and stratification of services, influences the decision-making process. Calling outside one's area of residence may be restricted due to the phone service one has. For example, if someone is living within a fixed budget, and if there are few, if any, resources in the area of residence, toll calls to numerous agencies

outside their area may not be an option. As a result, the simple act of making a phone call has a significant impact for those in the process of decision-making.

Equally problematic, the presence of caregiving resources in the environment does not necessarily translate to the utilization of those resources. Individuals and families may not be aware of the existence of resources such as senior centers, adult day care, meals on wheels, or in-home health care available in their surrounding area. Thus, caregiving decisions are made without the benefit of knowledge of all options.

Resource stratification influences the use of technology within society. This differentiation with regard to the use of modern technology can influence caregiving decisions. It is common to hear ads on the radio directing the listener to a web address in order to find more information, including information relating to eldercare. While this resource is available to some, it certainly is not equally available to all. The utilization of this resource depends on the listener not only having access to a computer, but also having the capability to access the Internet.

In a report for the Leadership Conference on Civil Rights Education Fund, given on September 20, 2005, Robert Fairlie noted the following statistics using “data from the Computer and Internet Use Supplement to the October 2003 Current Population Survey, [w]hich is conducted by the U.S. Census Bureau and Bureau of Labor Statistics.” (p.i)

1. The percentage of the population that had a home computer by race/ethnicity:
(p. 16)

Asian = 77.7%	Central/South American = 53.7%
White = 74.6%	Native American = 51.6%
Other Latino = 68.3%	Black = 50.6%
Cuban = 59.6%	Latino = 48.7%
Puerto Rican = 59.3%	Mexican = 43.9%

2. The percentage of the population that had access to the Internet at home by race/ethnicity: (p.18)

Asian = 70.3%	Central/South American = 43.9%
White = 67.3%	Native American = 40.9%
Other Latino = 54.9%	Black = 40.5%
Puerto Rican = 53%	Latino = 38.1%
Cuban = 50.4%	Mexican = 32.6%

Looking at these results, one can see that even if there is a computer in the home, not everyone has access to the Internet. On the high end, as many as 67.4% (Mexican), and on the low end 29.7% (Asian) do not have access to Internet technology.

The results are more impressive when looking at income and race (results were only available for the White, Black, and Latino population):

1. The percentage of the population that had a home computer by income/race: (p. 23)

<10,000	10 – 20K	20 – 40K	40 – 60K	>60K
White=~42%	White=~46%	White=~68%	White=~82%	White=~92%
Latino=~32%	Latino=~32%	Black=~52%	Black=~75%	Black=~85%
Black=~28%	Black=~30%	Latino=~48%	Latino=~62%	Latino=~82%

2. The percentage of the population that had access to the Internet by income/race: (p. 24)

<10,000	10 – 20K	20 – 40K	40 – 60K	>60K
White=~32%	White=~35%	White=~56%	White=~73%	White=~88%
Latino=~21%	Latino=~22%	Black=~40%	Black=~62%	Black=~80%
Black=~16%	Black=~20%	Latino=~35%	Latino=~51%	Latino=~75%

As can be seen, income has a significant impact on whether or not an individual is able to access the Internet from their home, even if they do have own a computer.

If only looking at those who are in the median range, making between \$20,000 and \$40,000 a year, forty-four percent (44%) of the White population, sixty percent (60%) of the Black population, and sixty-five percent (65%) of the Latino population are

not able to utilize the internet when searching for information on resources relating to eldercare.

Consequently, knowledge of resources, as well as the lack of knowledge regarding available resources, is a stratification issue that can significantly influence the process of decision-making and must be included within a sociological study relating to eldercare.

Family Social Milieu and Eldercare Decision Knowledge

Family sub-culture, which includes norms, values, and beliefs, affects the decision-making processes related to eldercare. Despite knowledge of resources, the individual may not be willing to utilize those resources available due to personal family beliefs and norms about eldercare. An illustration of this is in an interview completed for this study. The individual and his family lived on a working farm in a rural area. This farm had been in their family for over 100 years. The fact that he had lived in this community all of his life would suggest that he likely knew of resources available to him in his role of decision-maker / care-giving. However, when asked what agencies or resources he had contacted he responded “none”. When probed as to why he stated “none”, he replied, “There was no need to contact anyone. We have always cared for our own within our family and I have no intentions of changing that tradition” (Case #30 in Appendix B). This participant’s statement mirrored a comment made by a subject in the study *Family Caregiving in the U.S. – Findings from a National Survey*: “We were raised in our culture to take care of each other” (1997:12) Family beliefs and traditions, then, were the primary factors influencing their decision- making process, providing the rationale for the type of care they chose.

The *Process* of Decision-Making

A common theme of the eldercare literature asserts that once a decision is made the issue of uncertainty will dissipate. Within the study of decision-making related to eldercare, it is rare that only one decision will resolve an issue or problem. More realistic is that eldercare requires numerous decisions throughout the life of the elder. Eldercare decisions are likely to be temporary and do not provide a permanent solution for the elder, the caregiver, or the decision-maker. As the elder's health status deteriorates, several decisions regarding care will likely occur. The eldercare decision developed relevant to heart disease will likely not fit subsequent declines in mobility, vision, hearing changes, and cognitive declines. Future research on the decision-making process must be developed through the perspective of seeing that process as evolving through a sequence of individual, time-bound, decisions.

Sociology of Knowledge Perspective

Although the sociology of knowledge thesis has long and deep roots in the sociological tradition (Mannheim, 1936; Merton, 1968) this study will draw upon ideas provided by Berger and Luckmann (1966). These sociologists assert that creating knowledge is a social process and is a prerequisite to social action(s) (Wallace and Wolf, 1986). That theme is relevant to this study in that knowledge of caregiving possibilities are central to the decision as to what type of caregiving a family or individual should choose for the elder for whom they have care oversight. In that regard, Berger and Luckmann (1966) note that the initial step in the creation of knowledge preceding any decision for action(s) is "externalization". This helps us to understand how it is possible that subjective meanings come to be and become objective facticities.

For Berger and Luckmann (1966), externalization is defined as the process by which individuals, by their own human activity, create their social worlds. The social order is seen as an ongoing human production. The social order is both the “result of past human activity” and it “exists only and insofar as human activity continues to produce it” (Berger and Luckmann, 1966:28). Externalization, then, has two dimensions. On the one hand, it means that human beings can create a new social reality, like forming a new friendship or starting a new business. On the other hand, it means that human beings can re-create social institutions by their ongoing *externalization* of them, like maintaining and renewing old friendships and old businesses, or like paying income taxes (Berger and Luckmann, 1966). In other words, people in specific social situations such as elder-care-giving, create knowledge about these realities either by constructing new institutions or by re-affirming old institutions.

This **knowledge of reality** becomes the basis for the individual’s actions in these situations. In the context of the present study, it is assumed that the externalization process is fundamental to the individual’s “knowledge of reality about care-giving” that, in turn, becomes the basis for their “doing the right thing” regarding care-giving actions. Obviously, the externalization process has various outcomes regarding the content of the knowledge constructed. This study will seek to discover what social or cultural factors may influence the nature of the caregiving knowledge created by individuals and their families and, thus, their caregiving decisions.

A second concept embedded in the Berger and Luckmann thesis is “Objectivation” (Berger and Luckman, 1966). This concept also has utility for this study of caregiving decision-making. *Objectivation* is the process whereby individuals

apprehend everyday life as an ordered, prearranged reality that imposes itself upon, but is seemingly independent of, human beings. As the theorists put it,

The reality of everyday life appears already objectified, that is constituted by an order of objects that have been designated *as objects* before my appearance on the scene. (1966:22)

Language is the means by which objects are so designated. Here, Berger and Luckmann assert that,

The common objectifications of everyday life are maintained primarily by linguistic signification. Everyday life is, above all, life with and by means of the language I share with my fellowmen. An understanding of language is thus essential for any understanding of the reality of everyday life (1966:38).

This study seeks to investigate what *objects* (community resources) caregivers have identified as “obvious” for their care-giving contexts. Careful attention must be paid to the linguistic signification of the caregivers for evidence of the objectification at work in their care-giving decisions. For example, is elder caregiving my responsibility or that of professionals in the larger community? Is caregiving a burden or a “pleasurable responsibility”?

Lastly, Berger and Luckmann (1966) define a final phase in the construction of knowledge and reality process. This they do utilizing the concept of “internalization”. This idea refers to a kind of socialization by which legitimating of the institutional order is assured. For Berger, successful socialization means that there is a high degree of symmetry between both objective and subjective reality and objective and subjective identity. Berger has written that *internalization* means, “[e]verybody pretty much is what he is supposed to be” (1966:164). In this study we may think about internalization as

“common knowledge” of what it means to do the right thing with regard to caregiving decisions; who should care for my mom or dad, and where and how? This knowledge “internalized” is, in reality, conforming to the expectations of existing social institutions--family, religion, and so on. *Internalization* is what we will observe, primarily through words, as the caregivers go about deciding and implementing a course of care-giving actions.

Structures of Social Action (Parsons)

This study also incorporates the fundamentals of “structure-functionalist” perspectives on social behaviors. The decision-making process is, essentially, a social action and as such, strongly influenced by group and cultural forces. This line of theorizing about social behavior can certainly be traced to Durkheim (1951) and, more recently, to the perspectives of Talcott Parsons (1951) and Robert Merton (1968). Specifically, the view taken here is that the events of externalization, objectification, and internalization, inherent in the social construction of knowledge relevant to decision-making about elder care, are events much influenced by the actor’s social milieu. Systems of social action (Parsons, 1951), such as caregiving decisions and activities, are influenced by such “system” factors as (1) *culture and (2) individual actors interacting with each other in a situation where they are motivated toward the optimization of gratification*. Factor number two implies group life, which Parsons referred to as “social system level” in his conceptual framework. This theoretical framework encourages the perspective on caregiving decision-making and actions that emphasizes the group affiliations of caregivers and the associated cultural orientations of these groups. In short, the group affiliations and the associated “sub-cultural” norms and values of caregivers

should very much influence the decision-making knowledge and actions of these people. Here, it is argued that population groups may think differently about the caregiving process and, subsequently, demonstrate different caregiving decisions and implementations. For example, females or wives may have different cultural worlds about caregiving than males or husbands. Likewise, the norms and values of different social class groups regarding caregiving may be quite different. Thus, “doing the right thing” with regard to elder care may vary significantly by gender, social relationships, community type and social class. Certainly, structure-functionalism would offer that prediction for the present study.

Indeed, structural factors, such as economic level of the individual caregiver or his/her family, may limit the type of caregiving purchased. The structural factor of education level achieved will likely result in different “packages” of knowledge about caregiving options possessed by the caregivers. Thus, from the standpoint of functionalist theory, stratification and socialization are conditions and processes that very much influence the social actions undertaken by actors in care-giving situations. This general hypothesis is very much in keeping with the logics of functionalism as developed by Parsons (1951) and Merton (1968).

This research draws on Parson’s concept of the *pattern variables* (Parsons and Shils, 1951). Wallace and Wolf contend that this concept was added to Parsons’ functionalist theory to show that not all social situations are “entirely unstructured and uncertain” (1986:22). The pattern variables categorize expectations and the structure of relationships in various social situations, such as elder caregiving. Drawing upon Toennies’ *gemeinschaft-gesellschaft* typology, Parsons constructed the “expressive”

(choice) pattern variable and the “instrumental” (choice) pattern variable. Relationships in “traditional societies” were labeled “expressive”, as they are predominantly personal and stable. Relationships in modern societies, which are predominantly impersonal or businesslike, were labeled “instrumental” (Parsons and Shils, 1951:77). As noted by Wallace and Wolf (1986), Parsons went beyond a simple twofold typology and developed his pattern variables as a fivefold elaboration of the traditional-modern typology. His definition of a pattern variable became “a dichotomy”, one side of which must be chosen by an actor before the meaning of a situation is determinate for him, and thus before he can *act* (make a decision) with respect to that situation (Parsons and Shils, 1951). In other words, each pattern variable represents a problem or a dilemma that must be solved by the actor before action can take place (Wallace and Wolf, 1986). In this study, elder care giving decisions represent the problem or dilemma to be solved prior to action. Some individuals would be expected to “lean” toward the “expressive” orientation to elder care decision making; while others may be expected to orient their elder care decisions and actions in line with the “instrumental” theme. Table 5 summarizes the pattern variable scheme (see Wallace and Wolf, 1986:23).

Table 5: Parsons’ Pattern Variables

Expressive (Gemeinschaft)	Instrumental (Gesellschaft)
Ascription	Achievement
Diffuseness	Specificity
Affectivity	Neutrality
Particularism	Universalism
Collectivity	Self

Parsons advances the first choice actors must make is between *ascription and achievement*. The problem here is whether to orient ones-self toward others based on

what they are, that is on the basis of ascribed qualities, or on the basis of what they can do or have done (on the basis of performance). Will the elder caregiver orient his/herself according to who the elder is (my elderly mother or father) or according to what the care-recipient can do (a disabled person, a patient)?

The second problem to be addressed with regard to any caregiving situation is the “diffuseness vs. specificity” pattern variable. According to Parsons, the issue here is the range of demands in the relationship. If the number and types of demands or responsibilities are wide-ranging, it is a diffuse relationship; if the scope is limited or narrow, the relationship is functionally specific (Parsons and Shils, 1951). In the context of this study, if the relationship is defined as with my mother or father, husband or wife, much is expected (diffuse). By contrast, if the relationship is defined as with “a patient” or someone in need of care supervision, it is one oriented to “specificity”. In this case, the interest with the relationship is restricted to a particular responsibility, perhaps making sure that the “best possible professional care” is arranged with a nursing home in the area of residence.

The next pattern variable is “affectivity or affective neutrality”. As described by Parsons (1951) the issue is simply whether or not the actor can expect emotional gratification in the relationship. In an example used by Parsons (1951), an engaged couple can certainly expect to relate to each other with affectivity; on the other hand, a high school teacher and student are expected to opt for neutrality. In the context of elder caregiving decisions it is likely that the husband-wife relationship should yield a continuation of “affectivity” oriented choices such as keeping the individual in need of care at home; whereas more distant relationships should produce more affective-neutral

elder care choices, such as putting the elder in need in a personal care home or a nursing home.

As noted in Table 5, the fourth pattern variable is “particularism or universalism”. According to Parsons, the choice here is between reacting to the relationship based on a general norm and reacting based on someone’s particular relationship to you or one’s membership in a particular group (Parsons, 1951).

For this study, the issue may be reacting to your elder care relationship and decision questions based on the norm of securing professional care (universalism) versus arranging care for the “person you love and are devoted to” (particularism). In the context of universalism, the decision is likely to be place the individual in need of care in proximity to experts in the health care field; that is, in a medical institution. The “particularism” eldercare choice would probably involve electing to keep the individual in need of care with you for a continuation of your existing relationship; that is, care at home.

The last pattern variable, known as “collectivity versus self-orientation” involves the dilemma as to whether private interests can be gratified, such as maximizing the pleasures of one’s life, or some collective duty must be fulfilled (Parsons, 1951). It would seem that all caregivers face an issue as to how much they should sacrifice for the well being of the “other”(the elder in need of care) or the “others” (the other family members), in comparison to maintaining the life style that has been their routine. Can one’s interests be gratified if each day is like a “36 hour pattern of intensive care” (Mace and Robins, 1981)? Alternatively, will one be more likely to achieve some semblance of freedom and goal realization if the decision maker gives little or no care, and some outside agency

provides more of the care? (Self-orientation) By contrast, doing the right thing in eldercare may be decided by the collective norms of the family to provide nurture and care within the confines of family resources in the home (Collectivity).

