

You Never Know What's Going to Happen: Exploring Factors that Influence Older Women's  
Decisions to Make Arrangements for Future Long-term Care Needs

by

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While 70% of US elders will require long-term care, few plan accordingly and most decisions are made in a crisis. Data from two-waves of semi-structured interviews with a sample of 10 White and 10 African American, community-dwelling women ages 60-89 in eastern North Carolina are used to examine the relationship between long-term care planning and a range of demographic, social, and attitudinal variables. Ethnicity and experience making long-term residential arrangements for others were significantly associated with planning. Alternatively, having large social support systems inversely impacts planning.

Using Grounded Theory to analyze the qualitative data, three clusters of themes showed shared ideas about what it means to grow old and four clusters of themes that may impact women's views on long-term care planning and willingness to plan were differentially shared among the sample. Themes associated with non-planning include the belief that planning for the future is futile, that children will take over their care and decision-making, fear of becoming dependent on loved ones, and aversion to long-term care options that may keep older women from thinking about and talking about their options. Future applications include raising awareness about LTC by distributing information and hosting workshops through local senior centers to encourage conversations and concrete planning for future care needs.



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Decisions to Make Arrangements for Future Long-term Care Needs

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## **Chapter 1: Introduction**

The population of elderly Americans is growing rapidly as public health and biomedical advances are extending life expectancy. Aging often leaves a heavier burden on women who are more likely to spend most of their lives as caregivers, first for their children, then for their grandchildren or their own parents as they age, and for many, their spouses (Pope 2012). Because husbands tend to die before wives, elderly women are often left widowed, with no in-home informal caregiver to take care of them when they come to need it, and are more likely to live in poverty or near-poverty (Olson 1988).

Divorced, widowed, and otherwise single women are often at the lowest end of the poverty spectrum among older women and those who are not quickly deplete their incomes with hospital bills, nursing homes or assisted living facilities, or hiring in-home care. Some women who start out better off financially may be forced to spend all of their income in order to qualify for Medicaid benefits. Additionally, elderly women are more likely to experience chronic illnesses such as osteoporosis and arthritis that make daily tasks difficult or painful to manage alone (Olson 1988; Davidson, DiGiacomo, and McGrath 2010).

Many women do not have a plan for what will happen to them if their husbands were to die or if they were to suddenly become very sick or incapable of caring for themselves in their own homes (Girling and Morgan 2014). Urgent decisions are often made in hospital waiting rooms by their family members who are often ill-prepared to make these decisions and may not know what their mother or grandmother wishes (Nakashima et al. 2005).

The goal of this project was to explore the factors that influence women's willingness to engage in long-term care planning as well as the actual decisions they make in this regard by interviewing a sample of White and African-American, independently living women ages 60 and

over in Pitt County, North Carolina. For the purpose of this research, the outcomes or dependent variables include long-term care planning (LTC) defined as advance care directives, acknowledging a preference for specific long-term supports and services or residential care, and financial planning to ensure care for the future. Advance care directives include documents such as health care power of attorney, living will, medical orders for the scope of treatment (MOST), and do not resuscitate orders (DNR). Acknowledging long-term care preferences involves making an informal plan for the type of health care and residential option preferred, including formal or informal in-home care, assisted living facility, nursing home, continuing care retirement community, or simply downsizing to an apartment or condominium. These informal plans are often as simple as discussing the topic with loved ones. Financial planning includes any savings set aside for long-term care as well as long-term care insurance and transfer of assets, such as reverse mortgaging or selling property.

The factors hypothesized to influence planning include the independent variables of demographics such as age, ethnicity, and socioeconomic status; social variables like marital status, presence of children, levels of social support and the size of social networks; perceived health status and current health conditions; attitudes toward aging; and past experiences as caregivers for others are likely to influence a woman's willingness to make long-term decision as well as the particular options considered.

### ***Research Objectives***

1. To determine if older women in the sample have made or are considering making plans for future long-term care, if they are avoiding the topic, or if they are waiting for others to make these decisions for them.

2. To discover the level of planning these women are engaging in by assessing what specific decisions they have or have not made – such as advance care directives, purchasing LTC insurance or saving, and discussing these plans and preferences with friends, family, or health care professionals.
3. To identify what types of long-term residential and medical care elderly women prefer and why they prefer one solution or the other.
4. To investigate how older adults arrive at these decisions or non-decisions by eliciting information on demographic, social, attitudinal and health status variables and correlating those with both the action of making plans/decisions as well as the choices made.
5. To explore the extent to which the choices (outcomes) considered as well as the factors involved in decision-making vary by ethnicity
6. To develop a report of the findings that might be useful to personnel at the Pitt County Senior Center for working with the elderly in LTC planning.

This research is important for both aging women and their families. The majority of LTC decisions are made in crisis situations with heightened emotions and unprepared family members. Helping elders and their families prepare for these decisions may ease the stress of these situations and help families find accurate information to make better decisions for their loved ones. Additionally, this information could be used to put pressure on policy makers to create or adapt policies that could help provide services and resources to elders and their families.

## *Precis*

In the following chapters, I will review the literature describe the research methodology and sampling procedure, report the results of both the survey and the in-depth interviews and discuss the implications of these findings. In chapter two, I provide the demographic background that necessitates this research, discuss current LTC policy and funding, past research on factors that influence LTC decisions, and anthropological and public health approaches to exploring decision-making.

In chapter three, I detail my research design, hypotheses, sampling and data collection methods, and data analysis. Chapter four is split into two separate sections: survey results and analysis of survey variables and thematic results and analysis of themes. The final chapter summarizes the analysis and discusses the implications of the results.

## Chapter 2 - Literature Review

### *Informal Care, Older Women, and the Need for Future Care Arrangements*

The population of elderly Americans is growing rapidly as public health and biomedical advances are extending life expectancy. It has been estimated that 70% of elders will require long-term care (LTC) at some point during their lifetimes (Temple and Cockley 2012:46). Although early planning for long-term residential care, supports, and services has been shown to result in better psychological outcomes for older adults (Friedemann et al. 2004:520; Sorenson et al. 2008:329), but 54% of American adults age 40 and over claim they have done “little to no planning” for their future care needs (Tompson et al. 2013), leaving the most important LTC decisions to be made in a crisis situation (Robison et al. 2014: 298; Nakashima et al. 2005:82).

Women make up the majority of the elderly American population, representing two-thirds of all home care recipients and three-quarters of all nursing home residents (Clark et al. 2010:600). Elderly women tend to have worse health outcomes despite higher average longevity (Davidson, DiGiacomo, and McGrath 2010:1032); they also have higher rates of chronic conditions and nonfatal acute illnesses (Olson 1988:100), are more likely to be widowed (Olson 1988:99) and poor (Davidson et al. 2010:1034), and are more likely to provide eldercare for their spouses, parents, in-laws, or some combination (Pope 2012:508). Thus, elderly women are more likely to require formal long-term care or depend on their daughters, rather than spouses, for assistance (San Antonio and Rubinstein 2004:44; Temple and Cockley 2012:51).

A 2010 report showed that two-thirds of disabled elders receive care exclusively from an unpaid family caregiver (Family Caregiver Alliance 2015) and 22% of elders reside in nursing homes (San Antonio and Rubinstein 2004:37). Additionally, the use of informal care has increased in recent years (Federal Interagency Forum on Aging-Related Statistics 2004) and

about 34% of family caregivers are themselves elderly (National Alliance for Caregiving and AARP 2015). The AARP reports that in 2009, an estimated 42 million family members were providing eldercare and 60% of unpaid caregivers for elders were women (Schmitt 2015). For many, caring for elders falls naturally under a woman's job description and women are expected to sacrifice their own mental and physical wellbeing to care for others (Walker, Pratt, and Eddy 1995:402-403). Although informal family caregiving for elders is not always strictly negative, it comes with its own set of problems and stressors that can have a negative impact on women's health (Walker, Pratt, and Eddy 1995). Many women caregivers have higher stress levels, develop depression and anxiety, nearly one-third of caregivers provide eldercare while in poor health themselves, are more likely to suffer adverse health effects in the future, and less likely to engage in preventative care (National Alliance for Caregiving & Evercare 2006). These issues are intensified for minority women and those who are already poor to begin with.

Elder women are less likely to be prepared for LTC and more likely to need it. As the population of the elderly grows, this need will increase, as will the burden on family caregivers, an estimated 66% of who are middle-aged and older women (The National Alliance for Caregiving and AARP 2009). Nearly 25% of the 45 and older population are not financially prepared to pay for LTC (The National Alliance for Caregiving and AARP 2009). The question becomes, who will care for these women – who have spend much of their lives providing care for others – when they can no longer care for themselves? Women are more likely to age alone and in poverty than men, making access to formal LTC more difficult. Additionally, recent spikes in divorce rates and families choosing to have fewer children make it more important than ever for older women to make a plan for medical and residential LTC (Denson, Winefield, and Beilby 2013:3; Pope 2012:507; Robison et al. 2014:300). It is important to understand how

women think about and plan for their own LTC needs in order to help them make these decisions before a crisis.

### ***Long-term Care Options, Policy, and Funding***

The term “long-term care” refers to a multitude of services. Sometimes the line between nursing home and assisted living facility is blurred and often, different types of home care are not distinguished between in conversation. In reality, there is a difference between home health care and home care services. Home health care is provided by nurses while home care services are usually provided by personal care aides or homemakers. Home and personal care may be provided by hired help or family members and usually help elders who need assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)

Nursing homes are certified to provide skilled LTC services and may be funded privately or through Medicaid. They are required to have at least a minimal level of nursing staff to care for frail patients. Assisted living facilities are far less regulated and many different companies and organizations offer a diverse array of services under the same name. Typically, assisted living facilities (ALF) serve less disabled patients than those housed in nursing homes. Some offer special units for the cognitively impaired. There is typically more freedom in the routines of ALF residents than those residing in nursing homes. The majority of ALFs are financed privately and Medicaid coverage varies by state but is usually limited.

Adult Day Care facilities or Adult Day Health Centers are programs that provide care at a central location for different periods of the day and exist to provide assistance with ADLs, provide socialization and organized activities, and may have medical or nursing services available on site. These services are extremely helpful for caregivers who work or elders who live alone but are not always paid for by Medicaid.

Another option is Continuing Care Retirement Communities (CCRCs). These facilities are usually lifetime decisions that allow seniors to move in and live independently. The facilities have ALF and nursing home sections on site to allow residents to move to different areas as their needs change. While very practical, these facilities are typically very expensive (Kane 2011).

Many Americans believe that private health insurance policies and government provided insurance programs such as Medicare and Medicaid will cover the costs of long-term care services, however, the LTC coverage provided is very limited and not provided by all policies. Medicare provides the guidelines for most private health insurance policies and limits its LTC coverage to nursing home care provided for a limited period of time, usually 100 days following hospitalization. After day 21, a daily co-payment is required to continue services through day 100. Home care coverage is limited to skilled care considered medically necessary; no personal or custodial care is covered and insurance policies will not compensate family members providing informal care. Medicare and private insurance policies also do not cover assisted living facilities, continuing care retirement communities, and adult day care services. Medicare supplemental policies may enhance hospital and doctor coverage and cover the co-payment for LTC services, but do not increase the length of stay for those requiring LTC past the 100 days (United States Department of Health and Human Services 2013).