Parsons did not view the pattern variables as mutually exclusive choices (Wallace and Wolf, 1986). Rather, a given society or particular social situation, such as elder care giving decisions, is generally characterized by pattern variables that are related to each other. In particular, the pattern variables falling in the “expressive” category are likely to occur together, as are those located in the “instrumental” category (Wallace and Wolf, 1986). In this study, it is expected that elder care decisions are more likely to follow one set of pattern variables or the other. For example, an elderly woman facing the decision on how to care for her husband of 50 years who is in the first or second stage of Alzheimer’s disease, is more likely to follow the “Expressive” pattern as much as possible—resulting in considerable care being provided in the couple’s home over a relatively long period of time. By contrast, eldercare decisions in the hands of a person who is less close, geographically or personally, to the individual in need of care are more likely to be resolved on the side of the “instrumental” pattern. Here, the care deciders’ orientation would be to institutionalize the “patient” through assisted living placement, personal care home placement, or nursing home placement. Of course, this is a very general illustration of putting Parsonian ideas in practice in this research. In the real world, as the theory suggests, other structural factors, perhaps religion or economic status would be in play in influencing the pattern variables as they relate to caregiving decisions.

The Nature and Type of the Disease and Caregiving Decision Making

Gerontological literature suggests that the nature and progression of the disease experienced by the elderly patient may influence the eldercare decision (Wright, 1991). The care requirements demanded by type of disease and progression of the disease vary and present different “burden” levels for decision makers who may also be caregivers (Zarit, Todd, Zarit, 1986). For example, the care needs of an end-stage Alzheimer’s patient may vary considerably from those of a first-stage cancer patient or an older loved one with heart disease and arthritis. In short, the elderly patient with advanced Alzheimer’s disease may be much harder to care for at home (enhancing the caregiving burden) than the patient with cancer, heart disease, or arthritis.

This perspective reasons that “the nature and progression of the disease” is the most significant variable in the caregiving decision to institutionalize or not. It is certainly a line of thinking about eldercare decision-making that deserves empirical testing. This paradigm sees eldercare decisions linked to level of caregiver burden, in part, as determined by the disease(s) and stage of the disease(s) experienced by those for whom they are responsible. The impact of the elder’s disease is considered in this research as it may influence eldercare decision choice.

Shortcomings of the Literature

The literature on how the decision-making process progresses for an individual or family with regard to eldercare in sociology is limited. The majority of studies focusing on eldercare and decision-making concentrate on relationship matters such as female verses male caregivers; daughter verses son caregivers; and wife verses husband

caregivers. For example, “Gender Differences in Parent Care: Demographic Factors and Same-Gender Preferences” (Lee, Dwyer, Coward, 1993).

This study tested the hypothesis that, when aging parents are assisted in the tasks of daily living by their adult children, the gender of the child providing care depends in part upon the gender of the parent requiring care. (*Journal of Gerontology: Social Sciences* 1993:S9)

Additionally, Phyllis Braudy Harris, Associate Professor, and Director of the Aging Studies Program at John Carroll University published two (2) studies looking at men in the caregiving role. “The Misunderstood Caregiver? A Qualitative Study of the Male Caregiver of Alzheimer’s Disease Victims” (1993)

In-depth interview with 15 male caregivers from diverse backgrounds caring for their wives with Alzheimer’s disease revealed the following common themes: commitment, social isolation, the loss of companionship, control, sense of accomplishment, a problem-solving approach, burden lessening with years of caregiving, and limited expectations of children. (*The Gerontologist*, 1993:551)

The second study, “Listening to Caregiving Sons: Misunderstood Realities” (1998) looked at “30 sons actively involved in caring for a parent with dementia expand the understanding of sons’ caregiving experiences” (*The Gerontologist*, 1998:342).

Another study that focused on siblings and their decision outcomes for elder parents, is *Sisters and Brothers/Daughters and Sons: Meeting the Needs of Old Parents* (2002). This study concentrates on relationships in families. In the Preface the author, Sarah H. Matthews states:

“[S]tress” and “burden” are the principal outcome variables in much of the research literature. Adult children often are forced to describe their experience in these terms. Respondents for this study told

the interviewers how they and their siblings divided responsibility to meet their parents' needs. Most did not characterize this family labor as burdensome but, instead, saw it as an extension of normal family interaction. These findings, which are much more positive than those in the traditional parent-care literature, may alleviate some of the fears about growing old that both adult children and old parents may have. (P.2)

Economics is another area of study that measures the affect of decisions made relating to eldercare. Primarily, the focus of these studies has been to observe matters such as the cost of institutionalized care verses in-home care, how the demands of caregiving impacts the workplace, as well as concentrating on the cost of long-term care. The article: "When Worlds Collide: Elder Caregiving Poses New Challenges for Balancing Work and Life" (1998) is one such study. Published in *Employee Benefits Journal*, Meridy M. Rachor writes:

Elder caregiving's cost to corporate America will continue its steep incline as the baby boom generation matures. ...[L]ast year, the aggregate annual cost of lost productivity to U.S. businesses due to employees providing personal care to the elderly or sick was estimated to be as high as \$29 billion, according to a study by the National Association of Caregivers and the American Association for Retired Persons. (P.3)

An additional study, "The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved" (1999), which combined the efforts of the National Alliance for Caregiving and the National Center on Women and Aging at Brandeis University, took an in-depth look of financial costs and effect of 55 employees who worked and provided eldercare.

In the past, studies have measured the costs of elder-care by approximating the value of the services that would have been required if a family member did not

provide them. This study offers a more complete accounting of the losses faced by caregivers by measuring the long-term effects from wage reductions, lost retirement benefits, compromised opportunities for training/promotion, lost “plum” assignments and stress-related health problems. (P.2)

Numerous studies have come from the disciplines of social work, and psychology; often time collaborating with medical gerontological researchers to conduct their research. One such example, published in the *Journal of Marital and Family Therapy*, is the study “The Last Mile of the Way: Understanding Caregiving in African American Families at the End-of-Life”.

Our study, “End of Life Caregiving and Decision Making in the African American Community”, developed out a felt need to fill a gap in the literature as it relates to understanding the caregiving process and context of African American families. (Turner, Wallace, Anderson, Bird 2004:)

Another example is, “Caregiving for Parents and Parents-in-Law: Is Gender Important?” This study is the result from a collaboration of researchers from the schools of social work and public health. It was published in the journal *The Gerontologist*.

Hierarchical regression models were used to examine the additive and multiplicative effects of relationship status (parent or parent-in-law) and gender on caregiving activities, resources, and costs. Findings indicate that both the caregiver’s gender and the elder’s gender are associated with care provided to and from parents and parents-in-law. Results also show that daughters-in-law are especially vulnerable because they receive few resources from elders. (Ingersoll-Dayton, Starrels, Dowler, 1996:483)

These studies, and others like them, originate from a perspective that begins at the end stage of the decision making process. That is to say, the focus of these analyses begins after the *completion* of the decision-making process.

According to Ludwig von Bertalanffy the term *process* “is a naturally occurring or designed sequence of operations or events, possibly taking up time, space, expertise or other resources, which produces some outcome” (1968:84-85). It is the “outcome”, in which the current literature places the primary focus. Publications concentrating on the actual *process* of decision-making are sparse.

This study focuses on both the process of eldercare decision-making and the outcome of that process ~ the decision to institutionalize or to implement in-home care. Using sociology of knowledge and perspective of functionalism perspectives the decision-making process is seen as a social action, thus influenced by group and cultural forces. These forces include knowledge, beliefs, norms, and values relevant to caregiving. This perspective encourages the researcher to examine factors such as knowledge level and location in society toward a deeper understanding of the decision-making process and outcome.

Structuralism versus sociology of Knowledge and Functionalism Paradigm’s on Eldercare Choices

The pure structuralist paradigm noted in the literature (here as the stratification of resources theme) strongly suggests that caregiver decision makers are locked in by the number of, and variety of, formal services in their communities. Those in urban and suburban communities are situated in “resource rich” situations, this paradigm alleges. This condition provides the caregiver decision-maker with a wealth of alternatives to institutionalization for the elder receiving care. Thus, the institutionalization of the elder is much less likely.

The contrary is true in rural areas and resource poor communities. Research has shown that the supply of nursing home beds in rural areas is greater per capita than is the

case in urban areas (Dalton, Houtven, Slifkin, Poley, Howard, 2002). Additionally, rural areas lack the population scale and financial resources to support a large number or wide variety of resources to assist eldercare givers. Therefore, the structuralist perspective predicts that institutionalization of ill elderly is the more likely caregiving choice in rural areas. These predictions should hold true regardless of the type and severity of the illness or illnesses experienced by the eldercare recipient.

By contrast, the sociology of knowledge and functionalist models, when applied to eldercare decision making, yield different predictions. Here, the knowledge behind caregiving decision actions is socially constructed and should reflect beliefs, values and norms held by the actors (decision-makers)...not the relative availability of formal resources in their environments. The pattern variable orientations (knowledge), expressive or instrumental, should frame the eldercare decision-makers choice. Those with the “expressive” orientation should be much more likely to choose in-home care for the ill elderly under their charge. Those with the “instrumental” orientation should be much more likely to choose institutionalization as the eldercare focus.

Indeed, if the expressive orientation to eldercare is more likely among those living in rural settings, as an outgrowth of “*gemeinschaft*” – then eldercare decision-makers residing in farming areas or small villages should be much more prone to opt for in-home care for their ill elders, regardless of the nature and severity of the illness presented.

These literature and theoretical tensions on eldercare decision-making are addressed in this research.

Methodology

An inductive method approach was used for this study. That is to say, by observing and interviewing those in a caregiving/decision-making role I sought to discover patterns that would contribute to our understanding as to how families and individuals make decisions about elder caregiving. The unit of analysis is the individual who makes decision about the eldercare giving process. The research was completed using a 20-item interview schedule developed specifically for this study (see Appendix).

The interview schedule contains both closed and open-ended items. The questions were designed to secure the socio-demographic, cultural, and social structural level data needed to address the research question. The interview for each of the thirty-three (33) respondents required between 45 minutes to 2 hours to complete. The data from the closed ended questions were coded and entered into an SPSS file. The data from the open-ended items were summarized on a case- by- case basis. Subsequently, the responses given to the open-ended items were subjected to content analysis so that particular themes and variables, embedded in the responses, could be measured. In the main, then, a qualitative method of research was employed.

Conceptual Framework

In line with the decision-making framework for the research, certain socio-demographic variables were significant for the analysis of eldercare decision-making. Thus, the schedule contains questions on the respondent's sex, age group, size of household, length of residence, health status of the elder, health status of the caregiver, educational attainment level of the caregiver, and the occupation of the caregiver.

Social structural factors were included in the conceptual framework and particular items in the interview schedule were designed to collect information about these factors. Notably in this regard were questions dealing with his/her knowledge of relevant social services, and utilization of those social services. An item was included to learn the familial relationship between caregiver and care receiver.

The open-ended items are the main source of data on cultural factors, personality factors, particularly for measuring attachment to the pattern variables. These items asked for a description of the decision-making specifics relevant to the elder care-giving context experienced by each respondent.

The dependent variables are the caregiving decisions made by the caregiver including any subsequent or final decision about caregiving implemented by the caregiver. Data collected from question #9 and question # 13 on the survey was targeted to measure the dependent variable.

Sampling

A “snowball” sampling technique (Babbie, 2000) was used to acquire at least 30 decision-makers for elderly individuals who would be willing to participate with the interview. Individuals known by the researcher to be caregiver decision-makers were contacted first. They, in turn, were asked to identify other caregiver decision-makers they thought might be willing to participate in the study. Overall, 38 individuals were contacted to request an interview. Most, (N=33) of these individuals were most happy to participate in the survey. The interviews were completed in 2003 and 2004 in the homes or work offices of the respondents. The goal of the interview was to obtain as much in-depth data about the eldercare decision-making process as possible, given the time and

financial constraints for this study. All respondents were assured that their responses would be treated in an anonymous and confidential manner. The Duquesne University Internal Review Board (IRB) approved the field research.

Measurement of the Variables

Several of the independent variables were measured using nominal scales. Sex of the caregiving decision-maker was one such variable, as was caregiving decision-maker care recipient relationship. The “pattern variables”, likewise, were measured using the categories established by Parsons (1951) (affective vs. affective neutrality; universality vs. particularism, etc.). A third independent variable, “health status of the care recipient” was measured nominally as follows: Alzheimer’s disease only; Alzheimer’s disease and other illnesses; only other illnesses. Community of residence for the decision-maker was measured as a dichotomy: Urban-Suburban or Rural.

The other independent variables were measured by way of ordinal scales. These included age group of the caregiver, social class of the caregiver (upper, middle, working, lower), health status of caregiver (excellent, good, fair, poor), the positive aspects of caregiving (none, some, many) and the amount of caregiver stress (none, some, considerable).

Interval scales were used to measure the age of the care-receiver, the caregiver’s knowledge of social services (number of services known) and his/her use of social services (number of services used). An “activities of daily living completed” scale was also developed for the care-receivers and was measured by scores ranging from 0-5, depending on the number of activities of daily living normally completed by the elder

care receiver. This variable and measure was considered as a second measure of the “health status” of the care recipient.

Dependent Variable

The caregiving actions, launched by the decision-makers, are the dependent variables for this study. These processed-decisions were measured nominally within two (2) time frames: the initial decision process, the final decision process, if any, using these nominal measures: (1) institutionalized (includes nursing home placement, personal care home, and assisted living facility or (2) in-home (patient or caregiver’s) placement.

The quantitative data were coded and entered into an SPSS file (Statistical Package for the Social Sciences). Descriptive statistical analysis was accomplished for the quantitative variables using the SPSS program. Qualitative data analysis was carried out through the content analysis of the numerous open-ended items in the survey.

Particularly important here were the data on and measurement of “pattern variables”.

In the interview schedule, item #8 asked: “Describe the nature, or type of care, received by (elder’s name).” While item #9 asked: “Please describe for me how you arrived at the decision to have your loved-one cared for in this manner and chosen location”. The responses to these two items were reviewed carefully to measure the pattern variable orientations of the caregiver decision-makers. Specifically, information on the “ascription vs. achievement” pattern variable was sought by focusing on responses that distinguished the patient as a loved one versus the care recipient as a patient.

Similarly, information was gathered from the items that determined if the caregiver decision-maker felt widespread responsibilities toward the care recipient (diffuseness) or narrower care related obligations (specificity).

The third pattern variable is “affectivity” versus “affective neutrality”. From the responses to items #8 and 9, did it appear that the caregiver decision-maker could expect some emotional gratification from his/her role, or not?

Particularism versus universalism, the fourth pattern variable, was operationalized as an action orientation toward getting and relying upon professional care for the elder (universalism) or arranging care informally based on the personal relationship to the elder (particularism).

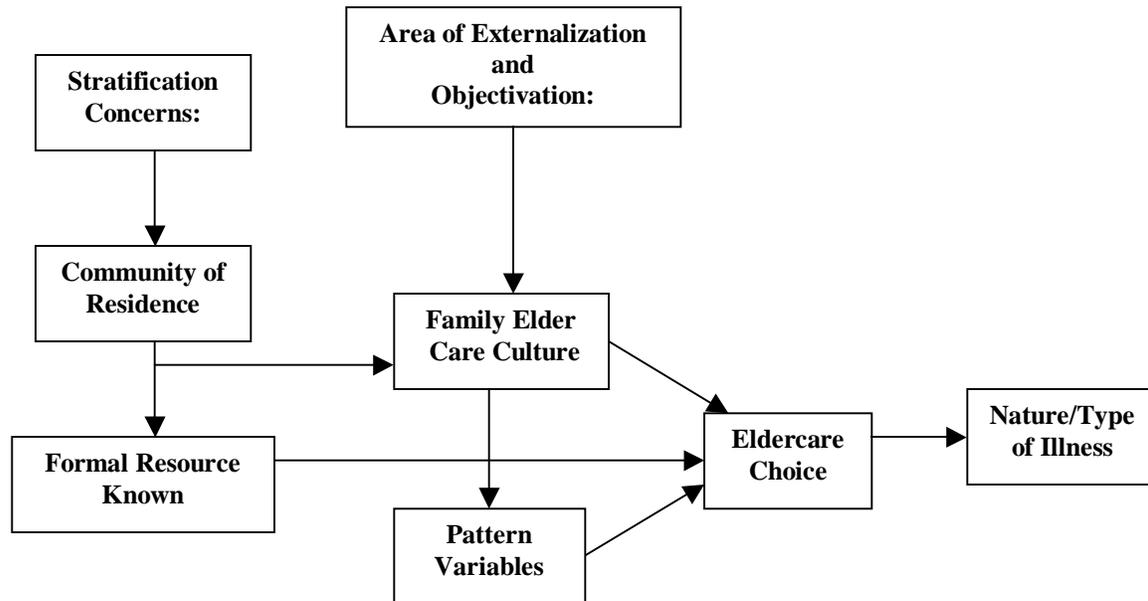
The final pattern variable is “collectivity” as contrasted with “self-interest”. If the respondent answers to items #8 and 9 seemed to describe orientation to protect the needs of himself/herself in the eldercare decision, this response was measured as “self-interest”. Those individuals who suggested in their answers that arranged care based on the larger concerns of the family were typed as the “collectivity” orientation.

Respondents were measured as “expressive” with regard to pattern variables if three or more of their caregiving decision orientations were ascription, diffuseness, affectivity, particularism, and collectivity. Respondents whose orientations to caregiving decisions were marked by three or more of the following were assigned the measurement of “instrumental”: achievement, specificity, neutrality, universalism and self.

Drawing on the theoretical perspectives of the sociology of knowledge particular focus will be given to the concepts of *externalization and objectivation*. Ultimately, two types of “internalizations” (Berger and Luckmann, 1966) will be studied as the dependent variables in this research. The concepts of “time 1 eldercare decisions” and “time 2 elder care decisions” are defined and developed to reflect the dynamic and longitudinal experience often associated with the caregiving decision-making process. Time 1 elder

care decisions are those that were initially made by the decision-makers. Time 2 eldercare decisions represent decisions that followed, including the final decision regarding care made by the decision-maker. (See below)

Overview: Major Explanatory Concepts in this Study



Guiding Hypotheses

The literatures reviewed suggest the following guiding hypotheses for this study:

- Hypotheses 1:** Caregivers residing in rural areas are less likely to know about found social / health care, services than those residing in urban/suburban areas.
- Hypotheses 2:** Rural caregivers are less likely to contact formal social and health care services than those residing in urban areas.
- Hypotheses 3:** Rural caregivers are more likely to choose to institutionalize eldercare recipients, regardless of illness-type, than urban caregivers.
- Hypotheses 4:** Caregiver decision-makers with an expressive orientation to caregiving are less likely to choose institutionalization for eldercare; those with

instrumental orientations are more likely to choose institutionalization.

Hypotheses 5: Caregiver decision-makers whose care recipients have Alzheimer's disease plus other illnesses are more likely to choose institutionalization.

Description of the Sample

Thirty-three (33) individuals completed the interview-based survey during 2003 – 2004. Most of the elder caregiving decision-makers (ECDM) interviewed were females (N=21, 64%). Only 36 percent (N=12) of the ECDM were male. This distribution shows a slight increase of male ECDM in this study when compared to the national level on this matter (36% compared to 28%) (American Society on Aging, 2003)

Most (58%) of the ECDM sample were in the late middle-aged phase of the life course (51-65 years of age). The next most frequent ECDM age group in this sample was early middle-agers (36-50 years old). These interviewees comprised 30 percent of the total sample. Thus, the “sandwich generation” or middle-agers together account for almost 90% of all ECDM surveyed – which is very consistent with national age patterns for caregivers.

This sample was relatively well educated as compared with education attainment distributions apparent in national populations. The range in years of education for this sample was 12 to 22 years. Eighteen percent (18%) completed high school, 12 percent (12%) had post-high school education but did not attain a college degree, and 23 percent (23%) completed a college degree or more.

Regarding the age distribution of the elders about whom elder care-decisions were made, the range of ages was 57 to 98. In this sample, the average age of the elder care recipients was 80 (mean), while the modal age was 78. There is nothing unusual about

this sample age distribution compared to the national population care recipient data.

The vast majority of ECDM had siblings (N=30; 91%). Most of the ECDM sample had one (1) sister (42%) and one (1) brother (46%). These data are important when considering the immediate family (potential) social supports during the care-giving decision making process, perhaps encouraging an in-home elder caregiving decision.

The community of residence distribution for the ECDM was as follows: nineteen (19) resided in urban/suburban places while fourteen (14) lived in rural areas. Thus, 58 percent (58%) of the respondents were based in metropolitan areas; 42 percent (42%) were situated in open farm or small village settlements considerably outside metropolitan areas.

Sample Characteristics: Social Structural Factors

The Decision Maker's Household

Most of the decision-makers were located in multiple person households (N=29; 88%). The modal pattern in this regard was that the ECDM was situated in a two (2) person household (N=17; 52%). Only four (4) ECDM (12%) lived in single person households.

The Elder Care Recipient's Status

Mothers were the most likely statuses to occupy the elder caregiving decisions attention. In this sample they constituted 58% of the cases (N=19). Fathers (N=8; 24%) and "Others" (N=6; 18%) were distant seconds with regard to eldercare recipient's statuses. Thus, six out of ten of these about whom care decisions were being made were mothers.

The Eldercare Recipient's Health Status

The respondents for this study faced eldercare decisions involving very ill people for whom they had primary responsibility. Eleven cases (33%) involved elders with dementia, including Alzheimer's type, and one (1) or more other illnesses. Two of the cases were elders with Alzheimer's disease only. Another 33 percent (33%) of the cases consisted of elders (11) who were suffering with two or more other diseases (e.g. stroke, heart disease, cancer, blindness, diabetes, etc.); while nine (9) cases had one (1) primary disease other than dementia or dementia of the Alzheimer's type (27%).

To further document the quite ill status of the elderly whose care was being overseen by the sample members, two (2) other measures of health status may be reviewed. First, using the Katz Index of Independence in Activities of Daily Living (ADL) it is noted that only six (6) (18%) of the ECDM assigned a score of six (6), indicating complete independence of the elders in matters of activities of daily living. In contrast, eighteen (18) (55%) of the ECDM scored those under their supervision with 0 – 2 scores - meaning no or very little independence in the completion of activities of daily living. This health status confirms those being supervised were in need of significant care.

The Lawton and Brody Instrumental Activities of Daily Living Scale (LADL) was used in this research as yet another way to measure the health status of the aged being cared for. This scale includes eight (8) instrumental activities of daily life (e.g. using the telephone, grocery shopping, taking medications, etc.) and asks whether the person in question can do the activities without help, needs some help, or is unable to do the activity at all. A scale score approaching sixteen (16) would indicate a health status

with little impairment, a scale score-approaching zero (0) is indicative of a health status involving severe activity impairments. Only two (2) of the elderly being cared for (6%) had a scale score of eight (8) or higher while twenty-five (25) (76%) had scores of four (4) or less. Three (3) of the elderly whose care was overseen by members of this sample were unable to complete the instrumental activities of daily living. The ECDM sample was dealing with very ill and dependent individuals.

Time Spent in the Decision-Making Status

The sample population of ECDM was clearly a bi-modal distribution. Many were relatively new to this process having been a decision maker for less than 1-½ years (N=15; 45%). However, thirteen (13) sample members (39%) had been decision makers regarding elder care for more than six (6) years. This “time in decision making” status may affect the knowledge of relevant social services that could influence the decision making process.

Health Care Status

Certainly, the health care status of the eldercare decision-maker could influence the eldercare decision-making choice. Table 6 contains the subjective health ratings provided by sample members.

Table 6: Health Care Status of Decision Makers

Excellent		Good		Fair/Poor	
N	%	N	%	N	%
23	70	8	24	2	6

Almost all (94%) of the sample members rated their health as excellent or good. Thus, in most cases, the health of the individual making decisions, in this sample, should not have impeded or restricted choices of action.

Summary Observation on the Elder Care decision Maker Sample and Those Who's Care was Being Supervised

- The ECDM were primarily early to late middle-age (58%),
- The ECDM household consisted of one (1) or two (2) others in the house (88%),
- Most of the ECDM sample (64%) were women who were related to care recipient,
- Most of the ECDM sample were daughters (55%) making decisions about care for their elderly mothers or fathers,
- All of the ECDM had attained a high school, or higher, level of education,
- Most of the ECDM sample rated their own health as excellent or good,
- Those elders whose care was being overseen by the ECDM sample were quite ill with serious primary illnesses, and several secondary illnesses,
- Those elders whose care was being supervised by the ECDM were very impaired and quite dependent regarding completion of activities of daily living.

Study Findings

Knowledge of Relevant Social Services Resources by ECDM

Prior to the interview surveys, twenty-three (23) social services very relevant to elder care were identified (see Appendix A). Caserta et al study (1987) also found a similar pattern with regard to number of resources known as compared with the number of resources actually contacted for help in the work of caregiving. Each respondent was asked whether he/she knew of these resources. More than seventy (70) percent of the respondents expressed knowledge of nursing homes, meals-on-wheels, home care, and hospice care. This is in contrast to those services known to thirty percent (30%) or less of this sample of ECGDM: Alzheimer's day care, tax benefit services, adult day care policy, senior center policies, and respite care services and policies.

People and Services Actually Contacted in the Decision Making Process

Of course, many different individuals and agencies could be contacted by ECDM during the decision-making process. How many and what types of contacts may be significant factors in the decision-making process. Twenty (20) such individuals or agencies were contacted by the ECDM sample. Only three (3) agencies (15%) were contacted by eight (8) or more ECDM in the decision making process. These agencies, the Office of Aging, Visiting Nurses Agency, and Hospice organizations were used by ECDM in the search for helpful knowledge. The other seventeen (17) agencies (85%), cited by respondents, were used by six (6) or fewer ECDM each.

Thus, it can be noted, that although many in the ECDM sample expressed knowing of numerous social service resources only a small minority of the ECDM actually contacted relevant social service agencies to gain additional knowledge regarding eldercare information. Similar findings were revealed in the study *The Caregiving Boom: Baby Boomer Women Giving Care*, conducted by the National Alliance for Caregiving.

On average, respondents report seeking information from two or three sources. The large majority reports seeking information from one or two sources (34%), another third contacting three or four sources (33%) and 14 percent contacting five or more sources (1998:11)

Culture (Pattern Variable Distributions)

As the reader will recall, this study taps the cultural orientations of ECDM by measuring their pattern variable data (see Parsons, 1951). According to the Parsonian (functionalist) paradigm, the actors (ECDM) must choose between five (5) value and norm dichotomies:

- **ascription** (oriented towards who he/she is) *vs.* **achievement** (oriented according to what he/she can do)
- **diffuseness** (responsibilities are wide-ranging) *vs.* **specificity** (responsibilities are limited or narrow)
- **affectivity** (emotional gratification) *vs.* **neutrality** (emotional neutrality)
- **particularism** (result- in home care) *vs.* **universalism** (result – more formal institutional care)
- **collectivity** (sacrifice for others) *vs.* **self** (self-orientation)

Content analysis of the responses to the open-ended items on the survey was accomplished to place each of the ECDM into one of two pattern variable orientations: “Expressive *vs.* Instrumental”. If a member of the sample had survey responses that reflected three (3) or more expressive type responses, he or she was measured as “expressive” regarding pattern variable orientation. By contrast, if the sample member had survey responses that reflected three (3) or more of the “instrumental” orientation, he/she was measured in that category.

Overall, twenty-two (22) (67%) of the ECDM sample fit in the “Expressive” pattern variable orientation. That is, their belief value and norm perspectives in the decision making process included a personal, emotional, and diffuse orientation toward others; with a willingness to sacrifice personal needs and goals for the well-being of

collectivity (others). Only one-third (N=11) of the ECDM demonstrated responses to the open-ended items that suggested an “Instrumental” value belief and normative orientation to decision-making.

Sociology of Knowledge: Externalization and Objectivication

What knowledge has been created and maintained in the sub-cultures of the ECDM that bears on the eldercare decision-making process? What knowledge was created on caregiving by the interactions involving ECDM and others, including care recipients that influence the on-going elder care process? The relevant knowledge here, from Berger and Luckman’s (1966) perspective, would be that elder caregiving is a human product and that elder caregiving is an objective reality. As a “human product”, elder caregiving can be a more positive or more negative experience; as an “objective reality”, elder caregiving can have high stress levels, or not. In this study, a quantitative measure of the positive aspects of elder caregiving is employed (externalization) as is a qualitative measure of eldercare stress (objectification). Knowledge created and maintained on these matters may affect the nature of the elder care decision-making process. Data on “externalization” and “objectification” were accomplished through content analysis of the open-ended questions of the survey.

In my sample, twenty-two (22) (64%) of the ECDM created knowledge that defined elder caregiving as a (generally) positive experience. Of course, one-third of the respondents defined caregiving as an (essentially) negative experience.

With regard to “objectivication”, the stress levels known to sample members were divided into three categories as interpreted from responses to the surveys open-ended questions: low stress, moderate stress, or high stress. Perhaps surprisingly, most cited a

low-level stress experience (N=16; 48%) for caregiving. An additional 46% (N=15) “knew” the care-giving experience to involve a moderate level of stress; while only two (2) respondents (6%) perceived elder care-giving as highly stressful.

To summarize on the externalization and objectivication measures for this sample, most saw the elder care-giving process as more positive than negative with only a low to moderate stress levels implicated.

Internalizations in the Decision-Making Process: Eldercare Decisions

Berger and Luckmann (1966) defined the internalization event in the process of knowledge creation as “a kind of socialization by which the legitimation of the social order is assured” (P.207). With internalization, there is symmetry between both objective and subjective reality. How the actors think and believe (their knowledge) is replicated in their actions - here in the eldercare decision process. In short, for purposes of this research, “internalization” is measured by a decision process regarding eldercare. In this study, the possibility exists for two (2) “internalizations” during the decision-making process, the initial care-giving decision, and the second or last care-giving decision.

The timing of such internalizations is quite varied. Table 7 displays the distribution of time taken by the ECDM sample to construct the *first* internalization (care-giving decision).

Table 7: Timing of First Caregiving Decision (N=33)

Within Days		Some Weeks		Some Months		Year or More	
N	%	N	%	N	%	N	%
12	36	8	25	6	18	7	21

For more than one third of the ECDM sample the initial caregiving decision process was very fast; within a few days of her/his assuming responsibility for such

decisions. Some of the ECGDM took a few weeks to reach an initial caregiving decision (N=8; 25%). Thus, for more than 60% of the decision-makers the initial decision was made in less than two (2) months. This certainly represents rapid socialization to the caregiving decision-making process; perhaps necessitated by the quick onset of an elder's disease event such as may be the case with a stroke. The rapid socialization may also be brought about by existing belief value and norm orientations (pattern variables) and/or by externalizations and objectivations already established prior to disease onset.

A majority of the ECDM sample has experienced a second decision process regarding eldercare (N=19; 58%). Note, from the data in Table 8, that the second decision process occurred with swift timing. Here, among those making a second decision, almost two thirds took less than two (2) months (some weeks, but less than some (2) months).

Table 8: Timing of the Second Care-Giving Decision (N=19)

Within Days		Some Weeks		Some Months		Year or More	
N	%	N	%	N	%	N	%
6	32	6	32	5	26	2	10

The survey discovered that a minority of the decision makers (14; 42%) needed to make a third caregiving decision. Here the “internalization” is not as efficient as the previous two (2) decisions. (See Table 9)

Table 9: Timing of the Third Caregiving Decision (N=14)

A Few Days		Some Weeks		Some Months	
N	%	N	%	N	%
4	29	4	29	6	42

Note that forty-two percent (42%) of the third decisions required several months of contemplation.

The Internalizations: The Caregiving Decisions

The nature of the caregiving decisions made, as many as three in number, is reviewed with a focus on where and how the elder is receives care. Table 10 reveals that the initial care decision involves much emphasis on some form of home-based care.

Table 10: Initial Eldercare Decisions (N=33)

Elder's Home		Decision-Makers Home		Nursing Home		Personal Care Home		Assisted Living Facility		Senior High Rise	
N	%	N	%	N	%	N	%	N	%	N	%
19	58	4	12	2	6	3	9	1	3	4	12

Decisions were made by sample members to occasion care at the elder's residence (N=19; 58%) or at the sample member's residence (N=4; 12%). Thus, about 70% of the initial decisions did not involve any form of institutionalization, partial or total. This type of eldercare decision process reflects the pattern variable orientation (Expressive) of the majority of the decision-makers. When the decision-maker constructs a caregiving decision from the value and norm orientations of personal and caring responsibilities toward the elder, particularizing the relationship with the elder, and perceiving diffuse relations with the elder, there is a much greater likelihood (25%) of home-based care. (see Table 11).