Medicaid is another common source of LTC funding but access is highly restricted. Medicaid will only pay for skilled nursing care deemed medically necessary and has strict income requirements. Elders must entirely deplete their income and assets to qualify for Medicaid – in North Carolina, the limit is \$2000 in money and assets. Medicaid does not cover assisted living facilities, except for some who qualify for special assistance programs. As for home health services, Medicaid will cover some home health care as long as it is prescribed by a



doctor. Additionally, Medicaid will cover personal care that is prescribed by a doctor up to 80 hours per month. Some waiver programs are available to extend home health and personal care services (United States Department of Health and Human Services 2013).

Long-term Care Insurance (LTCI) is another option, but unless it is purchased at a very young age, it is often too costly for most women to afford, making some who might could afford it choose not to spend the money on a “just in case” purchase. Eastman notes that LTCI policies can provide financial protection against health crises for many elders and although still known for being very expensive, the coverage has improved, making it a better investment (2015). She also notes that little effort has been made to create any effective LTC policies and suggests that future policies provide “cost savings, protect autonomy, and allow for preservation of assets for family and in-home care”(Eastman 2015). In a 2013 study of LTCI decision-making by married couples, Barnett and Stum found that spousal consensus and annual incomes over \$70,000 had a positive effect on LTCI purchases (Barnett and Stum 2013). Income and affordability were especially salient factors for married women’s LTC decision-making.

### ***The Role of Demographic Factors in Long-term Care Planning***

One objective of the proposed research is to assess the extent to which demographic variables affect women’s abilities and willingness to make LTC decisions. Studies have found correlations between demographic variables – such as age, race and ethnicity, income, sex, health status – and planning behaviors but the data on what these correlations mean and how consistent they are is mixed. Other factors that may contribute to LTC planning – including education, partnership status, insurance, and socioeconomic status – have been suggested (Clark

et al. 2010; Girling and Morgan 2014; Friedemann et al. 2004; Nakashima et al. 2005) but not confirmed or differentially supported by the literature.

For example, some studies have found that White women were more likely to plan for LTC needs than black women (Girling and Morgan 2014; Friedemann et al. 2004) but fewer studies have asked African-Americans about their LTC plans and decisions (Groger 1994:78). Mitchell et al. also noted the discrepancy between LTC needs of African-Americans and their representation in LTC facilities (2000:425), but found that among White and black adults surveyed in Eastern North Carolina, black elders were actually more likely to have made a plan for LTC than White elders (p. 432). As a group, African-Americans tend to have more social support than Whites, making informal family care more feasible and desirable, but it is important to consider that not all African-American individuals have the same amount of social or familial support (Groger 1994:91).

Natalie Pope (2012) found that a lack of financial resources could be a barrier to LTC planning in a study of female caregivers aged 50-64. While most caregivers realized the importance of LTC planning and had begun to take necessary steps towards developing a concrete plan, among those who had *not* started planning for their own future care needs, one of the primary reasons given was a lack of financial resources (Pope 2012:511). Similarly, in a study of long-term care planning styles across three cultures, Sorensen and Pinquart (2000) found that US women who did not plan for LTC needs were concerned with their own lack of financial and social resources (p. 359-360). The study also found correlations between education level and LTC planning, with those who were more educated being more likely to plan for future care needs. Finally, Broyles et al. noted that perceived financial or institutional instability was a hindrance to LTC planning and LTC insurance purchase (2015).

### ***Health Status, Disability, and the Decision to Plan***

The data on health status and planning behaviors is also mixed. Temple and Cockley (2012) surveyed 225 Virginia community dwellers age 40 and up about their long-term care knowledge and planning behaviors, finding that those with more chronic conditions and better knowledge of services available were more likely to plan for LTC (Temple and Cockley 2012:48). They also noted that older individuals, women, and those with better overall knowledge of supports and services available were more likely to plan for their own LTC (p. 48). Interestingly, this same study found that those who reported more difficulties with instrumental activities of daily living (IADL) were actually *less* likely to plan (p. 50). Similarly, a study of unmarried and sexual minority women's LTC plans found no correlation between number of health conditions and LTC planning behaviors (Clark et al. 2010:611). On the other hand, Robison et al. indicate that having a disability is increased the expectation for LTC needs and planning behaviors (2014:306), making it difficult to determine if current health status has any effect on LTC thinking and planning.

### ***American Exceptionalism and Asking (or Not Asking) for Help***

Personal attitudes and values may also have an impact on adults' LTC decisions. Natalie Pope (2012) found that within her sample of middle-aged caregivers, negative attitudes towards planning for the future were prominent among non-planners. Specifically, Pope's non-planners mentioned the limitations of planning for unknown future needs as being a major barrier to LTC planning (2012:511). Sorensen and Pinquart also noted that US women in their sample focused more on negative beliefs about planning, such as the perceived futility of planning for an unpredictable future, the perceived financial disadvantages of planning, and a belief that focusing on negative concerns for the future could make one physically sick (2000: 359-360).

Researchers have noted that American cultural values could be a hindrance to thinking about LTC decisions. Americans have higher levels of internal locus of control and lower levels of externality, reinforcing social values such as self-reliance and initiative, which may be related to fears of dependency and avoidance of planning behaviors (Sorensen and Pinquart 2000:376). Similarly, San Antonio and Rubinstein (2004) suggest that American cultural values create psychological barriers to thinking about the need for LTC planning, which could help explain the discrepancies between demographic variables and actual LTC planning behaviors. Values such as optimism, individualism, and the concept of an unchanging self keep many older adults from imagining themselves as future dependents and in need of help, which could prevent progress in LTC planning (San Antonio and Rubinstein 2004:39-40).

Research has consistently demonstrated that the values of health care providers, elders, and family members are not always in sync. Elders prioritize values such as autonomy, independence, environmental issues such as privacy and familiarity, and a sense of control over their future, while relatives and health care providers tend to prioritize health care and safety concerns over other needs (Stolee, Zaza, and Sharratt 2013; McCullough et al. 1993; Denson, Winefield, and Beilby 2013). In most cases, elders prefer to stay independent for as long as possible in their home environment. While family members list psychological wellbeing high on their list of concerns, concerns for autonomy and psychological wellbeing may conflict with their concerns for health and safety when the relative does not want cooperate in the decision-making process. Given that the majority of these decisions are made in a crisis situation, emotions run high and planning discharge can be difficult for both elder and family (Nakashima et al. 2005:82-83, 98).

A negative attitude toward nursing homes is common in American society, with many viewing care for elders as the family's responsibility and nursing home placement as shirking duties (Nakashima et al. 2005; Chen et al. 2008). This bias against nursing homes changes the way both families and elders plan for and make decisions about LTC. Families and elders may also have different ideas about informal family caregiving. Groger's (1994) study of black elders who had recently transitioned to nursing home care showed how family's often had different ideas about what solutions were not only possible, but realistic. One elder felt that her family should have taken care of her longer, however, her children did not see this as a realistic option and instead, helped her find a facility that suited her needs.

Similarly, Girling and Morgan (2014) found that a common goal for many elderly women was family caregiving but that many elders had not explicitly shared this with their children or families (p. 736). Some of these women believed that if they modeled the desired caregiving behaviors, their families would ensure their expectations were met (Girling and Morgan 2014:736). These values allowed elders neglect the need to plan, assuming that their children will take care of them without need for prior discussion. For other women, fear of being a burden to their families was enough to make them think differently about their LTC preferences and planning (Girling and Morgan 2014:737).

### ***Awareness, Knowledge, and Experience: The Impact of Caregiving Experience on Long-Term Care Planning***

Planners in Natalie Pope's study often cited their parents experiences in old age as an incentive for making concrete financial, residential, and medical care plans as well as for strengthening their social and familial networks while they were still able to, indicating that their may be some correlation between caregiving experience and willingness to make a LTC plan

(2012:514). Clark et al. (2010) also found that among unmarried women, being a health care proxy or current caregiver for an aging adult was associated with one or more LTC planning strategy (p. 611).

Girling and Morgan (2014) found a similar pattern among elders who had direct caregiving experience or who had witnessed the burden of caregiving on their loved ones; prior caregiving experienced influenced the pattern of LTC decision-making and planning among black and White women over age 64 (p. 742). Broyles et al (2015) found that exposure to caregiving helped facilitate LTC planning while child rearing acted as a deterrent for participants in their sample. Similarly, Finkelstein et al (2012) found that baby boomer caregivers were more likely to anticipate their own LTC needs, however, they are not taking specific actions to plan for these future needs and in a 2007 Connecticut survey, Robison et al. found no correlation between caregiving experience and LTC residential plans among upcoming baby boomers (2014:306). Caregiving certainly seems to impact the way elders conceptualize and plan for their futures, however, the extent to which it actual planning behaviors is unclear.

### ***Social Supports and the Need to Make A Decision***

Although the relationship between health and social networks has been well established, less is known about the relationship between social support, social networks, and LTC planning and decision-making. Social networks have been linked to lower mortality rates, and help to maintain better physical and mental health by providing a buffer from stress (Lubben 1988). Friends and family are also important actors in LTC decision-making. Stolee, Zaza, and Sharratt found that many elders prefer to make LTC decisions with their families rather than entirely on their own (2013:726). Nakashima et al. (2005) also found different decision-making styles among elders planning for LTC, with some preferring autonomous decision-making while others

preferred a more collaborative effort or delegated the responsibility to family members altogether. As noted above, consideration for how family caregiving could impact familial relationships changed the way both elders and their families made decisions about LTC (Stoller 1988; Girling and Morgan 2014).

In a study of the values considered in LTC decision-making by elders, health care professionals, and families, McCullough et al. (1993) found that relationships were an important factor in considering LTC options for both doctors and elders (p. 330). The study domain of “relationships” included having company, being with friends and family, having likable help, and pleasing others (McCullough et al 1993:328). In a similar study of values in LTC planning, Denson, Winefield, and Beilby (2013) found that after mental and physical health and wellbeing, social contact was listed an important factor by doctors, but not by elders or their families. Doctors were concerned that elders who chose to remain at home would suffer social isolation and felt that long-term residential care would help prevent this (Denson et al. 2013:8).

Social contact has been found to be an important factor in both deciding to move and adjusting to relocation. Henning-Smith and Shippee found that current living situation effected adults aged 40-65 expectations about their own future care needs, with those living alone being most likely to expect to need LTC services (2015). Chen et al. found that mounting social losses (contact with friends and relatives dwindling due to age, disability, and death) and proximity to family were important factors in adults’ decisions to enter an assisted living facility (2008:92-93, 97). Groger (1994) noted that elders who established a social role and took on special responsibilities in the group were better adjusted within the nursing home community (p. 94).

Sorensen and Pinquart found that a perceived lack of social resources was listed as a top reason for not planning among those who both avoided planning and those who thought about

potential future care needs but did not make a concrete plan (2000: 359, 362). Sorensen et al. found that higher levels of extraversion and interest in maintaining social connections was associated with more planning behaviors (2008:335). One study of how married couples make decisions about purchasing LTC insurance found that spousal consensus was particularly important from married women in making decisions about their future care needs (Barnett and Stum 2014). These studies combined suggest that more active and supportive social networks may have a positive effect on LTC planning behaviors but the dynamics of this relationship need to be fleshed out with more data.

### ***Retirement, Travel, and Family: Schema Theory and American Ideals of Growing Old***

There is a substantial theoretical literature on how people make decisions in both public health and anthropology. Studies in these traditions assume that people do actively make decisions and that they bring to the decision context sets of beliefs, attitudes and perceptions that influence the choices they make, either as positive motivators or as barriers to choosing particular actions or outcomes. Most of these theorists do not ask the primary question: are people actually making decisions or are they avoiding them altogether?