Table 11: Initial eldercare Choice by Pattern Variable Orientation

Residence	Expressive		Instrumental	
	N	%	N	%
In-Home	22	88	5	63
Institutionalization	3	12	3	37
Totals	25	100	8	100

The ECDM community of residence also appears to differentiate the initial choice about the place of eldercare (see Table 12). Those living in urban/suburban places were more likely (by 18%) to decide to care for the elder at home, either the elder's home or

the caregiver's home. As predicted, rural ECDM were more than two times more likely to choose institutionalization. Thus, there is support in these data for the structuralist (resource stratification) model for eldercare.

Table 12: Initial eldercare Choice by Community Residence of Decision Maker

Residence	Urban/Suburban		Rural	
	N	%	N	%
In-Home	17	89	10	71
Institutionalization	2	11	4	29
Totals	19	100	14	100

Did the disease type control the initial caregiving decision? Table 13 displays the relevant data distributions.

Table 13: Initial Eldercare Decisions by Type of Disease Experienced

Residence	Alzheimer's Only		Alzheimer's or Dementias and Others		One (1) Disease Other Than Alzheimer's		Multiple Other Diseases	
	N	%	N	%	N	%	N	%
In-Home	2	100	9	90	7	78	11	92
Institutionalized	0	0	1	10	2	22	1	8
Totals	2	100	10	100	9	100	12	100

It appears that the disease type does not differentiate eldercare decision; at least not with the initial choice of location associated with the first decision. The eldercare decision to institutionalize was most likely when the older person had only one (1) disease, not dementia, or dementia of the Alzheimer's type. This was counterintuitive in that I felt that those with dementia, Alzheimer's disease and one or more other disease would most likely have their care located in an institution.

The distributions of second decisions rendered (institutionalization #2) by ECDM are arrayed in Table 14. We observe that only nineteen (19) (58%) ECDM made a second

decision. This could mean that in a significant minority of cases no care changes were necessary due to stability of the elder's health.

Table 14: Second Care-Giving Decision (N=19)

Residence		N	%
In-Home	ECGDM	7	37
	Senior High Rise	3	16
Institutionalized Care	Assisted Living	3	16
	Nursing Home	4	21
	Hospice Care	2	10
Totals		19	100

Interestingly the most prevalent second caregiving decision involves moving the elder into the decision-maker's home and rendering care there (N=7; 37%). Also notable, are the decisions to move the locus of elder care to a nursing home (21%) or to an assisted living facility (16%); perhaps indicating the progression of primary and secondary illnesses accompanied by decreasing ability to care for the elder in need in a private residence.

Finally, Table 15 presents the data on the third care decision rendered by the fourteen (14) decision-makers who reported such. The reduction in the number of care-giving decisions may be the result of death of some elders, or relative stability in the health status of some elders following the second decision.

Table 15: Third Care-Giving Decision (N=14)

Residence		N	%
In-Home	ECGDM	5	36
	Elder's Home	3	21
Institutionalized Care	Personal Care	2	14
	Assisted Living	1	8
	Nursing Home	3	21
Totals		14	100

There appear to be two contradictory trends on display in Table 13. First, there are decisions that bring the elder's locus of care back to a home environment. It is appears that thirty-six percent (36%) of these decisions involved moving the needy elder to the decision-makers home for care. Additionally, twenty-one (21%) of the third decisions were to move the elder back to their own home for care. Taken together, these decisions account for fifty-seven (57%) of the total number of third care-giving decisions. Two phenomena may help explain this decision-making pattern. It represents the reality that for some elderly recently treated successfully in an acute or chronic care setting the logical move is to return home. Indeed, the limitations of health insurance programs such as Medicare and Medicaid may dictate the home-care outcome. Beyond the economic explanation for the return to home decision, we are reminded of the role of the "expressive" pattern variable and the externalizations (positive aspects of caregiving) and objectivication (little stress with care-giving) that have been documented as central cultural elements for most decision-makers in this sample. Leaning on the pattern variable externalization/objectivication theme, we find a cultural explanation for one of the third care decision trends.

The second trend evident in these third decision data is about institutionalizing the elder in need. Specifically forty-three percent (43%) of the third decisions result in the elder being moved to a nursing home, to assisted living, or to a personal care facility (see Table 15). This trend is almost identical to that described in the discussion of "second decisions" made by members of this sample. Two perspectives probably account for this trend; institutionalization decisions may be hastened by the progression of the disease, and the associated need to acquire skilled nursing services outside one's personal

residence. Here, some may comment: “the disease makes the decision.” However, a second more supportable perspective here is that our “insurance culture” makes the decision. As Medicare or Medicaid do not cover skilled nursing care in a person’s home, except for limited episodes, the care decision moves in the direction of the institutions that are supported by Medicare and Medicaid, that is, nursing homes.

Knowledge of Resource Services

The structuralist contention is that resource services to support the ECDM and his/her decision will be impacted by community of residence. With regard to this sample does that proposition hold true. Table 16 arrays the relevant data.

Table 16: Average (x) Number of Resource Services Known to ECDM by Community Type

Type of Community	Average Number (x)
Urban/Suburban	10.89
Rural	11.2

Surprisingly, the average number of resource services known to the ECDM was not significantly different for these decision-makers living in urban/suburban or rural communities. In fact, unexpectedly, the rural average was a bit higher than that of the urban/suburban respondents.

Eldercare Decision-Makers Use of Services

The thirty-three (33) eldercare decision-makers contacted Forty-six (46) services. Given the length of time the ECDM were providing care this appears to be a surprisingly low number of such contacts. The average number of contacts with such services was 1.40 per eldercare decision-maker.

The most frequently mentioned of the formal services contacted were those that would support home-based care of the ill elder. Specifically, ECDM cited contacts with

Hospice (7 noted), and Visiting Nurses (7 noted); followed by Home Health Nurses Aides (4 mentions) and support Groups (such as ALS Support Group and Alzheimer support Group – 4 mentions).

As noted earlier, these findings mirror those reported by Caserta, et al (1987).

They note that:

Consistent with what has been reported by others...
it is evident that awareness and access are moderate
at best in their relationship to service utilization.(p.213)
and...

Most of the services that were used by caregivers
consisted of respite, daycare, or in-home care, which
is germane to those providing care to a household
member with Alzheimer's Disease or similar dementia.(p.213)

In addition, the findings of both this study and Caserta's (1987) appear to demonstrate that regardless of caregiver burden and lower informal social support, some caregivers will not utilize services when available because of other considerations, which may need to be the focus of future investigations.

Summary and Conclusions

What have we learned about the nature and dynamics of the elder care decision-making process from the data collected and analyzed in this study? Specifically, what have we learned about the matter of eldercare decision-makers' attempts to "do the right thing"?

First, even from the limited data provided by this sample of thirty-three (33) individuals, the decision-making process with regard to elder care is often quite lengthy. Indeed, thirty percent (30%) of this sample had been participating in the process for more than eight (8) years, with almost one-fifth (1/5) of the sample making such decisions for ten (10) years or more. The extended period of decision-making with regard to eldercare is not frequently noted or discussed in the gerontological literature.

Second, the dynamics of the decision-making process involves numerous separate decisions made often over several years. Often times the decisions must be made quickly, such as when the eldercare decision-maker must decide on possible care changes three times in two years (see case #1 in Appendix B). Yet, the decisions for other overseers may be spread out over six to ten years (see case #3 in Appendix B). The salient point, however, is that the decision-making process associated with elder care is not typically a single decision. Rather, as the data from this study reveals, changes in the elder's health status and the health insurance realities of our culture require that eldercare decision-makers revisit eldercare issues frequently.

Third, for many decision-makers the process bears witness to a "revolving door" phenomenon. Again, disease progressions and health insurance realities often mean that eldercare decisions will move the elder in need in and out of private residences - the

overseer's home, as well as the elder's residence (see cases #2 and #9 in Appendix B). This "back and forth" residential and care changes flowing from decisions also involves institutionalization of the elder for various periods of time. It seems that despite the best intentions for "doing the right thing" for the ill elders the care decisions made inevitably result in residential and health care instabilities. Cultural realities and the current state of economic and medical institutions, including health care insurance protocols, contextualize "doing the right thing" with regard to elder care decision-making.

These data also seem to support the theoretical perspectives of functionalism and the sociology of knowledge as these are applied to an understanding of elder care decision-making at this time in American society. Under the umbrella of modern functionalism, the Parsonian perspective (1951) (see Table 5) decision-making as a social action directed by choices embedded in the pattern variables. In this schema, the master dichotomy involves the "expressive" vs. instrumental relations choices. The content analysis of the study's respondents answers to open ended questions, specifically those that allow them to describe their personal feelings and experiences associated with elder care decision-making, reveals that the majority were oriented to value and norms reflecting "expressive" choices. The pattern value orientation for at least twenty (20) decision-makers was measured as "expressive" (61%). These "choices" reveal a primary group or *gemeinschaft* context for making elder care decisions. This implies providing "home based/family based" care for the elder as much as possible (see cases #1, 2, 6, 7, 8, and 9 in the Appendix B for the "expressive relationship orientation). This finding documented in Tables 10, 11, and 12, indeed helps as we try to unravel why the first,

second, and third eldercare decisions made often result in the elder being moved back to their home, or that of the decision-maker, for care.

Berger and Luckmann's (1966) concepts (sociology of knowledge) assist this analysis as well. Particularly, the ideas of externalization, objectivication, and internalization are helpful in understanding the elder care decision-making process. The definition of the eldercare experiences as more positive than negative fits the theorists' definition of an "externalization" in the decision-making process. Twenty-two (22) of the thirty-three (33) respondents gave evidence of this "knowledge item" (see cases #1, 2, 4, 5, 12, and 13 in the Appendix B as illustrative of this "externalization"). Following the logic of this paradigm, if the elder caregiving experience is essentially positive then the process will likely be viewed as relatively stress-free (objectivication). Indeed, sixteen (16) of the thirty-three (33) respondents (48%) defined elder care matters as relatively stress free; while only two of the respondents perceived, or knew, the elder care process to involve a "high" level of stress" (7%). The "internalizations" here, as elder care decision actions, involve keeping the elder close to home, avoiding institutionalization as much as possible, seem a logical outcome of such knowledge bases.

It was also clear from these data that where the ECDM lives differentiates the choice of institutionalization versus in-home care. As Table 12 describes, urban/suburban ECDM were more likely to choose in-home care for those for whom they had responsibility (89%) as compared with rural based ECDM (71%). By contrast, rural area residing ECDM were almost three (3) times more likely to choose "institutionalization" (29%) than their urban area counterparts (11%).

Perhaps the structuralist paradigm when applied to eldercare decision-making

merits further note. Urban areas have a higher concentration of more diverse formal services to support in-home care of the frail elderly. I have referred to this as the “resource-richness”, relatively speaking, apparent in metropolitan areas. It seems, therefore, that urban/suburban ECDM have easier access to these important supports for in-home care.

However, just the opposite condition exists in the rural hinterland. National data documents more nursing home beds per capita in such areas as compared with urban areas (Dalton, et al, 2002). Thus, structurally, rural areas are more “resource rich” with nursing homes and nursing home beds. Relatively lacking in non-institutional based support services. Access to institutions, then, is easier for the rural based ECDM, thus narrowing his/her caregiving choices.

Hypotheses Revisited

The first guiding hypothesis for this study was:

Caregivers residing in rural areas are less likely to know about formal social and health care services than those residing in urban/suburban areas.

This hypothesis was not supported by the data. In fact, rural ECDM actually had a slightly higher average score on number of services known than their urban counterparts.

Hypothesis 2 stated:

Rural Caregivers are less likely to contact formal social services and health care services than those residing in urban/suburban areas.

As will be recalled from narrative and earlier tabular presentations, this hypothesis was also not supportable. The average number of services contacted and used

by the urban/suburban ECDM was 1.42, while the same statistic for rural ECDM was 1.21. Although the difference in the average number of resource contacts (.21) was in the predicted direction, the average difference was much too small to sustain the logic of the hypothesis. Both urban/suburban based and rural caregiver decision-makers made few external resource contacts, typically no more than three (3). Most of the eldercare decision making involved in-home care, with minimal help with the labor of caregiving.

Hypothesis 3 stated:

Rural caregiver decision-makers are more likely to choose institutionalization for their elderly patients (regardless of illness type) than urban/suburban caregivers decision-makers.

This prediction appears to be substantiated by the data (see Table 12). Rural ECDM are about three (3) times more likely to choose institutional options over in-home care possibilities, as compared with their urban/suburban counterparts. Of course, the majority of rural ECDM (69%) did choose in-home care for those elderly for whom they had responsibility. However, 29% chose institutionalization in one form or another, probably reflecting the abundant resource of nursing home beds in rural areas of the United States. This finding supports the structuralist model reviewed in earlier parts of this thesis.

Hypothesis 4 read:

Caregiver decision-makers with an “expressive” pattern variable orientation to caregiving, are less likely to choose institutionalization for elder-care; those with an “instrumental” orientation (pattern variable) are more likely to choose the institutionalization option.

This hypothesis was formulated from Parsonian functionalist perspectives and sociology of knowledge propositions. The data (see Table) lend clear support for this prediction. Twenty-five (25%) more of the “expressive” oriented ECDM chose in-home care than those ECDM who were “instrumental” oriented. Two points should be stressed here. First, vast majority of ECDM were measured to have the knowledge set labeled “expressive” in this study...with beliefs and values about elder caregiving that involved the pattern variable of *ascription, diffuseness, affectivity, particularism, and collectivity*. Second, almost all of those having this pattern variable orientation toward elder caregiving decision-making chose in-home care options (88%). Overall, these findings support the functionalist model of social action and stress the importance of existing cultural themes directing elder caregiver behavior.

The last hypothesis in this study focused on the health status of the elderly patient as such impacts the choices made by the eldercare decision-maker. Hypothesis #5 stated:

Caregiver decision-makers whose care recipients have Alzheimer’s disease or Alzheimer’s disease plus other illnesses, are more likely to choose institutionalization options.

It is important to remember that the majority of those elderly being cared for were very ill. The Katz Index scores and the Lawton/Brody Scores of these patients as discussed earlier, were very low...documenting that the care recipients were quite sick and much dependent on their caregivers. With that in mind it seems logical to imagine that care responsibilities would be very trying and extensive, suggesting moving the patients to institutions where professional staffs would do the caregiving work necessary.

However, as the data distributed in Table 13 reveal, this was not the case. The type of illness and its apparent severity did not significantly differentiate the eldercare

decision-maker's choice of location for care. The "expressive" cultural orientation to elder caregiving trumped the exigencies of the care recipient's disease or diseases. Here, the disease does not control the decision concerning the care option to be implemented. Cultural orientations and insurance dynamics seem to be far more important in shaping eldercare decisions in the United States.

Some Salient Summary Understandings on the Elder Caregiving Decision-Making Process

- The process may be quite lengthy, eight (8) or more years, yet some decisions must be made quickly;
- The process involves numerous decisions, not one, singular event;
- The process may produce numerous instabilities in the location and quality of care provided the affected elder;
- Value and normative orientations (pattern variables) held by the decision-maker significantly direct the elder care decisions across the duration of the process; (Culture) The density of available eldercare support services influences eldercare choices. (Structural);
- Economic institutions and medical institutions, particularly the protocols of health insurance for the elderly, impact the course of the decision-making process; (Structural)
- Knowledge developed about elder care, before and during the decision making process, influences the care decisions made. Much of the pertinent knowledge must be developed through interaction between care overseers and non-medical and non-social service agencies; (Non-experts – informal informants);
- Type and severity of illness does not appear to differentiate eldercare decisions to institutionalize versus provide in-home care.

Policy Implications

The data reviewed in the course of this research suggest several policy recommendations that bear on the lives of those family members typically trying to do “the right thing” for elders whose care they oversee.

First, the fact that the elder care decision-making process may be lengthy and fraught with changing conditions, suggest that stress and confusions may become pronounced for decision-makers. Serious illnesses related to these stresses and confusions may develop among the decision-makers. This was, indeed, an empirical reality for several members of this sample.

Don't let your own mental & physical health suffer!!
I acquired, after and during Mom's illness, Ebstein-Barr's Syndrome, a cancerous tumor on my neck, depression, and marital problems. You, of course, do not realize or acknowledge while giving intense care how much you are stressing yourself and letting yourself deteriorate. (Case #21)

If you have a difficult time caring for yourself due to stress, being tired and overwhelmed it will be much more difficult to care for your loved one, no matter how much you want to do so. (Case #9)

Family conflicts may also develop between decision makers and others related to the ill elder (Wright, 1991). This consequence was also documented for several members of this sample. A policy suggestion is that social service agencies should develop and promote support groups for elder care decision-makers. These support groups should have educational and counseling components, and they must be well publicized in print literature and media ads; not buried in phone books.

Although members of this sample professed knowledge of various social service and medical organizations in their areas, very few contacted such resources for any type of help or assistance during the duration of the elder care decision-making process. The

lack of contact with these social service and medical organization resources raises the question as to whether the sample members really knew much about these service agencies and their policies. More information is needed by the public on the existence and services of these formal resources.

Nonetheless, decision-makers did note several formal services that they found most helpful in helping them with elder care dynamics. These agencies were, 1) Area Agencies on Aging, 2) Visiting Nurse Agencies, and 3) Hospice Agencies. Clearly, these agencies need continued public support for their helpful service to the families of ill elders. These agencies, and others, need to educate the public about their services that affect elder care at one point or another in the process. About one/fifth of the ECGDM sample offered that none of the social service or medical agencies in their areas were helpful to them during the decision making process. Perhaps all County Offices of Aging should develop a manual that describes social and health care services available for those overseeing health care for an elder in their area. Such information, widely distributed, perhaps through area churches and shopping centers, may enable more overseers to make more informed care decisions affecting the well-being of the elders for whom they are responsible.

Finally, yet conceivably most important, the economic and medical dilemmas experienced by elder health care decision-makers need to be much reduced by a more enlightened health care policy. Specifically, health care decisions are structured by confusing insurance protocols that do not support family or home-based care for the ill elderly. This reality was noted in most of the interviews completed in this research. For the well-being of elders and those who are responsible for their care, a national health

care policy, with substantial provisions for expanded coverage for health care *in their residences*, is long overdue. This would involve much more generous insurance allowances in Medicare and Medicaid for home health care, respite care, and hospice care. Doing the right thing for loved ones will be greatly facilitated with such a policy change that supports existing individual and family cultures of elder caregiving.

Limitations of this Study and Suggestions for Future Research

The limitations for generalizations about eldercare decision-making from a small scale, qualitative research design must be acknowledged. Although the interviews with the thirty-three (33) sample members were lengthy and in-depth, the snowball sampling approach does not produce a random, representative sample. With substantial financial support and more time a national based survey would produce the volume of observations needed to support generalizations about the dynamics of elder care decision-making process.

Using the snowball sample produced a biased sample of observations. For example, all those interviewed were non-Hispanic whites. The sample was devoid of individuals from racial and ethnic minorities. In addition, members of this sample tended to be well educated and most could be situated in the middle to upper middle levels in the American stratification system. Under represented in this sample were the poor, members of the working class, and upper class individuals who were sons or daughters of the care recipients. Essentially, this was a study of the eldercare decision-making concerns of white, middle class people. Future research on eldercare decision-making must expand the size and representativeness of the sample. Certainly more husband or wife caregivers must be included.

Subsequent research on this topic would benefit from data gathering on the religious orientations of the decision-makers. How does religious socialization relate to the value and norm orientations of decision-makers and their eldercare choices.

Additional research on elder care decision-making needs to measure better the perceived positive aspects of elder caregiving that are more apparent in certain group cultures. What nourishes these concepts and how do they influence the elder care decision-making process?

This study raises questions about the socialization process. How much of the knowledge used by decision-makers in the course of formulating a decision is the result of very recent interactions and socialization, as compared with much earlier interactions and socialization? Asking decision-makers what they learned about eldercare responsibilities from childhood and adolescent experiences would be a start. Also, having questions in the survey that secure observations about decision-makers' views about elder care before their involvement with decision-making and after they have been involved would be a methodological improvement in future study. Additionally, as an issue for future research on elder caregiving, is the phenomenon of dual or multiple caregiving protocols. If there are two (2) or more elders in need of care at the same time is the nature of the decision-making process influenced for the ECDM? This research problem has been suggested by Dr. Merrill Silverstein at the University of California, Berkely.

Lastly, future research should pay attention to gender related differences, if any, in decision-making styles associated with eldercare and whether there are differences in

decision-making styles between decision-makers who are also caregivers and those who are not.

In our rapidly aging society, it is very important to build a larger fund of empirically grounded information on matters associated with eldercare to inform aging and family related social and public policy. As Styring and Dueterberg (1997) noted, in the near future eldercare policy issues will be the most important concerns of our society.

Appendix A

Participant Consent Form

Participant Survey

Consent to Participate in a Research Study

“Doing the Right Thing”: A Study of Cross-Generational Eldercare Decision-Making in Community and Disease Context

Investigator: Jeannie Baron-Yenerall
145 Thornhill Drive
Pulaski, Pa 16143
724-964-1173

Advisors: Dr. Norman Conti (412-396-6496)
Dr. Douglas Harper (412-396-6491)
Department of Sociology
Duquesne University

Please place your initials after each statement once you have read the statement, understand the statement, and either have no questions or have had your questions answered satisfactorily regarding the statement.

Source of Support: This study is being performed as partial fulfillment of the requirements for the Masters degree in Social Policy and Public Administration at Duquesne University. _____

Purpose: You are being asked to participate in a research project that seeks to investigate the knowledge you knew, or acquired, as it pertained to the resources available as you went through the process in deciding what type of care, as well as what type of facility would best suit the needs for yourself and your loved one. _____

Risks and Benefits: There are no physical risks to your participation in this study. There may be an emotional risk only in a sense that answering the questions, and discussing your personal situation, may bring memories that would cause momentary sadness, or on the other hand, moments of happiness in remembering certain situations and examples. _____

Compensation: You will not receive any monetary compensation in exchange for your participation in this study; nor will there be any monetary cost to you. _____

- Confidentiality:** Your name will never appear on any survey or research instruments. No identity will be made in the data analysis. All written materials and consent forms will be stored in a locked file in the researcher's home. Your responses will only appear in statistical data summaries. Any materials with your name appearing on it, i.e. appointment dates, notes, etc., will be destroyed at the completion of the research. _____
- Right to Withdraw:** You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time. _____
- Summary of Results:** A summary of the results of this research will be supplied to you, at no cost, upon request. _____
- Voluntary Consent:** I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project. _____
- I understand that should I have any further questions about my participation in this study, I may call Dr. Paul Richer Chair of the Duquesne University Institutional Review Board (412-396-6326). _____

Participant's Signature

Date

Jeannie Baron-Yenerall

Date

Case Number _____

1) Gender: ___ Male ___ Female

2) Age Group: ___ 25-35 ___ 36-50 ___ 51-65 ___ 66-75 ___ 76+

3) How many individuals are in your home and what is the relationship of those individuals to yourself, as well as their age?

___ (1) Only Self _____

___ (2) Self _____
________ (3) Self _____

________ (4) Self _____

________ (5) Self _____

________ (6) Self _____

4) What is the relationship to you of the individual for whom you are the decision-maker? What is/was the age of this individual _____?

___ Husband ___ Wife ___ Mother ___ Father ___ Child

___ Brother ___ Sister ___ Aunt ___ Uncle ___ Cousin

___ Other (please specify) _____

5) How long have you been/were you the decision-maker for this individual?

___ 1-6 months ___ 7-12 months ___ 13-18 months ___ 19-23 months

___ 2-3 years ___ 4-5 years ___ 6-7 years ___ 8-9 years

___ 10 years ___ more than 10 years (please indicate the number of years) _____

6) Where does the individual for whom you are the decision-maker for live?

___ his residence ___ her residence ___ your residence
___ nursing home ___ personal care home ___ (_____)

7) Please tell me which of the following illnesses and/or difficulties your loved one has experienced:

___ **Stroke** Date(s) diagnosed _____
___ mild physical effect ___ moderate physical effect ___ severe physical effect
___ mild mental effect ___ moderate mental effect ___ severe mental effect
___ unsure of physical effect ___ of mental effect

Comment _____

___ **Dementia** Date diagnosed _____
___ mild effect ___ moderate effect ___ severe effect ___ unsure of effect

Comment _____

___ **Alzheimer's Disease** Date diagnosed _____
___ 1st stage ___ 2nd stage ___ 3rd stage ___ unsure

Comment _____

10) Which of the following programs or resources were/or are you knowledgeable about.

	<u>Yes</u>	<u>No</u>
a) Nursing homes in your area.	_____	_____
b) Nursing home admission's policies.	_____	_____
c) Medicare policy on nursing home stays and insurance coverage.	_____	_____
d) Medicaid policy on nursing home stays and insurance coverage.	_____	_____
e) Personal Care facilities in your area.	_____	_____
f) Admissions and financing policies with regard to Personal Care Home stay.	_____	_____
g) Assisted Care facilities in your area.	_____	_____
h) Admissions and financing policies relative to Assisted Care facilities.	_____	_____
i) Meals on Wheels program in your area.	_____	_____
j) Home Health Care programs in your area.	_____	_____
k) Cost and means of payment for Home Health Care.	_____	_____
l) Hospice Care programs in your area.	_____	_____
m) Hospice Care financing policies.	_____	_____
n) Adult Day Care programs in your area.	_____	_____
o) Cost and means of payment for Adult Day Care	_____	_____
p) Senior Center programs in your area.	_____	_____
q) Cost and means of payment for Senior Center Programs.	_____	_____
r) Alzheimer's Day Care programs in your area.	_____	_____
s) Cost and means of payment for Alzheimer's Day Care.	_____	_____
t) Respite Care programs in your area.	_____	_____
u) cost and means of payment for Respite Care	_____	_____
v) State supported tax benefits for at-home eldercare providers.	_____	_____
w) Transportation programs for the needy aged.	_____	_____

11) What agencies, resources, or programs, if any, did you contact and at what level of support did they offer in assisting you?

Agency/ Resource	No Help	Some Help	Moderate Help	Very Help

12) Were there community agencies that you found to be most helpful in assisting you during the decision-making process? If yes, please tell me those agencies and briefly state what assistance they offered.

13) How long was it from the time you realized that you would need to make a decision rearing the care of your loved one, to the time that a decision was made?

1st Decision:

Number of days_____

Number of weeks_____

Number of months_____

A year or longer_____

2nd Decision:

Number of days_____

Number of weeks_____

Number of months_____

A year or longer_____

3rd Decision:

Number of days_____

Number of weeks_____

Number of months_____

A year or longer_____

14) Were/are there individuals who you found/find to be helpful to you are you proceeded with decisions relating to elder-care? _____Yes _____No

If yes, what is/was their relationship to you? (No names are necessary)

15) Do you have siblings? _____Yes _____No

If yes, how many sisters _____ and/or brothers _____ do you have?

16) If you have siblings, how did the decision come about that placed you in the role of “guardian”, “power of attorney” or over all “decision-maker”?

17) Is there any other information you could provide about the elder care decision-making process that we have not covered in this interview?

18) If a friend asked you for advice relating to elder care what one or two points would you offer?

19) How many years of formal education have you completed? _____

20) What has been your primary occupation? _____

Are there any additional comments that you may believe may be helpful or that you want to share?

Appendix B

Case Study Narratives and Time-Lines – Cases #01 - #33

Case Number: 001

Decision Maker: Daughter

Age Group of Decision Maker: 51 – 65

Length of Time Daughter was Decision Maker: 19 – 23 months

Elder: Father

Age of Elder: 81

Primary Illness: Stroke

Katz Index Score: 1

Secondary Illness: Paralysis, Depression, Irregular Heart Beat

Lawton/Brody IADL Score: 0

This is a situation in which the father experienced a stroke that caused severe physical effects and moderate mental effects. At the time, the daughter was working but stepped in to begin her role as “decision maker”.

The father spent approximately 9 days in the hospital and then, due to the physical effects caused by the stroke, he needed to be transported to a rehabilitation center. The daughter states she had 3 days to decide where her father would be placed. He spent 4 days in the rehabilitation center and then, due to an accident, was transported back to the hospital; where he stayed for almost 3 weeks. During this time, the daughter was conducting research and visiting centers for the purpose of placing her father in a different rehabilitation center where he would also receive skilled nursing care. The decision to place him in such a center was primarily due to the fact that her mother was unable to care for her husband due to her own medical difficulties, both brothers lived a bit further away and could not keep him in their homes due to their need to work, and she was also working full time. The primary reasons for choosing the center that was settled on was based on the location, the cleanliness of the center, and the type of care that would be provided. While he was a patient in this facility his wife spent her time there during the day, and the 3 siblings took turns spending evenings and weekend with him.

The father spent 14 months in the skilled care facility, after which time the daughter took early retirement and moved her father to her home. While she thought about this decision through the year she believes it took about a month to seriously consider this option and to start making the arrangements for the move. Her decision was made because she felt, and her mother and siblings concurred, that by moving him to a more intimate setting his emotional state would improve and his life would be more comfortable. She states that his emotional state did, indeed, improve and that “he loved being with family”.

Her father’s medical condition included paralysis of the right side, depression, incontinence, enlarged prostate, weight loss, chronic urinary tract infections, multiple infarctions, insomnia, and seizures. He was able to enjoy almost 4 months with his family before it was necessary to transfer him to the hospital due to experiencing another stroke. He died 1 month after being admitted in the hospital.

Timeline:

Hospital>>>Rehabilitation>>>Hospitalization>>>Rehab/N.Home>>>Daughter’s Home>>>Hospital
(9 days) (4 days) (3 weeks) (14 months) (3 months) (1 month)

↓
Daughter Begins Role as “Decision Maker”

Most helpful outside resource(s): Visiting Nurses

Additional advice or comments: Look for the best facility close to family, make decisions based on loved one’s level of care, having a support system is extremely important.

Case Number: 002
Decision Maker: Daughter
Age Group of Decision Maker: 51 – 65
Length of Time Daughter was Decision Maker: 1-6 months
Elder: Mother
Age of Elder: 86
Primary Illness: Stroke
Secondary Illness: Dementia

Katz Index Score: 4
Lawton/Brody IADL Score: 3

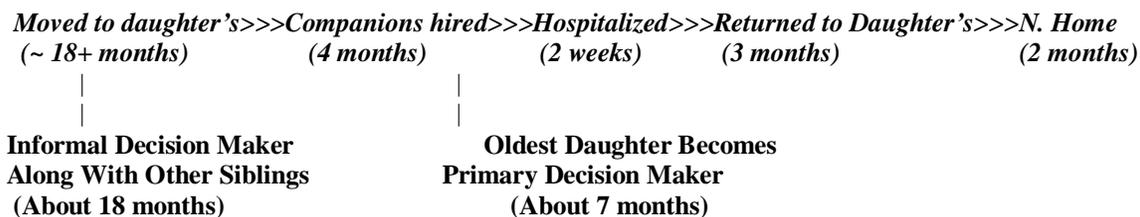
This individual's mother experienced a stroke that caused mild physical and mental effects. While this had not been her first stroke, the family felt it would be in her best interest, due to her age and the fact that she resided in another state, to be moved in to the home of one of her daughters. She also had osteoarthritis, which was causing mobility difficulties.

The daughter that accepted the role was the oldest sibling, as well as someone who had extensive medical knowledge. Her husband was at home daily thus allowing for a more secure atmosphere for her mother to reside.

During the initial 18 or so months, the role as "decision maker" was rather informal and included all 3 siblings. However, the mother-developed dementia and begun needing more care. At this time "companions" were hired to spend time with, and watch over, the mother. Once more and more decisions were being made regarding the mother's condition and needed care, the sisters decided that it was necessary to have a more formal, or legal, document so that decisions could be made without delay.