There is evidence that in the United States the cultural bias toward youth (Cruikshank 2013; Inhorn 2006; Porter 1996) and toward maintaining the self-image of an active, autonomous person inhibits people from confronting and thinking through the consequences of aging until they are forced by a crisis to do so (Denson et al. 2013; Groger 1994; San Antonio and Rubinstein 2004). Therefore, the most basic question to be addressed in this study is whether or not people are making decisions about their futures, and if so, which decisions are they considering and what factors are influencing the choices made. Particularly relevant to the design of the proposed project is descriptive decision theory in anthropology, the trans-theoretical



model of health behavior change and barrier models to change from public health, and cognitive schema theory from anthropology and psychology.

Anthropologists have a long tradition of studying decision making in natural contexts. A majority of this research attempted to predict the decisions people actually made as opposed to the focus by economists on the ones they *should* make using optimal strategies (Mathews 1987). Young (1981), for example constructed decision trees to show how the people in Pichataro, Mexico, made the decision about whether to see a local healer or a physician for the treatment of different illnesses. He first determined on the basis of participant observation and interviews what options were available for people to use in treating disease. He constructed a decision tree which ranked the criteria people evaluated sequentially including gravity of the condition, knowledge of a home remedy, faith in folk vs. medical treatment and the availability of money and transportation (Young 1981:154). He then tested the model on illness case histories he had collected and was able to account for initial treatment choices in 84% of the cases (Young 1981:165). Other anthropologists working in this tradition have studied farming decisions (C. Gladwin 1983), fishing marketing decisions (Quinn 1978), environmental decisions (Kempton, 1996) household task decisions (Mukhopadhyay 1984), and decisions about treating specific illnesses like diarrhea (Ryan and Martinez 1996). While all of these studies use ethnographic data to formulate decision models, which achieve high accuracy in predicting decisions, they most often predict routine decision (see Mathews 1987:55). These models fall short when it comes to explaining how individuals draw on cultural and personal knowledge to define, organize, and select among goals. In other words, it is important for anthropologists to understand the ways that individuals frame decisions they face as well as how they structure possible solutions.

First coined by Piaget, the concept of schema impacted psychology and education through the theories of the British psychologist Frederic Bartlett, who proposed that people actively reconstruct memories drawing upon dynamic schemas derived from engagements between the mind and the world. (1936:201). Schemas are defined as mental representations used to organize and simplify knowledge about the world, thereby influencing perception, interpretation, decision-making, and action (Casson 1983). In his famous example of the use of the word “bachelor,” linguist Charles Fillmore (1975) pointed out that words take meaning with reference to “frames,” which are schemas comprised of simplified or prototypical worlds. Scripts, such as how to behave in a restaurant, are simplified event-sequences that guide expectations and interpretations (Shank and Abelson 1977). Other schemas may consist of images, metaphors or propositions.

Strauss and Quinn (1997:48-88) summarize recent research that links schema formation to the connectionist theory of neural processing, arguing that repeated experiences activate associations between neurons, constructing webs of associated elements – or schemas – in the minds of individuals. Thus, they maintain, a schema can be understood as a generic version of (some part of) the world built up from experience and stored in memory. Moreover, as Quinn (2005:37) explains, “to the degree that people share experiences, they will end up sharing the same schemas – having, we would say, the same culture (or subculture).” Cognitive anthropologists have called these widely shared schemas “cultural models” (Quinn and Holland:1987). Cultural models are presupposed, taken-for-granted archetypes of the world that play an enormous role in people’s behaviors and understanding of their world. Although these models can change, the more a similar sort of experience is repeated, the more relatively stable it becomes, influencing people’s interpretations of subsequent experiences.

An important issue for cognitive anthropologists is determining how cultural schemas are internalized and how they come to motivate people's desires to take action. D'Andrade (1992:24) states that motivation is experienced as a desire or wish followed by a feeling of satisfaction if it is fulfilled or a sense of frustration if it is not. Cognitive schemas have the potential to instigate action because they often function as goals generating such desires and wishes. (D'Andrade 1992:29). The implication of D'Andrade's proposal is that motives vary culturally and are not restricted to a single fixed list such as those derived by psychologists (Bagozzi, Bergami & Leone 2003).

On the other hand, not all schemas have the same level of goal direction. According to D'Andrade, higher-level schemas, such as those for love, work, success, etc., often comprise a person's most general goals and might be thought of as master motives capable of instigating action autonomously (1992:30). Lower level schemas, on the other hand, such as the one for "hitting a baseball" may generate no goal-directed behavior unless recruited by a higher-level schema such as "playing a game." D'Andrade also proposes that mid-range schemas, like those for marriage and work, are mid-level motives; that is, they generally require the presence of other goal-schemas to instigate action but may on occasion instigate certain actions themselves (1992:31).

Nardi's (1983) study of reproductive decision-making in Western Samoa departs from decision modeling to attend to the ways people frame their goals. She argues that decisions are based not only on the decision maker's evaluation of mutable external factors but also on relatively stable, subjective, internal factors such as goals, plans and expectations that guide him or her in formulating the decision.(Nardi 1983:698). Nardi finds that people do not process fixed criteria sequentially in making a decision about whether to have children, nor do they respond to

external barriers. Instead, they envisioned ideal or prototypical scenarios of what life would be like with children. Her informants would envision themselves as older adults surrounded by children helping them do work or being cared for when they were elderly by their children. These were powerful emotional images that helped guide decisions (1983:703). The following excerpt from one of her respondents illustrates the use of this type of scenario:

When I'm old and I die I want someone to cry for me and I want someone to help me with my work. That is the main reason I want to have children; so that when I'm old they can do my work. Like getting water for my bath, getting some fire for my tobacco.

Things like that (Malia, age 28; three children). (Nardi 1983:703).

Typically, Nardi finds, these scenarios are “recruited by” or nested within what she labels a “life sketch.” The life sketch is a set of related scenarios that incorporate the major life goals of an individual. The five major goals of reproduction for Samoan women, developed in scenarios, encompass the entire life span of an adult woman. The problems these scenarios involve center around loneliness, work, money, marriage, and old age, taking a woman from child-less youth to the decrepitude of old age. Because the scenarios cover the entire course of adulthood, and because they are used over and over again to decide whether to add another child to the family, it appears that scenarios do not define a set of unrelated goals, or a “bundle” of independent, individual aspirations and aims. Rather, they are related to each other through compatibility (Nardi 1983:706).

It may be that older adults in the US engage in similar practices—constructing ideal scenarios of how they expect the end of their lives to unfold, which might also be related to more general life themes or life histories. If this is true, understanding how these scenarios are culturally determined could be an important step in determining how best to help older adults

plan for the future. For example, some older adults in the US envision retirement as a time when they can move to a warmer climate or a resort location, relocating permanently to what would otherwise be a vacation destination. When they imagine this possibility, they may visually see themselves fishing, riding bikes, relaxing by the pool, but they do not envision themselves isolated from friends and family in a community that may lack health care facilities and transportation services for the elderly.

In a preliminary interview collected for this project in Eastern North Carolina, a recently retired 61 year old woman who acts as an in-home caregiver for her mother admitted, “I would have thought that when I retired I would have been married. . . able to travel, to come and go as I wanted to, to spend more time at the beach – and none of that is reality.” Another woman, age 71, said:

“We’ve always tried to be frugal and save. We wanted to be financially secure so that we could travel and do fun things we when retired. I guess that’s one thing that comes up a lot in our conversations. We’re not getting any younger and we don’t walk as well as we used to, we better go ahead and make that trip. We’ve know so many people who, when they retired, didn’t live very long and didn’t get the opportunity to do fun things.”

One goal of this research is to explore the extent to which ideal scenarios of aging impact the decisions people make.

Alternatively, the use of scenarios to frame decisions for the elderly may work in reverse; that is, older adults who have been caregivers for elderly family members may be influenced by those experiences to think of their own futures in specific ways. Hallowell’s (2006) study on

genetic risk and ovarian cancer shows that cancer patients often imagine what their deaths will do to the people left behind or alternatively fear that they will die before having a chance to forge meaningful social relationships and continue family lines into the future. In interviews with women who tested positive for genetic risk for ovarian cancer in the US, she sought to understand how they made decisions about whether or not to take action on risk and pursue annual screening or prophylactic surgery. She found that many had witnessed first-hand the deaths of other female relatives and could provide graphic accounts of the pain and suffering that illness and death had caused family members. To avoid inflicting a similar fate on their families, many women sought to be proactive. In addition, many women feared that death from cancer would terminate their social relationships and cause their spouses and children untold suffering into the future. These women too chose to be proactive in treatment so that their perceived familial obligations would not go unmet in the future. While many of them suffered the anguish of knowing they were at risk of a deadly disease, their decisions emphasized the imagined risk of social loss and emotional pain they projected onto close family members.

Similarly, providing care for an aging adult can leave a lasting impression on the caregivers themselves, prompting them to think differently about their LTC choices. Studies done by Girling and Morgan (2014), Clark et al. (2010), and Pope (2012) confirm this tendency. A key informant contacted during the design of this research mentioned casually the formative experience of watching her mother-in-law experience a long and painful final year of life, prompting her to buy LTC insurance in her late 40s. She also noted after her own experience caring for first her mother-in-law and then her husband, she chose LTC insurance and preferred moving into an assisted living facility when she could no longer live on her own – despite offers

to help from her family – to “not become a burden.” Another woman, age 62, who had to move in with her mother to provide care remarked,

“We all would love to stay in our own homes, but that’s not always possible and that’s not always the best thing for everyone involved. . . I would not want my family to have to give up their life or their family situation for me to move in with them or them in with me. That’s not fair to them. They might be willing to do that, but that’s not what I want for them.”

While most anthropological studies of decision making focus on the individual as autonomous choice-maker, preliminary data collected for this project in Eastern North Carolina finds that at least some older individuals think that decisions about their care should be made by their families not themselves. For example, one woman, disabled by a stroke at 67, said:

“Families need to talk to the elderly about what they want before it gets to this point. Sometimes it’s the young people who don’t want to talk about it.” In other words, decisions may be socially distributed and older adults assume that others will take responsibility for letting them know when something needs to be done and for researching those options (Biley 1992). This is especially common among ethnic and racial minority groups who may place a higher value on community and family consensus decision-making (Kwak, Ko, & Kramer 2014). Groger (1994) notes that participation in LTC decision-making is not necessarily an all-or-nothing effort, but that adults having a say in their future care is extremely important (p. 80). Differences in care planning styles may include proactive and autonomous decision-making, while others may prefer more a more collaborative effort between themselves and their loved ones or delegating the responsibility to a trusted individual entirely (Nakashima et al. 2005; Girling and Morgan 2014).

It is also likely that older adults may segment decisions and deal with some but not others. For example, financial planning for retirement is a well-accepted goal in the US and people may feel more comfortable engaging in this type of planning as opposed to thinking ahead about being sick or disabled and what they might do. Robison et al. (2014) found that among baby boomers, 69% had made some type of financial plan for the future while two-thirds did not expect to need any long-term supports and services and had not made any arrangements for LTC. Clark et al. noted that over 60% of women in their sample had designated a health care proxy and executed a will but only 22.8% had discussed their long-term residential and medical care preferences with a loved one (2010:607). Tompson et al. found that while the majority of Americans over age 40 surveyed expected to need some level of LTC, they were more likely to make arrangements for their funerals than to prepare for their future LTC needs (2014).

Within public health, the trans-theoretical model of Stages of Change (Prochaska & DiClemente 1983; Prochaska, DiClemente, & Norcross 1992; Prochaska & Velicer 1997) is a model of intentional change focused on the individual, developed to assess when people are ready to make a decision and how they arrive at that point. Originally developed to assess how and when individuals were willing to make the decision to stop smoking, the model has since been applied to a variety of issues, including decisions about ending other addictive behaviors, obtaining cancer screenings, managing diet, etc. Central to the model is the assumption that people move through stages of readiness to make a change in health behaviors.

The model posits the following stages: contemplation, preparation, action, maintenance, and termination. Contemplation is the stage in which people are aware of the pros for making a change but also acutely swayed by the cons. Typically, people in this stage do not intend to do anything within the next six months. Preparation is when people intend to take action – usually



within the next month – and have a plan for doing so. Action is when people have made an actual change within the past six months. Maintenance occurs when the person has made modifications in behavior or undertaken actions but may still be tempted to revert to past behaviors or choices. Termination is when they are no longer tempted to reverse the decisions they have made (see Velicer, W. F, Prochaska, J. O., Fava, J. L., Norman, G. J., & Redding, C. A. 1998).

To progress through the stages of change, people apply cognitive, affective, and evaluative processes. Health interventions can act to promote change but to do so, these theorists argue, they must be targeted differently to people in each stage of readiness. For example, people in the Contemplation Stage need strategies of consciousness raising where they learn more about the need for a change and the positive reasons for making it, while people already in the Preparation stage may benefit more from supportive relationships or mentors who can aid them in formulating steps to action.

There have been many criticisms of this model. First, the model assumes that individuals make coherent and logical plans in their decision-making process when this is not always true. Second, it is a proscriptive model that assumes progress toward action and change is sequential and fixed in terms of discrete stages (Rakowski, Dube and Goldstein 1996). Yet, recent literature from cognitive and neuroscience argues that people are more likely to process information schematically and not sequentially (Smith and DeCoster, 1998). This model seems to work best for people who are trying to stop addictive behaviors and not so well when applied to intentional decisions to undertake a new behavior, such as getting a mammogram or other screening test (Spencer, Pagall and Adams 2005). Therefore, it is questionable how useful this approach would be to evaluating decision-making about future outcomes among the elderly. Alternatively, if an elderly person is faced with crisis, such as a major illness, loss of a spouse, etc., that necessitates

a change of circumstances, then the extent to which they are able to rationally evaluate alternatives and make a decision may well depend upon their stage of readiness cognitively to do so. Finally, the model has been criticized for not taking into account the social and cultural contexts that frame individual understandings and intentions (Glanz and Bishop 2010).

“Barrier” models in public health, on the other hand, assume that people will make decisions and take certain actions unless prevented from doing so. These models usually focus on external, environmental conditions that act to limit or constrain individual choice. Such approaches have been widely used in studies of decisions people make about whether or not to have a screening test for different types of diseases. For example, Urban, Anderson and Peacock (1999) studied barriers to mammography screening in older adult women. They found high cost, lack of screening facilities and lack of transportation to be significant barriers that kept women from having these tests. On the other hand, Young and Severson (2005) controlled for cost and found that behavioral variables including lack of knowledge about cancer and the importance of screening, as well as psychological fear of the disease, also prevented women from pursuing mammography. In the proposed study, older adult women may not consider alternative residential options as they age if they lack the financial resources to move or if they lack the information on alternatives to form choices.

Fears about what nursing homes or retirement communities are like could also be behavioral barriers to choice. American culture has a strong bias against nursing home care and it is commonly seen as a last resort option (Nakashima et al. 2005; Clark et al. 2010; Groger 1994). Fears of disability and death may further inhibit people from confronting the need to make decisions about health care and care givers as they age (Girling and Morgan 2014:727). San Antonio and Rubinstein (2004) note that envisioning oneself as old and disabled is a huge

psychological barrier for many Americans due to the devaluation of the elderly (who can no longer contribute to society through labor) and the culture's emphasis on individualism and the unchanging self. For many Americans, imagining oneself as disabled and dependent generates a sense of contempt and disgust at this possible future "other" self that provokes superficial comments on the possibility of suicide if this was indeed the case (San Antonio & Rubinstein 2004:42). These fears keep people from acknowledging the need for long-term care planning until they are presented with a crisis.

The majority of studies investigating long-term care planning and decision-making have been retrospective (Ball et al. 2009; Chen et al. 2008; McCullough et al. 1993; de Medeiros et al. 2013; Nakashima et al. 2005), focused on quantitative data from structured interview instruments (Clark et al. 2010; Friedemann et al. 2004; Mitchell, Mathews, and Hack 2000; Robison et al. 2014; Temple and Cockley 2012), or examined the planning strategies of middle-aged Americans and the "baby boomer generation," with fewer studies on how those over age 65 are planning for their own near futures (Finkelstein et al. 2012; Henning-Smith and Shippee 2015; Robison et al. 2014). There is also a deficit in recent studies on LTC planning, with nearly half of the articles reviewed for this study being ten years or older.

All too often, women's health is defined and determined by others in relation to reproduction and fertility, neglecting psychosocial, emotional, and structural factors influencing women's health and health care decisions (Inhorn 2006). This focus on reproduction neglects to examine factors that influence older women's health and health care decisions. In the US, women's health is primarily determined by the National Institutes of Health (NIH). The NIH defines its goals in terms of medicine and public health, limiting the narrative and removing the unique sociocultural framework of women's lives from the discussion (Inhorn 2006:349). The

underlying goal of this research is to acknowledge the cultural framework of women's lives and multiple roles in American society. This will be accomplished by assessing the effects of demographic variables, health status, attitudes and values, history of caregiving, and social support networks on LTC planning in an attempt to understand LTC decisions from a more holistic perspective. This perspective is essential for understanding how older women consider, process, plan, and decide on long-term residential and medical care.

### **Chapter 3: Research Design and Data Collection**

In order to better understand what factors lead senior women to advance planning and decision-making in regards to long-term care, this study took an exploratory approach, using a small, purposive sample of African- American and White community-dwelling women over age 60 living in Eastern North Carolina. This region still has a significant rural population, with high levels of poverty and low levels of education, resulting in higher rates of mortality and morbidity than the rest of North Carolina (Innab 2013:6)

A probability sample was impractical due to the depth and sensitivity of the topic under study, therefore, a small, purposely chosen sample of informants was appropriate. Purposive samples are particularly useful for pilot studies, in-depth research, and difficult to find populations (Bernard 2011:146) and small samples of 10-20 knowledgeable informants are typically sufficient for studies of lived experiences (Bernard 2011:154). Due to the exploratory nature of this project, the goal was to find a few individuals within the female elderly population who were both knowledgeable and open to talking about the subject.

Participant observation was conducted at a local senior center to provide context and background, as well as to recruit participants. Initially, participants were recruited either directly from a local senior center or through prior contacts in the community. Other participants were referred through a snowball effect until twenty-one participants were recruited. One participant dropped out after completing the first interview, leaving an analytical sample of 20 women total.

The study design included two interview instruments: a mostly structured, survey-type instrument (see Appendix A) and a more open-ended, semi-structured interview instrument (see Appendix B). These interviews were approved by the IRB at East Carolina University and written consent forms were obtained for each respondent. The structured interview gathered

basic demographic information such as age, race, ethnicity, income, health insurance, family medical history, and health status (Appendix A, questions 1-7; 23-30). Social networks were measured using a slightly modified version of the Lubben Social Network Questionnaire (Appendix A, question 22), which is designed to measure the basic network size and strength of elderly persons social networks, and social support was measured with a series of open-ended questions targeting instrumental help and emotional support (Appendix A, questions 18-16). The survey also included a vignette and several open-ended questions regarding LTC planning to assess general attitudes towards LTC, awareness of resources, and advance planning (Appendix A, questions 17-21).

The second, more in-depth interview included a series of open-ended questions about family, work history, caregiving experience, personality, aging, health status, LTC preferences, and LTC planning decisions. This interview also collected responses regarding attitudes towards aging and health (Appendix B, questions 9-15), personality (Appendix B, question 1-2, 12), and personal history (Appendix B, questions 3-8, 13), in order to assess any possible correlations between personal experience and LTC planning. I let informants define caregiving for themselves using several versions of questions and probes to understand their experience providing care for another aging individual (Appendix B, question 5-8). These individuals typically included parents, grandparents, siblings, spouses, and in-laws. Caregiving also includes care occupations such as nurses, nurse and medication aides, doctors, and other service occupations in which caring is a part of the job description (Appendix B, question 8). Health status was self-reported and based on conditions listed, pain levels, mobility, and degree of interference with the individual's lifestyle (Appendix A, questions 6-7; Appendix B, question 14). Long-term care planning decisions (or non-decisions) and preferences were assessed using

an open-ended set of questions about future planning, imagining future scenarios, and family support in planning and decision-making (Appendix B, questions 16-20).

After the participant was recruited and verbally consented, the participant chose a time and place for the first interview, usually in the participant's home. I met them in their homes, consented them, and read aloud survey questions while responses were recorded on a digital voice recorder. After the initial interview, a second interview was scheduled at least one week after and at most four months later. This time was necessary to review my notes, transcribe the interview, and prepare notes for the next interview. The second interview was conducted in much the same way: I met the participant in their home and the interview was recorded and later transcribed. The initial survey interviews lasted 20-90 minutes and the second interview took anywhere from 45 minutes to three hours, averaging around an hour to an hour and a half.

### ***Description of the Sample***

Ten black and 10 White women were recruited and one woman came from a Hispanic background. Their ages ranged from 60-89 with most of the women coming from the 60-69 range (8), six came from the 70-79 range, and six came from the 80-89 range. The mean age was 73.35. The majority of participants had completed at least high school (16), with nine completing some college or an associate's degree and three completing graduate degrees. Four women had completed some high school or less. 16 of the women were no longer employed but four worked part-time. 19 of the 20 women had health insurance. 10 (50%) of the women interviewed made less than \$25,000 per year. Three (15%) brought in \$25,000-50,000, and six (30%) made more than 50,000. One declined to answer. Each of the women was given a pseudonym to protect their privacy. The table below (table 1) describes the socioeconomic background of the participants.