For 3 or 4 months the companions helped with ADL (activities of daily living) care for the mother, as well as helping the husband care for the house. The mother was hospitalized for 2 weeks in order to do a thorough evaluation of her mental and physical status. She was able to return home (her daughter's residence) for 3 months, after which time she was admitted to a skilled nursing facility. Her mental and physical condition declined rapidly and she died 4 months later.

Timeline:



Most helpful outside resource(s): Church

Additional comments or advice: Accept support

Case Number: 003
Decision Maker: Daughter
Age Group of Decision Maker: 51 – 65
Length of Time Daughter was Decision Maker: \geq 10 years
Elder: Mother
Age of Elder: 91
Primary Illness: Dementia
Secondary Illness: Cancer

Katz Index Score: 2
Lawton/Brody IADL Score: 1

Daughter's decision making role began more than ten (10) years earlier and four (4) years after the mother was diagnosed with breast cancer; although the mother lived in her own residence until several years later.

Twelve (12) years later the mother was diagnosed with "severe" dementia and needed round the clock care. She lived with the daughter for approximately three (3) months but was very unhappy and wanted to move back to her home. For the next nine (9) months the mother was able to stay in her residence. Her daughter stayed with her during the day and an assistant was hired to stay with her through the night. During this time period the cost of a private assistant and the strain on the daughter became very difficult. It was decided that the mother would be admitted to an assisted living facility where she received total assistance with all ADL, with the exception of feeding herself. She stayed at the assisted living facility for two (2) years; at which time she was admitted to a psychiatric hospital for an evaluation. While in the hospital she contracted pneumonia. After she recovered, somewhat, she was transferred to a rehabilitation center for one (1) month so that she could receive physical therapy. She was then transferred to a skilled nursing facility and remains a resident at this time.

Timeline:

Her Home>>Daughter's Home>>Her Home with Assist.>>Assist. Living>>Hospital>>Rehab>>

| (3 months) (9 months) (2 years) (~2 wks) (1 mo)

In Nursing Home @ Present Time

**Daughter Assumed the Role
 Of Decision Maker Several
 Years Prior to Her Mother
 Moving in With Her**

Most helpful outside resource(s): Meals on Wheels

Additional comments or advice: "Don't do it"

Case Number: 004
Decision Maker: Son
Age Group of Decision Maker: 51 – 65
Length of Time Son was Decision Maker: 7 - 12 months
Elder: Mother
Age of Elder: 90
Primary Illness: Diabetes
Secondary Illness: Heart

Katz Index Score: 2
Lawton/Brody IADL Score: 0

During all of their years of marriage his mother and father were inseparable, so it was very important that any care she needed be given in her home. Up until his father had a stroke he provided most of the care his wife needed. After his stroke, however, if became necessary for someone else step in to assist in making any necessary decisions. It was at this time that this son, the oldest living son, and his family accepted more responsibility in making decisions.

His mother had been wheelchair bound for about seven (7) years due to blindness caused by diabetes, hearing loss and fragility due to aging; thus she needed constant care.

This family had a good support system for each other and came together to share responsibilities and to help care for the mother. They did have hospice come daily to bring any needed supplies, as well as provide services, which helped with the activities of daily living. In addition to hospice, two (2) CNA (certified nursing assistants) came four (4) times a week to stay with her when necessary and to help with any ADLs. Many times dinner would be prepared, or brought, to the parent's home in order for everyone (son(s), daughter-in-law(s), and grandchildren) to share dinner together. The mother never had to leave and was able to die in her home.

Timeline:

Homecare provided by the husband>>>Homecare with son, aides, hospice, & family
(Approximately 4 years) (Close to a year)

|
 |
 |
 |
**All Decisions and Care Provided
 By the Husband**

|
 |
 |
 |
**Decision Making Responsibilities Assumed
 By Son**

Most helpful outside resource(s): Hospice and Meals on Wheels

Additional comments or advice: 1) If there is family, decisions should be made together
 2) We did not realize she was eligible for VA benefits, more information should be given."

Case Number: 005
Decision Maker: Son
Age Group of Decision Maker: 25 - 35
Length of Time Son was Decision Maker: 7 – 12 Months
Elder: Father
Age of Elder: 66
Primary Illness: Brain Tumor
Secondary Illness: N/A

Katz Index Score: 3
Lawton/Brody IADL Score: 2

The situation with this family came in acute manner when the father was diagnosed with a malignant brain tumor. While it was known that his condition was terminal, it was hoped that removing the tumor and receiving radiation treatment his life would be extended. The surgery was performed and successful in removing the tumor. He then had radiation treatment for four (4) weeks. However, within two (2) months the tumor returned.

For the next nine (9) months the family cared for him in his home. His condition deteriorated quickly and the last three (3) weeks of his life he was admitted in to a nursing home in hopes that he would receive the best care possible and be kept as comfortable as possible.

Timeline:

Hospitalized for Surgery/Treatment>>>In Home Care>>>Transferred to Nursing Home
(Off & on for 1 months) (9 months) (3 weeks)

|

Son shares role of decision-maker with mother

Most helpful outside resource(s): Hospice

Additional advice or comments: None

Case Number: 006

Decision Maker: Daughter

Age Group of Decision Maker: 25 - 35

Length of Time Daughter has been Decision Maker: 6 – 7 years

Elder: Mother

Age of Elder: 64

Primary Illness: Dementia

**Secondary Illness: Severe Osteoarthritis, Severe Asthma,
Unstable Vertebrae**

Katz Index Score: 2

Lawton/Brody IADL Score: 2

Although the daughter has her own young family (husband, 9 year old daughter, 10 year old son, and 11 year old daughter) and works full time, she goes to her mother's home daily to bathe her and provide assistance with regard to ADLs. Her father lives in the home with her mother but he has physical and mental difficulties and is considered legally blind. He is also someone who is "very mean" to his wife and is simply unable to contribute care for his wife.

The mother developed asthma approximately ten (10) years ago that causes severe attacks and requires the administration of many drugs to assist in controlling the attacks. Additionally, she suffers from osteoarthritis and takes narcotics in order to control the pain. A few years ago she had to have a rod inserted into her back to stabilize her back due to calcification of the cervical vertebrae. She also has experienced hardening of the arteries, which has caused dementia to develop; and she high blood pressure and has lost most of her eyesight.

Her daughter has decided to care for her mother for as long as she can because, as she states, her mother is a very private person and because she (the daughter) worked in a nursing home she is of the belief that they are notoriously understaffed; thus, she would not be comfortable in placing her mother in an institutionalized setting.

Timeline:

**Cared for in her home primarily by her daughter
(6 – 7 years)**

Most helpful outside resource(s): Hospital Social Worker

Additional advice or comments: None

Case Number: 007
Decision Maker: Daughter
Age Group of Decision Maker: 36 - 50
Length of Time Daughter was Decision Maker: 1 – 6 months
Elder: Mother
Age of Elder: 77
Primary Illness: Cancer
Secondary Illness: N/A

Katz Index Score: 6
Lawton/Brody IADL Score: 6

This daughter and mother lived in different states and it was not until her mother was hospitalized and diagnosed with stage four cancer did she know that her mother's health had been failing. As she stated "[w]hen my mother was first hospitalized, she had lied and hid her failing condition for so long, she was almost dead."

The daughter came home to stay with and assist with all aspects of her mother's needs. After the mother's initial hospitalization (15 – 17 days), she was to receive six (6) chemo treatments three (3) weeks apart. The first chemo treatment was in the hospital. She was then transferred to a skilled nursing facility to receive rehabilitation to help her speak, get on her feet, and learn to feed herself through her feeding tube. The tumors and chemo had done damage to the involuntary and voluntary muscles and nerves in her throat and she could no longer really eat or speak.

She then came home and received visiting skilled nursing care. She was transported via ambulance for her next three (3) chemotherapy treatments. After the mother's initial return home from the hospital the daughter stayed for an additional three plus weeks, until right before the third chemotherapy treatment. Because the mother seemed much better after the 2nd treatment the daughter returned to her home. The brother and a friend stopped by the mother's home daily and the daughter called her daily.

Right before the fifth chemotherapy treatment the daughter returned to her mother's and stayed an additional two (2) weeks. The mother had never really felt well since her 3rd treatment and continued to get worse over several weeks. Finally, due to her weakness, inability to consume food, even through the feeding tube, and the onset of severe headaches she was admitted in to the hospital again. At this point the cancer has spread to her spine and brain. The daughter authorized that all treatment be stopped, including food and water, except for those medications that controlled her mother's seizures and pain. The daughter then had her transferred to a skilled nursing facility and hospice was called in. The mother died three (3) days later.

Timeline:

Hospital>>>Rehab Cntr>>>Home with Visiting Nurses>>>Hospital>>>Skilled Nursing Facility
(2+ wks) (2-3 wks) (4 months) (4 days) (3 days)

|
|

Daughter had always been authorized Decision Maker. Mother resigned living will every year

Most Helpful Outside Resource(s): Insurance Company Nurse, Hospital Social Worker, and Hospice

Additional advice or comment(s): 1) My Mother's condition actually dictated the decisions. Had the situation been more chronic, I was glad that I had her long term care policy in place. I convince her that it was important to get because it would give her more choice, if something happened. I split the annual premium with her and it gave me peace of mind. Unfortunately, once a need is imminent, long-term care policies are not an option.

2) It makes it a lot easier if the person making the decisions is close to their loved one and can freely discuss their desires in this type of situation. My decisions were made by my Mother; even if they were not communicated at that time.

3) I would maybe suggest that people with EAP's (employee assistant program) through their employers or therapy benefits talk to someone regarding their own personal fears and concerns regarding illness, aging, and dying. How can one be expected to make these types of decisions for someone when they are afraid to consider them for themselves?

Case Number: 008
Decision Maker: Son
Age Group of Decision Maker: 51 - 65
Length of Time Son was Decision Maker: 13 - 18 months
Elder: Mother
Age of Elder:
Primary Illness: Heart
Secondary Illness: Diabetes

Katz Index Score: 2
Lawton/Brody IADL Score: 3

His mother had a moderate heart attack during a time when his father was being cared for in a nursing home facility. While in the hospital she had an angioplasty and was placed on a regiment of medications for her heart. Her heart condition was also complicated by arthritis and insulin dependent diabetes.

After she stabilized she was able to return to her home and resume a rather normal routine. Several months after the heart attack she sold her two-story home and bought a one-story home in order to remove some of the physical strain that was unavoidable in caring for a larger home. Though she was able to maintain her life-style she enjoyed prior to the heart attack her family and friends looked in on her frequently.

Almost a year later she suffered a severe heart attack and was life-flighted to the hospital where a pacemaker was implanted and another angioplasty was performed. She was diagnosed as having congestive heart failure and given less than one year to live

Neither she nor her children wanted her in a nursing home, particularly given her husband's experience when a residence in one. During the last 8 months of her life she had visiting nurses and hospice at-home care, additionally, her children and other family members visited daily.

Regarding the decisions that were made, her son stated the following: "Given my mother's desires regarding lifestyle and living at home, and our interest in keeping her within her home was very important in the decision-making. Also, my mother had numerous family and friends in her home town to provide care and oversight routinely."

Timeline:

Home>>>>Hospital>>>>Home>>>>Hospital>>>>Home with Skilled Nursing and Hospice
(2+ weeks) (1 year) (2+ weeks) (8 months)
 |
 |
(Son begins role as Decision Maker)

Most helpful outside resource(s): Visiting Nurses, Hospice

Additional advice or comment(s): My father's decline associated with a massive stroke was a contextual matter in care-giving decisions for my mother.

Case Number: 009
Decision Maker: Niece
Age Group of Decision Maker: 36 - 50
Length of Time Niece was Decision Maker: 1 - 6 months
Elder: Aunt
Age of Elder: 79
Primary Illness: Stroke
Secondary Illness: Alzheimer's Disease

Katz Index Score: 2
Lawton/Brody IADL Score: 3

The aunt and mother of decision maker were sisters and lived together for many years; as a result, even though they lived in different states the aunt and niece were very close. The year prior to the aunt having a stroke she was diagnosed as having Alzheimer's disease. Once she experienced a stroke, which had minor physical effects and moderate mental affects, the symptoms of Alzheimer's progressed quickly. While the aunt was in the hospital the niece went to see her and to speak with her physician. While visiting there were discussions with her son and daughter as to what may be in her best interest. Due to the closeness of the sisters it was thought that both would do better if they were able to stay together. The sister felt strongly that she wanted to try to care for her sister. While being cared for by her sister in their home, her daughter made trips to help out the best she could. The daughter lived over an hour away, worked full time, and had a family to care for, consequently it was difficult for her to provide the kind of help that was needed. The son lived much closer but for unknown reasons provided minimum assistance. After 2 – 3 months the sister thought it was too difficult to provide the kind of care her sister needed and it was therefore decided, by her daughter and sister, that she needed to be admitted to a skilled nursing facility.

The aunt was transferred to a nursing home that was located closer to her daughter. She was there for _____. No one in the family was comfortable with her being there and it was at this point the niece offered to care for her. Because arrangements had to be completed the aunt moved back to her home (with her sister) until the niece was able move her.

Within a couple of weeks the aunt was moved into her niece's residence. Many arrangements had to be made in order for the niece to continue working yet making sure her aunt was not left alone. Consequently, every morning the aunt was driven to another relative's home to be watched over during the day and then picked up after the niece had completed the workday. Additionally, the niece had other obligations requiring her to be away two (2) evenings a week. A home health care assistant was hired to stay with the aunt during those times.

A month after the niece assumed the responsibility for her aunt, her mother also moved in with her. During this time she lost her job, where she had been employed for more that fifteen (15 years). There were two (2) reasons for this, 1) several changes relating to her work schedule were necessary in order to accommodate her role as care-giver, and decision maker for her aunt and mother, and 2) her employer did not philosophically agree with her decision to assume the role of decision-maker and care-giver for her family members; believing that this task was so monumental that she would not be able to fulfill her employee role responsibilities.

Inside a month of the aunt's move she suffered another stroke and was hospitalized for one (1) week. After her discharge and due to her insurance requirements, she was admitted to a skilled nursing and rehabilitation facility. The paperwork, and time required for the process of the paper work to be completed in order for the insurance to pay for the aunt to be care for in her niece's home, was very lengthy (a minimum of 1 month) and the aunt died before being able to return to her niece's home. Her death occurred five (5) months after moving in with her niece.

Case Number 009 Continued:**Timetable:**

Home>>Hospital>>Home w/Family Assist>>Nursing Home>>Home w/Family Assist>>
 (≤ 1 wk) (~2 months) (< 1 week) (2+ months)

Transferred to Niece's Home>>Hospital>>Nursing Home

|

Niece assumes role as decision maker

Most helpful outside resource(s): Physician, Physician's Social Worker, Nursing Home Director

Additional advice or comment(s): 1) Make sure all legal affairs are in order; i.e. obtaining power-of-attorney.

2) Try to learn of elder's wishes regarding care prior to finding yourself in a situation that requires you make all decisions based on what you think the elder would want.

3) Accept help. If you have a difficult time caring for yourself due to stress, being tired and overwhelmed it will be much more difficult to care for your loved one; no matter how much you want to do so.

Case Number: 010
Decision Maker: Daughter
Age Group of Decision Maker: 66 - 75
Length of Time Daughter was Decision Maker: 8 – 9 years
Elder: Mother
Age of Elder: 92
Primary Illness: Stroke
Secondary Illness: Heart

Katz Index Score: 4
Lawton/Brody IADL Score: 0

The elder in this situation has experienced numerous mild strokes over the past several years, as well as open-heart surgery in the more recent years. Her age and the aforementioned maladies has contributed to her physical status. At this point, however, one of the primary incidents that occurred was a fall that produced a severe break in her femur, which required surgery to insert pins and plates in order to stabilize the femur. While recuperating after the surgery she developed a blood clot and needed additional hospitalization. From the hospital she was transferred to a rehabilitation center in order to receive physical therapy. Once her therapy came to an end she returned to her home. She continued to fall. Another contributing factor was the considerable loss of her eyesight. Because of her physical difficulties it became necessary to place her in an assisted living facility. The assisted living facility was chosen because the daughter did not feel she and her husband could care for her in their home.