Pseudonym	Age	Race	Partnership Status	Income	Education	Planning Score
<b>Lynn</b>	68	White	Single	\$50,000-75,000	Some college/Associates	3
<b>Helen</b>	69	White	Partnered	\$75,000-100,000	Some college/Associates	3
<b>Eleanor</b>	71	White	Single	\$75,000-100,000	Some college/Associates	3
<b>Alice</b>	71	White	Partnered	\$75,000-100,000	Graduate School	3
<b>Joan</b>	66	White	Partnered	\$15,000-25,000	Graduate School	2
<b>Mary</b>	66	White	Single	\$15,000-25,000	High School	2
<b>Beatrice</b>	68	White	Single	< \$15,000	Some college/Associates	2
<b>Martha</b>	71	White	Partnered	\$50,000-75,000	Some college/Associates	2
<b>Ruth</b>	83	African American	Single	< \$15,000	High School	2
<b>Susan</b>	86	White	Single	\$25,000-35,000	Graduate School	2
<b>Dolores</b>	86	White*	Single	\$15,000-25,000	High School	2
<b>Charlotte</b>	60	African American	Single	\$15,000-25,000	Some high school	1
<b>Lucy</b>	66	African American	Single	< \$15,000	Some college/Associates	1



<b>Evelyn</b>	71	African American	Single	\$35,000-50,000	High School	1
<b>Mildred</b>	73	African American	Partnered	\$50,000-75,000	Some college/Associates	1
<b>Ethel</b>	81	African American	Single	N/A	Less than High School	1
<b>Cora</b>	89	African American	Single	< \$15,000	Some college/Associates	1
<b>Grace</b>	68	African American	Partnered	\$25,000-35,000	Some college/Associates	0
<b>Dorothy</b>	70	African American	Partnered	< \$15,000	Some High School	0
<b>Cynthia</b>	85	African American	Single	\$15,000-25,000	Less than High School	0

**Table 1, Participant Demographics (\*indicate Hispanic ethnicity)**

The majority of participants were widowed (8 or 40%) and 30% (6) were currently married. In all, 15 (65%) were single and seven (35%) were partnered. Only three of the women in the sample were childless while for the rest, the number of children ranged from one to six with an average of 2.6 children. 60% (12) women lived with their partner or family members but 40% (8) lived alone. The majority of the women reported they were in good health (12, 60%) and another 3 (15%) reported their health was excellent, while five women (25%) reported that their health was fair.

African American participants were more likely to have less education, lower income, and were more likely to be disabled or unemployed rather than retired. African American women in this sample also had more children on average (3.5) than White women (1.7).

### ***Data Analysis***

After all interviews were transcribed, survey responses were coded into a Microsoft Excel data sheet and qualitative interview responses were imported into ATLAS.ti. I used SPSS to generate descriptive statistics, frequencies, and run chi-square analysis. Due to the relatively small sample size, Fisher's exact test for significance was used to determine whether or not the results were statistically significant (McDonald 2009: 70-75). In order for the survey responses to be useful analytically, many had to be recoded.

Partnership status was recoded into "single," which included divorced, separated, single, and widowed women, and "partnered," which included women who were currently married and one woman who was engaged at the time of the interview. Living situation was recoded into living alone and living with others. The categories of education were reduced to less than high school, high school diploma or GED, some college or associates' degree, and bachelors' degree or higher. Preference for specific types of long-term supports and services were recoded as formal and informal care; formal care included assisted living facilities and hired home help while informal care referred to different levels of care from loved ones.

To analyze social support, the number of individuals available for a particular form of support, the total number of individuals available for all forms of support, and the category of social relationship were coded. Social relationship categories were reduced to social network, family network, and religious network. Social networks included friends, neighbors, and acquaintances. Family networks included related and non-related individuals made accessible

through family relationships (such as in-laws, half and step relations). Religious networks included church members and friendships made through the church, pastors and religious workers, prayer partners, and extended church networks or acquaintances. The most important criteria for religious networks and what distinguishes them from social networks are that they would not be possible without some sort of religious community.

This study examined three aspects of LTC planning: Advanced Care Directives (ACD), financial planning for LTC, and discussion of plans and preferences with loved ones. Participants were scored on planning and could receive one point for evidence of preparations made in each of the three dimensions (legal, financial and future care/residential choices). The maximum possible score was 3 (complete plans) and the lowest was 0 (no plans). These scores were used to split the participants into planners (score of 2-3) and non-planners (score of 0-1).

Interview transcripts were coded using a grounded theory approach; looking for common words and phrases, and similarities in reasoning. I focused on explanations for behaviors in the second interview rather than the behaviors themselves, providing a broader context for explaining decision-making. The most prominent codes (both those discussed by the majority of participants and those that stood out among participants) were analyzed to determine their association with LTC planning and decision-making. The codes were clustered into themes and the themes were clustered into five core groups based on their connections both within and between narratives. The results of the variable and thematic analyses are detailed in the following two chapters.

## Chapter 4: Survey Results: Limited Economic Resources and Abundant Social Capital

The goal of the initial interview was to get to know the participants and collect basic demographic information, health and family backgrounds, and ideas about LTC (see research objectives 2 and 4). The variables examined in the survey were analyzed in SPSS using chi-square and frequencies. In order to make this data statistically useful, participants were scored on planning and could receive one point for evidence of preparations made in each of the three dimensions (legal, financial and discussion of future care/residential choices). The maximum possible score was 3 (complete plans) and the lowest was 0 (no plans).

Respondents scoring 2 or 3 were grouped as “planners” and those scoring 1 or 0 were grouped as “non-planners” for the chi-square analysis. The independent variables were correlated to the overall planning score as well as to the individual steps in the planning process which included 1) having made legal arrangements such as designating ACDs, 2) having made financial arrangements, or 3) having discussed the topic of future aging and possible plans with family members. Table two shows each participant along with their planning score and planning decisions. Names were changed to protect identities.

Table 2, Participants' Long-term Care Arrangements

<b>Pseudonym</b>	<b>Ethnicity</b>	<b>Planning Score</b>	<b>Legal</b>	<b>Financial</b>	<b>Discussion</b>
<b>Lynn</b>	White	3	Yes	Yes	Yes
<b>Helen</b>	White	3	Yes	Yes	Yes
<b>Eleanor</b>	White	3	Yes	Yes	Yes
<b>Alice</b>	White	3	Yes	Yes	Yes
<b>Joan</b>	White	2	Yes	Yes	No
<b>Mary</b>	White	2	Yes	Yes	No
<b>Beatrice</b>	White	2	Yes	No	Yes
<b>Martha</b>	White	2	No	Yes	Yes
<b>Ruth</b>	African American	2	Yes	No	Yes

<b>Susan</b>	White	2	Yes	No	Yes
<b>Dolores</b>	White	2	Yes	No	Yes
<b>Charlotte</b>	African American	1	No	No	Yes
<b>Lucy</b>	African American	1	Yes	No	No
<b>Evelyn</b>	African American	1	Yes	N/A	Yes
<b>Mildred</b>	African American	1	No	No	Yes
<b>Ethel</b>	African American	1	Yes	No	No
<b>Cora</b>	African American	1	No	N/A	No
<b>Grace</b>	African American	0	No	No	No
<b>Dorothy</b>	African American	0	No	No	Yes
<b>Cynthia</b>	African American	0	No	No	No

Only four of the twenty women surveyed had made preparations in all three planning dimensions (legal, financial, and discussion of preferences) while another seven made preparations in two. Six women had only planned in one dimension and three had made no preparations whatsoever. Thirteen women had made legal arrangements, seven had made financial arrangements, and thirteen had discussed the topic with loved ones, although these reported discussion varied in length and seriousness of purpose. None of the African American women who volunteered to answer the question had made any financial arrangements; few had talked with their loved ones about the topic of long-term care and or made legal arrangements for ACDs. Three African American women had made no plans, arrangements, or discussed the topic at all.

### ***Correlations between demographic variables and planning***

Survey variables associated with different stages of planning include ethnicity, income, past health crisis, family history of dementia, education, family support and overall levels of support, LTC caregiving arrangements, size of family support system; variables associated with preferences include location of children and number of children. Statistically significant

variables are listed in Table three and detailed in the following paragraphs. The Lubben social network score, family medical histories, relationship status, household size, and age were not associated statistically with planning nor were any trends apparent in these correlations..

**Table 3, Statistically Significant Variables**

	Planning	Legal	Financial	Discussion	Formal Care
Ethnicity	0.000***	0.057	0.004**	0.170	0.656
Income > \$50,000	0.177	1.000	0.035*	0.044*	0.628
Previous Health Crisis	0.041*	0.119	0.170	1.000	1.000
< High School Education	0.026*	0.101	0.119	0.255	0.582
Experience Making LTC Arrangements	0.005**	0.329	0.049*	0.158	1.000
Family Support	0.670	0.015*	0.637	0.648	1.000
Overall Support	0.022*	0.017*	0.121	1.000	0.653
Local Children	1.000	0.642	0.627	1.000	0.020*

African Americans were less likely to plan overall ( $p < 0.001$ ), and specifically, to plan financially ( $p < 0.01$ ). Looking at the participant chart, it becomes clear that income plays a role in planning, especially at the highest and lowest income levels. Income was not significantly related to planning overall but was significantly associated with financial planning, at the \$50,000 and up level ( $p < 0.05$ ). Education follows a similar pattern with the highest levels of education seemingly associated with more planning and the lowest levels of education associated with the least planning. Statistically, only those with less than a high school education were less likely to plan ( $p < 0.05$ ).

While caregiving experience does not have a direct effect on planning because seventeen of the twenty women in the sample had previous caregiving experience, specific experience with navigating the LTC system by making arrangements for others (negotiating with insurance companies, figuring out the limits of Medicare, Medicaid, and Social Services, finding local facilities and resources) does have an impact. All seven women who made arrangements for others scored 2 or more on the planning scale. ( $p < 0.01$ ) and made them more likely to make financial arrangements for themselves ( $p < 0.05$ ). None of the African American women sampled had experience making arrangements for others.

Those with smaller overall support networks (eight or fewer reported support resources) were more likely to plan overall ( $p < 0.05$ ) and more likely to arrange for ACDs ( $p < 0.05$ ). Smaller family support networks (fewer than three family members available to assist with daily tasks and crises) were more likely to have ACDs ( $p < 0.05$ ).

With such a small sample size, it is difficult to come to any definitive conclusions about associations between demographic variables and planning; thus patterns and frequencies were examined in addition to chi-square analysis. Patterns indicate that other potentially affecting

variables include having a family history of dementia or Alzheimer's and number of children. Having a family history of dementia may be related to planning, as four of five women with this history were planners.

### ***Long-Term Care Preferences***

Participants addressed potential preferences for LTC arrangements in both the survey and the in-depth interview enabling the cross-tabulation of responses and some assessment of the consistency of preferences. In the survey, respondents were read a vignette about a woman in her 70s having a stroke and needing care and then were asked several questions about what this woman and her family should do. Finally, they were asked what they would prefer if they were in that particular situation (Appendix B, Question 17 a-f). Five said they would go to assisted living facilities, seven said they would rely on family care, three said they would hire help, and three said they would hire help and rely on the family. Alice and Helen, both White, hoped they would be able to go through rehabilitation and return home to live independently while Cora, African-American, replied that she hoped she would die. For the purposes of further analysis in the in-depth interview data, hiring help and choosing assisted living were grouped as a preference for formal care (while relying on family support was grouped as preference for informal care).

Only one demographic variable – local children (defined as children living in the same county as the elder) – was associated with a preference for informal care ( $p < 0.05$ ). Similarly, not having any children was associated with a preference for formal care as was having fewer than two children but neither correlation was statistically significant. Preference for a particular style of LTC seems to be more associated with attitudes than with demographic or social variables, and these will be examined more closely in the next chapter.



In the in-depth interview, respondents were asked more generally about what type of LTC they would prefer if they needed care in the future: five responded assisted living, ten said family care, and three said they would hire home-based caregivers. While the core of their responses remained the same, some of the nuances changed. In referencing themselves, no one said they would combine home hired care with family support or going to rehabilitation. Although death was sometimes mentioned, respondents tended to say that they hoped death would come before disability rather than giving death as an answer to the question.