She resided at the assisted living facility for approximately one (1) year – until she became ill and had to be hospitalized. From the hospital she returned to a rehabilitation center to help her regain her strength. After a couple of weeks of rehabilitation she was transferred to a skilled nursing. At this time, she has resided there for four (4) years.

Timeline:

Hospital>>>Rehab>>> Elder's Home>>>Assisted Living>>>Hospital>>> Rehab>>>N.Home
(3 wks) (1 mo.) (2 months) (1 year) (2 wks) (3 wks) (4 years)

|
 |
Daughter had been Decision Maker for several years prior to this hospitalization

Most helpful outside resource(s): Private physician

Additional advice or comment(s): When technology can keep you alive do you really want it?

Case Number: 011
Decision Maker: Son
Age Group of Decision Maker: 66 - 75
Length of Time Son was Decision Maker: \geq 10 years
Elder: Mother
Age of Elder: 93
Primary Illness: Stroke
Secondary Illness: N/A

Katz Index Score: 4
Lawton/Brody IADL Score: 3

Even though the son stated that he had been the Decision Maker for ten (10) years, he also stated that he has "always taken care of her."

Up until two (2) years ago his mother was quite healthy. It was at that time she experienced a stroke, which caused moderate physical effects and, at the time, only mild mental effects. At this point, he states that the mental effect has progressed to moderate in that she has also been diagnosed with dementia. In addition, her eyesight has decreased so that she now only sees shadows.

He wants to place her in to an assisted living situation but she is not willing to make that move. He stated that it took several years to convince her to move in to a senior high-rise because he felt she would be safer and would not be alone. Once she moved in to apartment she suffered from depression for approximately six (6) months. She then became more active in participating in various activities and began feeling better. Since losing her eyesight she has become depressed once again. He has hired an individual to come in the morning to help her get dress, make sure she takes her medication, and gets her settled in for the morning. She also comes several times during the day to make sure she is all right. In addition, she runs any errands that may need done through out the day. The son also speaks to often and checks on her several times a week.

When asked why he, and not his brother or sister, is responsible for his mother he stated; "I'm the oldest...she's my mother and needs to be taken care of." Although, he also stated that "I feel that my brother and sister could do more to make it easier for her".

Timeline:

Private Home>>>>>>>Senior Citizen High Rise with daily assistance
(3 years)

Most helpful outside resource(s): Private Physician

Additional advice or comment(s): 1) "I feel like...you're in your mid 60's and you're expected to care for someone else."

2) "It's important to secure credit cards...secure finances."

Case Number: 012

Decision Maker: Daughter

Age Group of Decision Maker: 51 - 65

Length of Time Daughter was Decision Maker: ~ 10 years

Elder: Mother

Age of Elder: 78

Primary Illness: Stroke

Katz Index Score: 5

**Secondary Illness: Macular Degeneration, Depression,
Memory Loss**

Lawton/Brody IADL Score: 3

The daughter was officially placed in the role of decision maker when her mother signed over power-of-attorney to her. This occurred shortly after the mother suffered a stroke that caused severe physical effects and moderate mental effects. Prior to this time, however, the daughter assisted her mother in making decisions and, at times, made decisions independent of her mother.

The mother spent two (2) weeks in the hospital post the stroke event. During this time the daughter researched rehabilitation centers. After her mother was discharged from the hospital she was then transferred to a rehabilitation facility to continue the care she needed and for physical therapy. She spent six (6) weeks in the rehabilitation center. Upon release from the rehab center her physician advised that an assisted living situation would be in her best interest. The mother was accepted in to a Hud senior citizen hi-rise, which allowed for a more secure residence and an elevator. While the mother was still in need of physical care the daughter was helped by a home health care agency. At present, the daughter oversees her mothers medications, takes her to the doctors, organizes and takes care of her finances, and does the grocery shopping.

Her mother's medical condition includes a loss of short-term memory, difficulty comprehending conversations due to hearing loss, depression, macular degeneration, problems with balance and weakness, and no organizational skills.

When the daughter was asked why she is in the role of decision maker rather than any one of her other siblings, she stated that it was her mother's decision, which was most likely based on the fact that she is the oldest and, due to having no children, viewed to have a more secure family. She does speak to her siblings frequently and credits them as being helpful to her.

Timeline:

Hospital>>Rehabilitation Facility>>Secure Senior Citizen Hi-Rise – With Assistance
(2 weeks) (6 weeks) (~ 10 years) (Last 2 years)

|
 |
Daughter Given Power-of-Attorney

Most helpful outside resource(s): Support Group; Department of Aging; Access;
 Benedum Geriatric Center

Additional advice or comments: 1) It's important to take of yourself...get plenty of rest.
 2) Try to have a Gerontologist rather than family physician

Case Number: 013

Decision Maker: Sister

Age Group of Decision Maker: 51 - 65

Length of Time Sister Has Been Decision Maker: ~ 10 years

Elder: Mother

Age of Elder: 52

Primary Illness: Mental Health Disability

Katz Index Score: 6

Secondary Illness: Poor Co-ordination and Eye Sight

Lawton/Brody IADL Score: 9

This sister needs supervision and assistance due to mental health issues that have worsen over time, neurological problems, which causes poor coordination, causing her to fall frequently, poor eyesight, and diabetes, which is controlled by oral medication. In addition, she tends to “embellish” reality. While she resides with her mother in a secured environment, her mother is unable to assist in her care due to her own medical and mental limitations, which are the result of a stroke.

Even though her sister needs assistance with such things as medication and completing various forms, which are necessary in order for her to receive State funded medical assistance, she is able help her self a great deal. In addition, she was trained to accompany others to doctor appointments through a non-profit organization that provides training for individuals who have mental health issues.

Timeline:

Home with Mother>>>>>Home with Supervision

(always)

|

(has progressed over the last several years)

Sister became decision maker/guardian after mother had stroke

Most helpful outside resource(s): Ursuline Center and state funded medical assistance

Additional advise or comment: None

Case Number: 014

Decision Maker: Daughter

Age Group of Decision Maker: 51 - 65

Length of Time Daughter Has Been Decision Maker: 1 – 6 months

Elder: Mother

Age of Elder: 91

Primary Illness: Mobility

Secondary Illness: N/A

Katz Index Score: 5

Lawton/Brody IADL Score: 5

This situation is one that had been in the making for at least one (1) year, and seems to have been thought out fairly well. This mother and daughter were living in separate states when the mother asked the daughter to start looking for assisted living facilities in her (the daughter's) area.

The daughter states that her family has a long history of longevity and good mental and physical health. Her mother has had mobility difficulties for about a year and walks with a walker. She does have a problematic disc in her back and, possibly, osteoporosis. Thus the services offered by assisted living, encompasses those areas of physical limitations, as well as many others.

The particular assisted living facility was chosen by the daughter because she was comfortable with the appearance of the facility and with the services they provide; such as cleaning her room, changing her bed, doing her laundry, getting her medications and dispensing the medications as stated, taking care of her mail, providing her meals, as well as snacks and fresh water throughout the day.

The mother chose this daughter, rather than the other daughter, to be the decision maker because the other daughter is married with a family, which the mother believes should be the primary focus for her daughter. In addition, the daughter lives much further away and the mother did not want to move there. The fact that the daughter chosen is single was another contributing factor for the mother to choose her, believing that she has more free time.

Timeline:

Home (in another state) >>>>> Assisted Living Facility

| (2 months)

|

Daughter became decision maker during the mother's transition of moving from another state to the facility

Most helpful outside resource(s): Area Agency on Aging and the Directors of the facilities that she looked at.

Additional advice or comments: 1) Go to look at facilities
2) Understand the personal finances

Case Number: 015

Decision Maker: Daughter

Age Group of Decision Maker: 51 - 65

Length of Time Daughter Has Been Decision Maker: 13 – 18 months

Elder: Mother

Age of Elder: 72

Primary Illness: Cancer

Secondary Illness: N/A

Katz Index Score: 3

Lawton/Brody IADL Score: 4

Until the mother was diagnosed with an inoperable abdominal tumor she had been very healthy and very active. Once the diagnosis had been made she was told she had approximately six (6) months to live. She did receive chemotherapy and radiation treatment and lived a total of fifteen (15) months.

The mother requested that she be cared for at home as much as would be possible as she wanted to spend time with her family and oversee her home; thus, the family never considered nursing home care as an option.

During the time she was cared for at home there were three (3) physicians involved throughout the fifteen (15) months, as well as a team of visiting nurses who made frequent visits. In addition, her daughter and son assisted with her direct care, i.e. administering injections and medication. She also received both inpatient and out patient chemotherapy.

While the whole family, father, son, and daughter, as well as the mother, shared in decisions regarding her care the daughter was the primary caregiver; which was decided from the beginning of the mother's cancer diagnosis. The daughter stated that "I had a very close relationship with loved-one; her personal care required a female".

Timeline:

**Cared for at home with skilled nursing and family assistance
(15 months)**

|
|

Daughter stepped in immediately

Most helpful outside resource(s): Oncology visiting nurses (moderate help)

Additional advice or comments: 1) Family dynamics play a key role in decision-making. The adult children will assume a role reflective of their behavior in the family system.

2) Do not neglect self. If young children in family communicate reassurance, and be honest with them (age-appropriately)

3) The time & energy devoted to your loved one, although stressful and often unbearable, is an honor. There are rewards later on, specifically fond memories and peace of mind, after the loved-one has passed on.

Case Number: 017
Decision Maker: Daughter
Age Group of Decision Maker: 36 - 50
Length of Time Daughter Was Decision Maker: 1 - 6 months
Elder: Mother
Age of Elder: 69
Primary Illness: Mental Health Disability
Secondary Illness: N/A

Katz Index Score: 6
Lawton/Brody IADL Score: 8

Mother moved in with daughter, coming from another state, when it became obvious that she was unable to care for herself financially or otherwise. At the time the daughter was also caring for another family member, as well.

There had been no firm diagnosis made relating to the mother, although she did have a history of neurological difficulties, as well as mental health problems. The only thoughts the daughter had was that the mother's mental capacities were diminishing and there was evidence that she was unable to care for herself properly. The fact that the two lived in separate states, thus making it difficult for the daughter to be of much help in keeping watch over her mother, was a determining factor in the daughter's decision to bring the mother to her home to reside.

Shortly after moving in with the daughter, (a little over 2 months) the mother died suddenly after suffering a stroke.

Timeline:

Own Home>>>>>Daughter's Home
 (2+ months)
 |
 |
Daughter becomes Decision-Maker

Most helpful outside resource(s): None

Additional advice or comment(s): 1) Have a care-giving plan in place, preferably prior to any unexpected care-giving or decision-making emergencies.

2) While my mother died suddenly, I believe it is important to care for a loved one at home if at all possible. Hopefully, then, they can die more peacefully....surrounded by things that are familiar to them.

Case Number: 018
Decision Maker: Son
Age Group of Decision Maker: 51 - 65
Length of Time Son Has Been Decision Maker: 19 – 23 months
Elder: Father
Age of Elder: 86
Primary Illness: Stroke
Secondary Illness: Dementia, Heart

Katz Index Score: 4
Lawton/Brody IADL Score: 2

When the mother was still alive there were many family members, as well as professional services, helping to care for her, as well as the father. Since the mother's death, this son has taken on most of the responsibility for the father, although, the rest of the family does help out in various ways.

Over the last 10 – 15 years the father has experienced a series of medical and mental difficulties including a heart attack, open heart surgery, two (2) hip replacements (same hip), as well as several strokes, which have left him with moderate physical effects and mild to moderate dementia. His son stated “[h]is thinking and talking are pretty good for his age and all the problems he has had. He recently salted his napkin and told me ‘I always do that’”. His son helps him to dress when necessary, prepares their meals, helps him in and out of the shower or tub, and transport him where- ever he needs to go. In addition, his siblings and families help with bringing in food and/or meals. “Dad likes to have someone eat with him”.

When asked how he arrived at the decision to care for his father he stated:

Pretty much decided to handle this on my own. I wanted to care for mom, also, but at that time, my retirement benefits would not suffice. Yet I took early retirement to deal with this – quit about 1 ½ years early – I don't get max retirement pay and benefits, but, I thought how will Dad be in a year or so? You don't know – so I took early leave. I also bought a smaller home to make our lives easier.

Timeline:

He and His Wife's Home>>>>He and His Son's Home (jointly owned)
(almost 2 years)

|
 |
Son Began Decision-Maker & Caregiver Role

Most helpful outside resource(s): Veteran's Administration (very helpful)

Additional advice or comments: 1) People do better at home. When your parent has to go to another place, such as an old person's home, they die more quickly.

2) You need to have patience and a sense of humor

Case Number: 019
Decision Maker: Great Niece
Age Group of Decision Maker: 36 - 50
Length of Time Great Niece Was Decision Maker: 6 – 7 Years
Elder: Great Aunt
Age of Elder: 84
Primary Illness: Stroke
Secondary Illness: Heart, Persistent Pneumonia

Katz Index Score: 2
Lawton/Brody IADL Score: 3

The niece in this situation offered to assume the role of decision maker after having a conversation with her aunt and learning of her concern with having her only child, whom she could not depend on, step in to the role of decision maker if that time would ever come. Even though the two lived apart in separate states they felt comfortable with this arrangement.

Two years prior to the niece becoming decision maker the aunt was diagnosed with congestive heart failure. This condition began as mild but over the years progressed to a severe condition requiring blood transfusions and hospitalizations. Five years after being diagnosed with congestive heart failure, she had a stroke that caused her to experience some forgetfulness. Physically, in addition to her heart problems, she was hospitalized yearly for treatment for pneumonia. After her hospital stays for pneumonia and congestive heart problems she would return home and receive care and assistance from visiting nurses, home health care aides, other care-giving specialist, friends and neighbors.

As her physical condition started to deteriorate she and her niece discussed the best possibilities regarding her care. It was very important to the aunt that she stay in her home. When discussing this during our interview the niece stated:

One of the reasons I was comfortable with her decision to try remain in her home was the strong support and care she received from friends and neighbors. In the last few months of her life they assisted with many daily activities such as cooking, cleaning, errands and banking.

One week before she died she had gone into hospice to receive respite care. As explained by the great niece, “my aunt had been an RN who helped found the hospice. They took great pains to provide a place for her when the time came and they took very good care of her. So for us the answer was easy, as easy as it could be.”

Even though the niece and aunt lived in different states, the niece was assisted a great deal by the staff at the hospice center.

Hospice had financial advisors who assisted me and they also had nurses and case managers who assisted me in keeping track of the progression of her illness and care.

Timeline:

Home>>>Hospital Stays>>Home with Visiting Nurses, Health Aides, Friends>>>Hospice
(off and on for 7 years) (1 week)
 |
Niece becomes Decision Maker

Most helpful outside resource(s): Hospice Facility

Additional advice or comment(s): Find someone who can help you sort out legal & financial matters – someone who really understands the law(s).

Case Number: 020
Decision Maker: Daughter
Age Group of Decision Maker: 36 - 50
Length of Time Daughter has been Decision Maker: \geq 10 years
Elder: Mother
Age of Elder: 90
Primary Illness: Dementia
Secondary Illness: Osteoarthritis

Katz Index Score: 2
Lawton/Brody IADL Score: 1

At this time the mother lives in an assisted living facility, which is paid for on a daily basis, and stays with her daughter, usually on weekends.

The mother's change of resident started several years ago when she would come and stay a few weeks with her daughter. Over the years the time she stayed went from weeks to months. This routine progressed and she finally moved in with her daughter. She does have another daughter living in another state but due to family dynamics is not involved in any decision-making.

The mother's primary physical problem is severe osteoarthritis, which effects her mobility. In addition, she has mild dementia, which is attributed to her age.

Timeline:

Home>>>Back & forth between her home & Daughter's home>>>Moved in with Daughter
(Over approximately 10 years) (~ 2 years)

Assisted Living Facility during the week, Daughter's home most weekends
(1 year)

Most helpful outside resource(s): Friends in similar circumstances. No formal resources.

Additional advice comment(s): 1) Be sure to get power-of-attorney and have living wills in place prior to a crisis.

2) Public agencies need to be more pro-active; since they are not, you need to gather as much information as possible.

Case Number: 021

Decision Maker: Daughter (with consults with father & sister)

Age Group of Decision Maker: 36 - 50

Length of Time Daughter was the Decision Maker: 13 – 18 months

Elder: Mother

Age of Elder: 74

Primary Illness: Cancer

Katz Index Score: 0

Secondary Illness: Osteoporosis, Secondary

Lawton/Brody IADL Score: 0

Infections Due To Cancer Treatments

Mom was diagnosed with lung cancer four (4) years prior to death. She was cared for at home for the entire progression of disease. Once the cancer migrated to her brain she lived for seven (7) months, even though her oncologist stated she would live only two (2) to three (3) months. During the last several months of her life she suffered with severe dementia. In addition, she contracted several bladder and urinary tract infections, associated with chemotherapy, causing her to become incontinent. Prior to the diagnosis of cancer she endured osteoporosis.

Once the cancer moved to the brain, and her physical and mental capacities diminished severely, she needed constant care, as well as heavy doses of pain medication. At this point her oldest daughter discussed moving her to a skilled nursing facility. The husband stated “this would never happen” and the youngest daughter agreed; consequently the oldest daughter was overruled.

As a result the two (2) daughters assisted their dad and took over more and more of her personal care. The oldest daughter took a leave of absence from her employment and cared for her mother four (4) days a week, traveling 40 miles one way. The youngest daughter cared for her two (2) days a week. While there was also a brother, he did not participate in his mother care due to feeling uncomfortable with such task. Additionally, visiting nurses came two (2) days week and then three (3) days a week, and hospice workers came three (3) to four (4) days a week. Hospice was always available to all questions and was always supportive of family decisions during the care-giving time, as well as for two (2) years after the mother’s death.

During the last year of the mother’s life the family also received help from the minister of their church. He came by the house frequently, offering support and prayers, which was important and beneficial for the family.

Timetable:

Home with Husband>>>Home with care-giving from Daughters
(3 years) (Throughout but constantly for 1 year)

|
Daughter Becomes More Involved with Decision-Making)

Home with Assistance from Family, Visiting Nurses, and Hospice
(Last Several Months)

Most helpful outside resource(s): Visiting Nurses, Hospice, Minister

Additional advice or comment(s): 1) Get as much knowledge about care as possible – all aspects – there is much to be learned. Find out about all available resources.

2) Be alert to family dynamics as conflicts may develop. Caregivers need as much help/support as the patient.

3) Don’t let your own mental & physical health suffer!! I acquired, after and during Mom’s illness, Ebstein-Barr’s syndrome, a cancerous tumor on my neck, depression, and marital problems. You, of course, do not realize or acknowledge while giving intense care how much you are stressing yourself and letting yourself deteriorate.

Case Number: 022
Decision Maker: Son
Age Group of Decision Maker: 51 - 65
Length of Time Son Has Been Decision Maker: 7 - 12 months
Elder: Mother
Age of Elder: 81
Primary Illness: Macular Degeneration
Secondary Illness: Diabetes

Katz Index Score: 5
Lawton/Brody IADL Score: 6

Son and mother live in separate states but are in constant communication. The mother's primary disability is blindness; although she has changed her lifestyle and has adjusted well there is a need for her to have assistance so she may live in her home.

Between the brothers, neighbors and hired care there is a system in place that allows for whatever care the mother may need to be taken care of. The hired assistant comes in every afternoon and makes sure that the mom takes her medications, runs errands, and takes care of the house. There is a neighbor that lives close enough to check on her daily, a brother who lives near by stops to "check-up" on her a couple days per week and this son stays with her for a weekend once a month.

While this son is the primary decision maker, decisions are discussed and made in unison with his mom, his brothers, and the neighbor. All involved are determined to do what is necessary in order for her to stay in her home for as long as possible.

Timeline:

Home>>>>Home with assistance from family, friends, and hired help
(progressed over 1 year)
Son has always been primary decision maker

Most helpful outside resource(s): Community Library, Private Care-Giving Assistant

Additional advice or comment(s): 1) Family should decide, in consult with the parent needing care...at issue is how many family and friends can help out.

2) Keep flexible - care decisions may need to change as elder's health changes.

3) Always consult with the one needing care about care matters.

4) Family must keep each other informed on how much care and assistance each member can or will provide.

Case Number: 024

Decision Maker: Daughter, in Consult With Her Sisters

Age Group of Decision Maker: 36 - 50

Length of Time Daughter Was Decision Maker: 1 - 6 months

Elder: Father

Age of Elder: 67

Primary Illness: ALS

Secondary Illness: N/A

Katz Index Score: 0

Lawton/Brody IADL Score: 0

The father was diagnosed with ALS (Lou Gehrig's Disease) only a couple of months prior to moving in with his daughter. For him, the disease progressed very rapidly. The following narrative is in her words.

When my sister learned of the diagnosis and told me, we all went into high gear to get as much information as we could; almost immediately we all knew there was no way my Dad could stay in Florida, where he lived alone. Not only was he alone, there was not an ALS Center. There are only a handful of ALS centers in the United States.

My husband and I knew we had the best space and we agreed that my Dad should come to live with us; while my sister dealt with many of the logistics involved with moving my Dad's belongings to New York, I got busy transferring his military medical coverage and Social Security benefits up to New York; then I made contact with the ALS center and made an appointment for him to be seen within two (2) weeks of his arrival in New York; from the onset, however, my Dad was determined not to "spend a goddamn penny on this disease"; so, really, while I could recommend things, and he was willing to be seen at the ALS center, **he was in charge**; he knew there was no chance of recovery, and so we were all pretty much on board to help him be comfortable. We gave him great food, wine, and whiskey, great movies we all watched together, scrabble games until he couldn't hold the tiles, cigars outside in the fall, and a couple of grandchildren who he helped with their homework even though he couldn't move his hands.

Mostly, there were things that, toward the end, he wouldn't submit to, and that hastened his death. He wouldn't see a pulmonologist, for example, to be fitted for a BiPap; the device would have increased his comfort level by helping ease daily headaches caused by carbon monoxide buildup, but it also would have kept him alive, immobile as he was, and he didn't want that.

Regarding the question relating to community agencies that helped me with decisions... agencies and resources I contacted were helpful in answering questions, but it's important to know that my father died very soon after diagnosis. He moved into our home in August, and he died in early December; the day before he died I called the social worker at the ALS center to tell her that I needed her help in making a case for hospice care, but she told me that my Dad's vital capacity was too high; we knew he was taking a nose dive, but everyone was shocked when he died that night.

Timeline:

Home>>>>>>Daughter's Home with Assistance from Visiting Nurses & Physical Therapy

(~ 4 months)

|
|

Daughter Becomes Primary Decision-Maker

Most helpful outside resource(s): Military Health Services, ALS Association, ALS Center, Visiting Nurses, Rehabilitation Center, Paralyzed Veterans Association.

Additional advice or comment(s): 1) Do what you can do.
2) Find a great social worker to help out during transitional periods.

Case Number: 026

Decision Maker: Daughter-in-law

Age Group of Decision Maker: 51 - 65

Length of Time Daughter-in-law Has Been Decision Maker: 8 – 9 years

Elder: Father-in-law

Age of Elder: 73

Primary Illness: Dementia

Secondary Illness: Alcoholism

Katz Index Score: 6

Lawton/Brody IADL Score: 0

The father-in-law was diagnosed with dementia, due to Wernick's Encephalopathy, nine (9) years ago. Up until he was admitted into the facility where he now resides, they had great difficulty finding a place that would take care him due to the fact he suffers from severe alcoholism. Additionally, the daughter-in-law and her husband have had to cope with countless situations of being called in the middle of the night due to him being picked up by police – or – worse, found passed out. They have also had to deal with the great financial debt he incurred.

Their care-giving difficulties began approximately nine (9) years when he was admitted to a psychiatric hospital. After spending six (6) months in the hospital he was transferred to a personal care facility. However, after spending five (5) months in the facility he was "kicked out" due to his behavior, which was caused by his alcoholic disease. From that facility, he was admitted into an assisted living facility. But again, after living there for about one (1) year his family had to find another facility for him. From the assisted living facility, he was admitted into a skilled nursing "lock-down" unit. He was able to stay there for six (6) months, but since he did not need skilled nursing care he had to leave. At that point, he was accepted into a personal care facility, where he has been for the past five (5) years.

Timeline:

Home>>>Psychiatric Hosp.>>>Personal Care Home>>>Assisted Living Facility
 | (6 months) (5 months) (1 year)
 |
 | **Nursing Home Lock-Down Unit>>>>Personal Care Facility**
 | (6 months) (5 years)
 |

Daughter-in-Law, in Conjunction with Husband Becomes Decision-Maker

Most helpful outside resource(s): Alcoholics Anonymous

Additional advice or comment(s): None

Case Number: 028

Decision Maker: Daughter

Age Group of Decision Maker: 36-50

Length of Time Daughter Has Been Decision Maker: 1 - 6 months

Elder: Father

Age of Elder: 78

Primary Illness: Stroke

Secondary Illness: Dementia, Depression

Katz Index Score: 1

Lawton/Brody IADL Score: 2

While the father lives in his own residence, with his wife, his daughter over sees any care that is necessary for him to receive. Her father experienced his first stroke seven (7) years ago, which caused severe physical effects and moderate mental effects. He has had other strokes since then and has very limited mobility. According to his daughter he “needs assistance for most tasks, except eating”. He was also diagnosed with dementia four (4) years ago. The effects from the dementia vary, going from somewhat mild to rather severe (not knowing family members that he sees daily, etc.). In addition to these physical and mental difficulties, he has high blood pressure and a heart condition, which required open-heart surgery three (3) years ago; and he experiences depression.

When the daughter was asked to describe the care her father receives and how she had arrived at her decision to have him cared for in the manner she stated:

[He] was hospitalized several times in the last 7 years – in 2000 his appendix burst and he was not expected to survive past surgery. [H]e was in ICU (intensive care unit) for 2 weeks. Transferred from hospital, with feeding tube and minimal self-care ability, to a rehabilitation center, where he stayed for 3 months. Other than his heart surgery, he has been home since then.

She had “no choice” regarding the course of action as her father’s doctor recommended the care.

I would like to see my parents in assisted living but they have no intention of leaving their home and have stated repeatedly they will die at home in bed.

Timeline:

Home>>>>>Hospital & Rehabilitation>>>>>Home with Family Assistance & Private Care
(off & on for 7 years) (last 3 years)

|
 |
**Daughter has become Decision-Make
 over the past 6 months**

Most helpful outside resource(s): Private care provider

Additional advice or comment(s): 1) At first signs, no matter what age the elder, research community resources and meet with the elder’s doctor(s).

2) It is frustrating to see your parent become the child and depend on you to eat, and get dressed, and move from bed to chair. The emotional cost of that shift in relationship roles is high and I don’t know how someone prepares for that.

Case Number: 029
Decision Maker: Stepson
Age Group of Decision Maker: 36 - 50
Length of Time Stepson was Decision Maker: 4 – 5 years
Elder: Step-Father
Age of Elder: 87
Primary Illness: Alzheimer’s Disease
Secondary Illness: N/A

Katz Index Score: 4
Lawton/Brody IADL Score: 0

Stepfather was diagnosed with Alzheimer’s disease four (4) years prior to his death. During those four years his mental capabilities were effected between mild and moderate. He never progressed past 2nd stage due to suffering a fatal stroke.

During our interview the son told many stories relating to his stepfather. A few of the situations he shared with me are below:

He called his second wife (this person’s mother) by his first wife’s name – but after awhile everyone just went along with it. He also insisted on doing chores such as mowing the lawn, but would forget what he was doing and would either mow the same area over and over – or he would just walk away from the still running mower. For a short period of time, after he was diagnosed with Alzheimer’s he continued to drive but would forget where he was going and we would have to go looking for him.

The stepfather was able to stay in his residence, with his wife, for most of the time because he lived on the same property (a farm) as the stepson. If there were difficulties the stepson was right there, which made the situation a more positive one for all concerned. The stepson stated that the thought of placing the stepfather in a more formal facility was never something he considered and he didn’t believe there would have been any situation that would have changed his mind.

Timeline:

Home>>>>>Home with Family Assistance
 | (3 years)
 |
 Stepson Becomes Decision-Maker

Most helpful outside resource(s): None

Additional advice or comment(s): Go with the flow...validate their reality, validate what they see, hear, etc.

Case Number: 030
Decision Maker: Son
Age Group of Decision Maker: 51 - 65
Length of Time Son was Decision Maker: 4 – 5 years
Elder: Mother
Age of Elder: 88
Primary Illness: Heart Disease
Secondary Illness: N/A

Katz Index Score: 2
Lawton/Brody IADL Score: 6

The mother's primary physical problem was heart disease. As a child she contracted rheumatic fever, an inflammation of the heart valves, caused by a bacterial infection (strept throat). The heart valve most commonly affected, as in her case, is the mitral heart valve. Over the years her heart condition progressed to severe, causing marked valve damage and a pacemaker was inserted.

Because her son and his family lived next door, and assisted with any help the mother needed, she was able to stay in her own residence throughout her physical decline.

Her son stated the decision to keep his mother at home was not really a "decision" as he would have never allowed her to be transferred to a skilled nursing facility. His family had a long tradition of caring for their folks at home and he had no interest in changing that tradition.

With the efforts of the son, his wife, and their children, they were successful in caring for the mother at home, right up until her death.

Timeline:

Home>>>>Home with Family Assistance>>>>Son's Home>>>>Home with Family Assistance
| (3 years) (6 months) (1 year)
|
Son becomes Decision-Maker

Most helpful outside resource(s): None

Additional advice or comment(s): If possible, care for an elder at home for as long as you can.

Case Number: 031

Decision Maker: Daughter with Son-in-law

Age Group of Decision Maker: 51 - 65

Length of Time Daughter & Son-in-law were Decision Makes: 6 - 7 years

Elder: Father-in-Law

Age of Elder: 78

Primary Illness: Parkinson's Disease

Katz Index Score: 0

Secondary Illness: N/A

Lawton/Brody IADL Score: 1

The father was diagnosed with Parkinson's disease five (5) years prior to moving in with his daughter and son-in-law. This was also during the time that he discontinued his medication; allowing the disease to take its course.

During the last two (2) years, the father steadily lost control over his body and during the last year his physical condition was "very bad" and he needed assistance with all ADLs (activities of daily living). For the duration of the last year it became necessary to have a 24-hour care-giving system in place so as to ensure the father was never left alone. During the week the brother came and stayed with father and then the daughter and son-in-law cared for him on the weekends. This system continued up until the father died.

Timeline:

Home>>>>>Daughter's Home with Family Assistance

| (2 years)

|

Daughter becomes Decision-Maker

Most helpful outside resource(s): None

Additional advice or comment(s): Respect their desires relating to their treatment

Case Number: 033

Decision Maker: Daughter

Age Group of Decision Maker: 36 - 50

Length of Time Daughter has Been Decision Maker: 2 – 3 years

Elder: Mother

Age of Elder: 85

Primary Illness: Mobility Difficulties

Secondary Illness: Blood Disorder

Katz Index Score: 2

Lawton/Brody IADL Score: 3

While the mother and daughter have always lived together, it has only been over the past couple of years that the daughter formally became the decision-maker. This was due to the fact that the mother is aging and her physical health is deteriorating. She has difficulty with her balance and walking, as well as pain in her back due to compression fractures, as a result of a car accident. Furthermore, she had polio when she was much younger which contributes to the problems she experiences with mobility.

She is able to get around with the use of a walker but needs assistance with ADLs (activities of daily living) such as taking a bath and getting dressed. Since her daughter works full-time she hired a private caregiver to stay with her mother during the time she is away. The assistant helps to bath and dress the mother, cooks for her, and ensures that she takes her medication.

The daughter states that as – or - if her mother's health deteriorates she will do what is necessary to keep her mother at home for as long as she can.

Timeline:

Home>>>>>Home with Private Care

| (2 years)
|

Daughter has always been in a Decision Making role – both in an informal & now formal role.

Most helpful outside resource(s): Challenges - (offers home-health care providers and other health related services.

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