Preference for specific types of LTC also had a slight racial breakdown with the six out of ten African American respondents preferring informal family care while the six out of ten White respondents preferred formal care options such as hiring help or moving into an assisted living facility. Only three African American women preferred assisted living and one preferred to hire help. Although the difference is not dramatic, it may indicate a broader pattern given a larger sample size.

### ***Discussion of Survey Results***

Women in this study made more legal arrangements for their hypothetical future care than they did concrete and specific plans for residential LTC, such as financial arrangements. Most of the women interviewed have designated a health care power of attorney and signed a living will or other orders about their medical treatment, but only seven have made financial plans, which could be the result of the availability of these legal forms at hospitals and a recent push from the community to make sure seniors are legally prepared for their future. The local Pitt County Council on Aging, East Carolina University, Vidant Medical Center, and the End of Life Care Coalition are just a few organizations offering classes and workshops on the need for advanced directives and health care planning in later life. There is also a group of local attorneys

that runs the Senior Helpline, a program that provides free legal services to anyone over age 65. The number of women who have made legal arrangements may be more closely related to this push towards awareness and availability than to a realization that they need to plan for their future care.

Ethnicity had a major impact on planning, which may be due to a combination of socio-economic status and differences in family form. African American women in this study were less likely to plan but more likely to be poor and have less education than White women. The relationship between income, education, and planning is not clear in this exploratory study but suggests that having such resources may increase planning or at least give women the ability to plan, if not the willingness. The ethnic differences in planning may also be more related to family form; African Americans are more likely to live in large extended family households (Bailey 2001). Half of the African American women in this study lived in extended family households, usually with at least one grandchild. These expanded households allow coherent grandparents to provide childcare for their grandchildren and provide live-in care for elders in the family that require care. African American women may plan less, assuming that their family will care for them just as they have cared for their families.

One such example of life experiences shaping planning decisions is the relationship between caregiving experience and planning. While caregiving in and of itself is not associated with any particular type of planning, specific caregiving experiences such as making arrangements (legal, financial, and residential) for loved ones had a significant impact on whether or not women planned for their own future care needs. In the process of arranging care for others, these women gained better knowledge of the different residential options and local resources available in their communities. Navigating the legal and financial side of LTC

arrangements provides caregivers with knowledge about insurance benefits, including when Medicare and Medicaid apply and how much money is available through these outlets and what types of legal arrangements are required. They may also acquire knowledge about the best way to save or invest for the future, how to liquidate assets to fund LTC or qualify for Medicaid, and the cost of different LTC options. Through navigating the health care system, these women learned the ins and outs, the requirements – both legal and financial – as well as the support available.

Direct caregiving may be the only economically feasible option for some families; thus, caregivers may not have the same knowledge of LTC options and resources, or how to navigate the financial and legal side of aging. Caregivers also witness first-hand the unpredictability of aging. Women in this study who served as caregivers watched their parents outlive prognoses or conversely, saw their parents take a sudden turn for the worse. Those who had experienced LTC indirectly may be most likely to prepare because they understand how to navigate the financial, legal, and medical aspects of planning, and because they have witnessed what happens either when arrangements are *not* made in advance or how smoothly things go when arrangements *are* made. This previous experience provides them with both the incentive to plan and the resources to go about it. Those who provide eldercare directly may not possess the knowledge and resources to plan because of their different experiences. All African American women in this study who had caregiving experience provided direct care or worked as a paid caregiver. This may help explain the dramatic ethnic difference in planning. If arranging care for others better prepares women to plan for their own care and African American women are less likely to have this experience, they may be less prepared to make decisions for their own future.

Those with smaller support networks were more likely to plan for LTC needs. This was true for overall support networks and for family support networks. It is possible that having more social resources makes planning less necessary; a larger support network means more people available to call on in a crisis. Having fewer social resources may prompt women to make arrangements in case there isn't anyone around to help if the time comes.

A family history of dementia or Alzheimer's was also associated, although not significantly correlated, with planning. Four of the five women who knew of a family history of memory loss were planners and the only woman who did not plan claimed she had been trying to get her husband to go with her to sign their legal documents. The experiences of watching their family members lose their memories weighed heavily on them and combined with the fear of losing their dignity through mental illness may have prompted them to make arrangements for their own future care. This topic is discussed more in-depth in the next section.

The number of children and location of children relative to the parent had an effect on planning preferences. African American women in this sample had more children (an average of 3.5) than White women (averaging 1.7). Those with children living nearby were more likely to prefer informal care while those with no children or children living far away were more likely to prefer formal care. Practically, children living nearby are more likely to provide informal family care when needed and it is a shorter distance to move if live-in assistance is required. Similarly, not having any children makes it more difficult to find an informal caregiver; partners and siblings may be too old or sick to provide the care necessary. Those with more children have more potential caregivers. Because African American women in this sample had more children overall, this may help explain why they are less likely to plan than White women. They may feel they do not need to plan because at least one of their children will be able to provide care.

For some participants, death was more appealing than life in a nursing home. Nursing homes are thought of as the end of the line – the place you go to die or the last stop. Planning for the actual end – death – is much easier than planning for the experience of dying because it is considered inevitable and accepted rather than unknown and ambiguous. Designating a power of attorney, writing a will, and making funeral preparations are considered necessary to plan for the eventual end. Death is a more acceptable topic of conversation because it is something every one has in common and no one can deny. Dependency and the need for LTC is something that can be ignored, avoided, and put off and it does not have the same acceptance as a conversation topic. Death is an accepted outcome, planning allows some control whereas nursing homes are associated with dependency and lack of control.

The results of the survey analysis show several potential factors influencing women's decisions regarding LTC. Demographic factors such as race, income, and education have an impact but the extent of this impact cannot be determined from this sample. The survey also showed that certain life circumstances such as experiences with caregiving, size of social support networks, and family history of degenerative mental illness may impact women's willingness to make decisions about LTC. Factors that influence LTC preferences may include practical considerations such as location and number of children; however, these may be more strongly related to the themes discussed in the next chapter.

## **Chapter 5: Interview Results: How to Age Gracefully**

The goal of this research was not only to determine if aging women are making decisions about their future and what factors influence these decisions, but also to determine if there are any culturally shared schemas related to aging, and if these schemas have any impact on how these decisions (and non-decisions) are made. The second interview was designed to elicit schemas about growing older, retirement, and marriage, as well as values related to aging, health, family, and LTC (see interview instrument, Appendix C).

Themes were analyzed using a Grounded Theory approach to find keywords and phrases that “bubbled up” from the participants’ narratives. The most common of these keywords and phrases became themes and themes that co-occurred in the narratives formed clusters. These themes and clusters were compared with planning outcomes to determine if they had any effects on decision-making. While none of these clusters appeared to be expressed or linked schematically in the discourse of respondents, shared themes regarding aging did recur across the respondent sample. The first three clusters to be discussed reveal broad value orientations toward aging that are likely widely shared in American culture. These include three clusters labeled, Aging Gracefully, Mind Over Body, and Body Over Mind. The themes in each of these clusters focus on the causes and consequences of aging and general attitudes about envisioning the future (see Table 4). They serve as frames of reference in terms of which respondents think about what it means to grow older both generally and personally.

The final four clusters to be discussed include more specific themes that are more directly related to planning for aging but that are not predictive of any specific instances of decision making related to aging. These clusters include The Future is Uncertain, I Don’t Want To Be a Burden, Role Reversal, and No One Wants To Be in a Facility (see Table 5). The themes

discussed in these clusters relate to whether or not future uncertainties encourage or inhibit planning, the complex emotions that come with being cared for by others, and stereotypes about care facilities. These themes do not predict whether or not women plan but delve deeper into the complexities involved in the decision-making process and what decisions are preferred and why. The first section of this chapter will detail the general values shared by most participants while the middle section will explain the more specific themes related to planning; the final section will discuss the relationships between these themes and planning.

**Table 4, Shared Value Orientations**

Cluster	Theme	Examples
1. Aging Gracefully	Do What You Can	<i>“Just accept what comes, try to make the best of it and do what you can to keep your health.”</i>
	Envisioning the Future	<i>“Picture retirement? When I got married? No! You see, it’s like, it’s forever away, you don’t even know. But it comes quickly.”</i>
	Avoiding the Topic	<i>“Don’t want to think about it. Don’t want to get old. Or, I don’t want to be able to not take care of myself. . . That’s the worst thing, to me. Is not “being able to do that kind of stuff.”</i>
2. Mind Over Body	You’re Only as Old as You Think	<i>“I think it’s all in how you feel, what your outlook is, what you think of yourself.”</i>
	Negative Thinking Makes You Sick	<i>“If you concentrate on how bad you’re hurting, you’ll hurt worse.”</i>
	Giving In Makes You Old	<i>“They just don’t want to continue to be a viable, active person.”</i>
3. Body Over Mind	You’re as Old as You Feel	<i>“If my body was as young as my mind feels, there’d be no stopping me.”</i>
	Paying the Price	<i>“Slowing down, getting more rest, not pushing as hard. Well, you can push hard but then you’re gonna pay the price.”</i>

## ***General Value Orientations***

The first three clusters and the themes that comprise them reflect broadly shared American notions of aging as reflected in many key phrases used by respondents to voice these. All of these are expressed at times by the respondents in the sample but some give primacy to one cluster over others. Even respondents who discuss the same cluster of themes, however, may interpret the application of them differently. This section presents the results of the value orientations found in the in-depth interviews as summarized in Table 3.

### **Cluster One: Aging Gracefully**

The first cluster focuses on what participants think it means to “age gracefully.” Most of their answers focused on “accepting what you cannot change,” staying active and taking care of yourself, and not seeing yourself as old and dependent. Helen describes what it means to her: “*I think to age gracefully is totally a mental, like, I’m going to be 70 years old this year. Oh well! It’s not a big deal, it’s just another year and I’m thankful to be here.*” Sometimes this included avoiding the topic of future care needs, which involves admitting that LTC may one day be required. Mary explains, “*I don’t like to think about that kind of stuff. It’s too depressing. I don’t like to get depressed.*” Needing LTC implies dependency, fear of which was mentioned in every interview.

The first theme in this cluster, *Do What You Can*, refers to this intense fear of dependency and how participants combat this by taking preventative measures, such as eating better and getting more exercise. Participants emphasize acceptance as a key component of aging gracefully but insist that accepting age and declining abilities does not mean giving in to the aging process, but staying active and continuing to do what you can, while accepting that there are some things you can no longer do. Eleanor explains, “*You have to make a realization that*



*you're not as young as you used to be, but that doesn't mean you have to give up everything that you enjoy doing.*" Beatrice answered that aging gracefully meant *"accept[ing] it, I guess, and do everything you can to keep yourself from going downhill fast."* Both of these quotes show that "doing what you can" means more than just staying active; it includes the realization that a person is aging and may have to change the way she does things.

Ruth spoke fondly of growing old, *"it's a blessing for one thing, to grow to be old, especially in your right mind and health and you can do for yourself. Even if you can't do everything, enough to keep yourself going."* Still, some felt that there was also a threat to becoming too comfortable with aging. Ethel claimed, *"If you don't use what you got, you lose it,"* and Mary reiterated, *"as long as you can still do for yourself, you should do for yourself."*

In juxtaposition to the first theme, the second one, *Avoiding the Topic*, gives voice to the opposite value: that it is better to avoid thinking about aging altogether, in part because if you do not think about it, it might not happen. Many respondents expressed this sense of avoidance, claiming they "just don't think about it." Grace responded, *"I ain't even got that far! I'm just trying to deal with this week."* Evelyn spoke similarly, *"I really never thought about it. Truly, I don't think about being elderly."* Alice, links the avoidance to the hope things will just continue on as they are. She stated that she and her husband were not truly prepared to make a decision regarding LTC. *"[We] have talked about it often, and I've talked a little bit about it with my sisters, but we haven't really made any hard and fast decisions about what would happen. . .we all keep hoping that everything is gonna be hunky dory."* Similarly, Mary said, *"I don't want to think about it, don't want to get old. Or, I don't want to be able to not take care of myself."*

While housework and yard work were becoming harder for she and her sister, she thought it was

not yet time to deal with the situations. She said, *“when it gets to when we can’t do any of the housework by ourselves . . .that’s the time to start discussing it.”*

The final theme in this cluster is *Envisioning the Future* and relates to how women pictured old age and retirement when they were younger. Thirteen of the women interviewed said they had no concept of growing old or retiring when they were younger. *“Picture retirement? When I got married? No! You see, it’s like it’s forever away, you don’t even know. But it comes quickly,”* Helen explained to me. Alice and her husband felt the need to plan financially but had no idea what retirement would look like: *“I don’t know that I thought about retirement much when we were first married. We did think about it in that we were planning for retirement form the very beginning, but I don’t know that I can say that I had pictured how it was gonna be.”*

There was a slight racial bias in the way respondents thought about retirement, however, it was not dramatic enough to concretely suggest a pattern. Seven African American women said they did not think about retirement while the other three had some idea of what it might look like; five White women did not consider it while four had pictured what it might be like. One woman (Mary) was not asked this question due to a missed interview question.

Some women’s backgrounds did not allow them to think too far into the future. Ethel, African American, explained why retirement was never something she pictured as a young woman,

*“I didn’t think about retirement, I thought about surviving. We had to survive. Back in those days, you grew up poor, you married poor, you had four children, and just living from week to week, to me that was my lifestyle. I hadn’t thought about retirement. When you’re young and you’re keeping food on the table, it*

*wasn't easy. So you don't think about retirement, you don't think about old age or anything, you're just at that moment, at that time."*

Ruth, also African American, explained that retirement was not an option for her when she was a young factory worker, *"When we first started working at the plant we didn't have no retirement in there. In the plant, you never retire."* Grace chose to focus on present needs rather than look to a hypothetical future,

*"I guess I was right here at the present, now, thinking about doing now, then finding a job and finding out when I worked at the hospital for 10 years and I retired from there, they asked me if I wanted them to keep my money – I said, 'give me my money!' Because tomorrow is not a promise, you know what I'm saying?"*

Those who did envision what their future would look like had only vague ideas, but most mentioned having free time and the ability to travel. Dorothy (African American) said,

*"[I pictured it] a whole lot better than what it is. When we first got married, we were both working and we had a little nest egg saved, but when he got sick, we had to use it because we didn't have no medical insurance. [We thought] that maybe after all our kids got grown we could travel a little bit but after we used it, our little nest egg, we have not been able to regroup, you know?"*

Mildred (African American) pictured *"retirement as my time, being my own and my husband and I doing things together – you know, like cruises and things like that. Husband and wife togetherness."* Lynn (White) said, *"We talked about wanting to travel and getting another smaller camper and just do stuff together. Not have to get up and go to work everyday."* Evelyn (African American) had a similar idea, *"We wanted to get a camper and go from one end of the states and*

*go around to the other end – go one way and come back another way.”*

Beatrice and Susan, both White, had very simple ideas of retirement. Beatrice said, *“I pictured me and [my husband] growing old together, sitting on the couch, holding hands. Maybe getting to travel some.”* Susan explained, *“That was going to be the time I had to do all the things I wanted to do that I didn’t get to do while I was working. I wanted to be a writer. I never had time to do it.”*

Although Charlotte, African American, did not picture what retirement might look like, she thought about what growing old would look like: *“old with a cane and no teeth in my mouth, glasses, bent over – I ain’t want to live like that.”* Martha, White, painted the most detailed picture of growing older:

*“I guess I pictured being very old in retirement, and my husband and I both, we certainly don’t feel old. . . one of the things that attracted me to this house was it reminded me a lot of my grandmother’s house. I think I pictured sitting a lot more than I get to do now, but cooking for the family and family dinners, grandma brining in the plates of food, you know, and I’m getting to do that kind of thing. So yeah, it’s not that different from what I pictured except I don’t feel as old as I thought I would be.”*

Overall, none of the women had any concrete ideas or plans of what their futures would look like. Those who did vaguely pictured having more free time, relaxing with their partners, and traveling. Two of the women pictured getting old but both noted that their picture was nothing like reality. Charlotte explained, *“It don’t bother me now! Because getting older and retired, I still could go, I got my life, health, and strength. I’m able to go places, still drive, you know, independent! Still independent. So it don’t bother me. It’s just the age.”* Martha said, *“I*

*thought I'd be old! And I don't feel old!"* Just as most of the women avoided thinking about being dependent in the future, they did not give much thought to being older in the past.

### **Cluster Two: Mind Over Body**

The next clusters focus on the processes of aging and what makes a person "elderly." The second cluster, *Mind Over Body*, suggests that the body can slow you down, but it is ultimately the mind that controls the aging process. Attitude is seen as a key factor in what makes a person elderly and respondents claim that thinking can make you feel better or worse.

The first theme in the Mind Over Body cluster, *You're Only as Old as You Think*, maintains that age is mental rather than physical. Joan explains, "*You're only as old as you think you are. Getting old does not mean that you have to quit living.*" Grace admits, "*I know, my body tells me my body is not as young as it used to be, but I won't let it take over me, you know, to the point where I stop doing certain things.*" Grace noticed her physical limitations but refused to let them slow her down. Martha expands this sentiment,

*"I don't think I'm there yet! I suppose, every time you lose the ability to do one of the things you've been able to do since you were three or four years old, I think that brings you closer to that elderly stage. I don't know what it's gonna take for me to say, 'Oh, well I'm an old lady now,' cause I certainly don't think that right now."*

Related to this idea that you're only as old as you think is the theme, *Negative Thinking Makes You Sick*. Just as you can think yourself younger, you can think yourself older and sicker. Evelyn states, "*If you put it in your brain that you're old and you can't do this or that, you're not going to do anything.*" Helen notes, "*If you worry about things before they happen then you're only asking for trouble. It just causes stress and worry and they can cause lots health issues that*

*you wouldn't have otherwise.*” Helen’s comments explain that negative thinking not only affects a person’s attitude, but also their physical health and wellbeing. The most extreme demonstration of this idea is the notion that negative thinking can actually kill you. Ethel told of her sister’s death and how she had warned her of it far earlier, *“She never was a happy person, always so negative. I used to tell her, ‘If you don’t stop it, if you don’t change, you’ll destroy yourself, it’ll kill you.’”*

Others saw hope and positive thinking as being able to keep you alive, but if a person lost hope, she could cause her physical body to give up and die. Grace attributes her father’s death to “giving up,” explaining, *“As strong willed as my Dad was, I think he just gave up. Because he’s a fighter and when he left that nursing home, he was determined he wasn’t going back, and he didn’t.”* Eleanor told a similar story of her father’s death after a massive stroke,

*“He really thought he was gonna get well. Every time I’d see him, he’d tell me, ‘When I get well, I’m going to do such and such.’ The doctor said the only thing keeping him alive was sheer will, because he wanted to do these things. I think when he realized he wasn’t going to get any better three years later, he gave up.”*

Both women spoke of how strong their fathers were and how as long as they had something to live for, they stayed alive. They felt that the loss of hope caused the men’s decline.

The final theme in this cluster, *Giving In Makes You Old*, ties the two prior themes together. Women who expressed this theme felt that those who give in to their aches and pains rather than resisting them become older faster and begin to “act elderly,” preferring inactivity or the attention that comes with dependence. Whereas giving up is seen as a loss of hope, giving in is seen more as a choice. Alice explained that being elderly meant, *“Not wanting to take, not wanting to do for yourself, or wanting someone else to care for you, make your own decisions, I*

*mean, somebody to make decisions for you.” Grace had a similar experience caring for her mother-in-law, “She was the type that like attention, so in her wheelchair, she could get the attention she needed.”*

Evelyn saw aging more as feeling sorry for yourself than wanting the attention:

*“We do so much damage to our health and our body by just thought – ‘oh I can’t do this’ or ‘I can eat this’ or ‘I don’t need to exercise’ – we do our bodies injustice. They get pain and they rehearse it, they nurse it, it just consumes them. I think that’s what I see and what I don’t want in my life as I grow older.”*

On the other hand, Susan saw aging as more of a character trait, “[It’s] self-centeredness. If they’re concentrating on what they want and how they think and feel, it comes on rather quickly.” Martha’s response was similar, “Defeatist, you know, just giving up. As long as you keep trying to do things, even if you don’t do them as well as you did when you were in your 40s and 50s, as long as you keep trying and as long as you enjoy being around other people.” Each theme in this cluster derives from a common idea that thoughts and choices rather than chronological age or health status make you elderly. This idea of “mind over body” was common in nearly all the women’s narratives.

### **Cluster Three: Body Over Mind**

This third and final general cluster, *Body Over Mind*, is the opposite of the second in philosophy. The themes in this cluster focus on the idea that health status and chronological age can trump mindset, making one feel or act “old” or “elderly.” These physical factors have the capacity to slow down even those with a “young mindset.”

The first theme in this cluster is the idea that *You’re Only as Old as You Feel* and pinpoints the body as the source of age, rather than the mind or attitude. Mary explained, “I

*don't feel elderly. I'd like for my body to be as young as my mind is. If my health or my body was as well as I feel now, there'd be no stopping me. I'd be out trying all kinds of things. I'd be skydiving, trekking down the Nile, anything."* Helen said, *"I think it's where we get to a stage where we're not able to do the things that we used to do when we were young. I think health has a huge, health and mind, have a huge part to play in defining elderly. It's not an age."*

Alice admitted, *"That's when you really do feel old, when you have trouble getting out of the chair, when your joints ache."* Eleanor explained getting older as *"your body is slowing down, your brain is slowing down, you're not capable of doing all the things you used to."*

The second and final theme in this cluster is *Paying the Price*, the idea that you can push through your physical limits and difficulties but you will pay for it later. You either slow down or pay the price. Helen sums up this theme: *"I have to be honest, I do have moments where I know that my body is aging and I can't physically do what I could do when I was 21. I could go 8 hours a day without stopping, but my body will pay for it."*

Grace explains how *Paying the Price* works in practice, *"Last night I was gonna wash clothes, but I washed two loads and said, 'you know what, I ain't gonna wash no more.' I came home and did some other stuff and it's like, it's time to stop and rest. I talk to me like that, because you know, I wanna be here a long time."* Joan admits she had also has to slow herself down, *"I had to stop pushing myself as hard as I could do and realize I needed to take rest breaks. . . Slowing down, getting more rest, not pushing as hard. Well, you can push hard but then you're gonna pay the price."*

### ***How General Value Orientations Frame Planning Decisions***

Although none of the above themes relate directly to planning, they may impact the way women approach the topic. These general themes show how participants in this study attempt to



strike the balance between learning to cope with their declining physical abilities – the way their bodies felt – and their mindsets – which they felt did not match their chronological or physical ages. Doing what you can and accepting what you cannot was core to what these women saw as aging successfully – or aging gracefully. Accepting changes in the body was key, but so was avoiding thinking about the future and the potential for dependency and disability. These women said that they avoided discussing plans for LTC because it is “depressing” or they “just aren’t there yet,” just as they had no picture of old age or retirement when they were younger because “it was too far away.”

This avoidance is likely related to the intense desire to stay independent and a belief in the continuity of the self, demonstrated in the women’s comments that LTC planning is “depressing” and about not “feeling” old, despite physical changes. For some, it was easier to think about death and dying than to think about living with disability or impaired abilities and depending on others for help. It may also be related to the intense public interest in and media coverage of battles over when a life truly ends and how long is it ethical to keep a brain-dead person on life support. Highly publicized court cases increase awareness about end-of-life issues, making them easier and more common to discuss than issues of LTC.

The second and third theme clusters, Mind Over Body and Body Over Mind, appear to contradict each other in theory but not necessarily in the participants’ dialogues. The same women who stated that age is a mindset also admitted that their own health impacted how old they felt and their abilities to complete daily tasks. These themes are more fluid and interwoven than they appear at first glance: some women’s narratives concentrated on the mind’s ability to set aside physical limitations and do what you can, while others’ focused on how sometimes, the body set hard limits that the mind cannot overcome.

The American biomedical healthcare system enforces the view of the body, mind, and self as separate. We treat the body (or the mind) separate from the person. This separation of the body alienates the person (their mind or sense of self) from the experience, reinforcing the split. This may help explain the resistance to the term “elderly” and the need to “keep your mind young” while at the same time accepting declining abilities and new physical limits. Being elderly is a mind experience while being old is a body experience. As long as these two are separate, both Mind over Body and Body over Mind do not contradict each other.

***Themes Framing Long-term Care Planning***

The second group of four clusters and the themes that comprise them examine specific themes related to planning, caregiving, and LTC options. Although these themes are not predictive of specific decisions in any straightforward way, these themes relate more specifically to the difficulties of predicting an uncertain future, fears of dependency, fears of becoming a burden on loved ones, desire to be cared for, and the potential risks of being in a facility. This section presents the results of these planning-specific topics as summarized in Table 5.

**Table 5, Themes Affecting Long-term Care Planning**

4. The Future is Uncertain	It’s the Luck of the Draw - So You Gotta Live in the Moment	<i>“Why do some people get sick, why do some young people end up with cancer, why do some people with similar lifestyles end up with heart disease and somebody else who’s lived the same way, smoked, not taking care of themselves, don’t?”</i>
	You Never Know What’s Going to Happen or When	<i>“Because, as with my husband, you never know when it’s going to happen or what’s going to happen.”</i>
5. I Don’t Want to Be Dependent	I Don’t Want to Be a Burden	<i>“I hope that I’m never a burden or an added responsibility to them.”</i>
	I Don’t Want to Be an Intrusion	<i>“But I also don’t want to be an intrusion, because I know they have their own thing going too.”</i>
	I Don’t Want to	<i>“I guess It comes down to that lack of dignity. I</i>

	Lose My Dignity	<i>think that's the one thing, more than loss of mobility or anything else, that loss of dignity."</i>
6. Role Reversal	Don't Tell Me What to Do	<i>"They think they wanna handle you like you're a child. They want to tell you what to do, don't tell me what to do. I'm the mother"</i>
	I Took Care of Them, They'll Take Care of Me	<i>"I know they're gonna be here. I believe family is one that you can depend on."</i>
	I Trust Them To Do What's Best	<i>"I just, I trust what they would do for me. Because of the relationship we have."</i>
7. No One Wants to be in a Facility	People Feel Better at Home	<i>"I think she would be, get better a whole lot sooner and quicker if she was at home in her own surroundings."</i>
	A Facility is the Last Resort	<i>"That that's about the last stop on the road of life. That more than likely, you never get out of there, alive."</i>
	Don't Forget About Me	<i>"I've seen people get left out, nobody ever comes to see them."</i>
	If it Comes to That, I Hope I Can Make Myself Happy	<i>"I would, my prayer is that I can make myself happy at whatever facility is best determined for me."</i>

#### **Cluster Four: The Future Is Uncertain**

The majority of participants (17) talked about the uncertainties of the future but how they interpreted this idea and related it to planning varied. The first theme in this cluster, *It's the Luck of the Draw*, refers to those who saw the future's uncertainties as a deterrent to planning while the second theme, *You Never Know What's Going to Happen* refers to those who see uncertainty as a reason to plan.

The first theme, *It's the Luck of the Draw (So You Gotta Live in the Moment)*, focuses on the future as unpredictable and planning as futile since, all you can do is "live in the moment" or take life "one day at a time." Grace explained her reasoning: *"Anything can happen so I just try to stay within my thought range and that's not a whole lot. You know, I can plan this week, I can plan next week, but I can't go too far because you never know what's going to happen, so I just*

*never thought about.*” Evelyn echoed this sentiment, *“I don’t know what the future holds and I’m not going to get all these plans and it don’t – no, I ain’t got time for that. No. I could walk out here and die today.”* For these women, making plans was futile since they don’t know what they are planning for. As Evelyn stated, she could plan for LTC needs and die suddenly in a car accident and never need it.

With regards to planning for future care needs, Martha saw luck as having more to do with it than being prepared,

*“Why do some people get sick, why do some young people end up with cancer, why do some people with similar lifestyles end up with heart disease and somebody else who’s lived the same way, smoked, not taking care of themselves, don’t? Whether you wanna call it fate or luck or whatever, I don’t know.”*

Martha noted that some things you cannot always prepare for and you cannot predict what will happen to people just based on their health or lifestyle any more than you can predict the future.

Six women emphasized aspects of “luck” or “future uncertainty” while another six focused on the “one day at a time” part of this theme. The end result was the same – live in the now and do not focus on the future. Nearly every non-planner (eight of nine) mentioned this theme in their narratives while only four of eleven planners referenced it – nine African American and three White women. Martha in particular brought up more specific concerns about planning for future uncertainties from her own caregiving experience: *“You don’t know when these accidents are gonna occur and if they don’t occur on the day that the person is coming in to bathe her, then you’re going to have to do it anyway. There’s just so much that you can’t anticipate as you get into situations like this.”* She felt *“you have to see one of these situations,”* and noted that *“Sometimes opportunities just present themselves,”* speaking of another

participant, Susan, who decided to move into a staged assisted living facility after her sister's fall put her in the same facility with skilled care.

The second theme, *You Never Know What's Going to Happen or When*, pinpoints the future's uncertainty as a reason to plan. Lynn, for example, realized she needed to plan after her husband's sudden death. She explains,

*"I told [my boys] I'm going to pick my own assisted living place, there are power of attorneys in place as far as my health is concerned, there are power of attorneys in place for my finances and bank accounts and everything, beneficiaries have been put on everything, I've planned for my funeral, paid for it. Because, as with my husband, you never know when it's going to happen or what's going to happen."*

For her, planning is essential because anything could happen at any point. Rather than seeing planning as futile, she views planning as essential to maintaining as much control over the situation as possible. Helen's answer was simple and straightforward. She and her husband had their house built so that they could live entirely on the first floor: *"You're gonna age and things will happen. We designed this house with that in mind and we'll live here as long as we can."*

While five of the women who talked about uncertainty as a reason for planning were planners, four were non-planners, three of whom saw the future uncertainty as a reason not to plan but to "live one day at a time." Ethel is one such example; although she thinks it is important to live in the moment and not plan too far ahead, she admits that sometimes you have to plan for future uncertainty, as she did when she moved, *"I was looking ahead, that's the reason I chose this particular floor plan, with the wide doors and everything. Not that I feel like I'm gonna be sick, but in case, cause we never know."* As Dorothy says, *"do the best you can*

*with what you got and take it one day at a time. Cause yesterday is in the past, today, you got to live today out but we don't know what tomorrow may bring.*” Still, she chose to live in the present, *“I'm still living and I'm still moving and I'm still able to do for myself. I don't like to think about negative things, although negative things do happen to you. I try to think about the positive things, what's happening today, and lord you gave me another good day.”*

Mildred, a non-planner who claimed she would make arrangements soon, explained, *“At this point, you never know. That's why I said to her, ‘if I lose my faculties, remember that I told you when I was thinking straight that I'd rather go to a facility for something like that than to go into your home.’”* Her daughter experienced a sudden health crisis that gave her a different perspective on this issue. *“When something happens and you're emotional and everything, it's more difficult to deal with something like that. If you do it upfront, your loved ones don't have to deal with it.”* Grace told me near the end of our interview, *“People are so busy living and not thinking about tomorrow – and there is gonna be a tomorrow, whether you're in it or not!”*

Overall, five African American and four White women took this perspective on planning for the future. While all four White women who mentioned it used it as a reason for planning, the African American women who had this perspective had not yet made plans but suggested that they would (or should) make plans in the future.

Although the concept of an uncertain future behind the two themes in this cluster is the same, the way it is interpreted and acted on is very different, and although it does not necessarily predict planning, it provides a framework for decision-making. For those who had experienced a sudden death or health crisis, the idea of an uncertain future became a reason to plan. Those who did not want to think about the topic chose to live in the moment and take it one day at a time without trying to anticipate future outcomes.

### **Cluster Five: I Don't Want To Be Dependent**

The fifth cluster focuses on fear of dependency and its impacts on the elderly and their caregivers. There are three main themes discussed in this cluster: *I Don't Want to Be a Burden*, *I Don't Want to Be an Intrusion*, and *I Don't Want to Lose My Dignity*. For the most part, these themes focus on barriers to informal family care and somewhat on barriers to accepting care from anyone – strangers, friends, or family members.

The first theme, *I Don't Want to Be a Burden*, was usually based on past caregiving experiences of respondents or on a fear of interfering with the lives of potential future caregivers. Beatrice claimed she'd rather go to a facility than live with a child caregiver, "*I wouldn't want that burden on my children.*" Evelyn expanded, "*I want them to continue to have life. I don't want them to feel they have to take care of me – they need to live.*" Still, most women who said they would not want to burden their caregivers admitted they would prefer a family caregiver if they could be sure the caregiver was willing to do it. Eleanor explained, "*If I had a family member that I knew really wanted to because they loved me, that would be my first choice. But I just would have a hard time getting over the feeling of it possibly being done out of feeling of obligation.*" This theme came up in fourteen of the women's interviews but only eight saw the concept of being a burden as a barrier to discussing informal care options. Of these eight, six were White and two were African American. Three viewed it as irrelevant and three saw it as a potential future issue, all African American. It came up in the narrative of seven planners and seven non-planners in all, although it was considered more of a barrier (six) for planners while non-planners were more likely to see it as becoming an issue in the future (two) or irrelevant (three).

As mentioned in the prior chapter, nearly all the participants had prior caregiving experience and many drew on these experiences in framing their own decisions. Helen described the physical stress caregiving caused her husband:

*“My mother-in-law took a toll on my husband, being an only child and sole caregiver because when we sold her home, he went over there and painted and got it ready for sale. He had a heart attack about a year after she died.”* Martha described a similar experience, *“I don’t want my girls to have to tend to me the way we had to tend to [my mother-in-law].”*

Lynn described the complex emotions she felt caring for both of her parents after the sudden death of her husband in detail.

*“It was like I was on call 24 hours a day. . . in fact, about 18 months after I moved back, they put me on blood pressure medicine and 13 months after Daddy passed away, they took me off. The doctor said he had decided that he thought my blood pressure problems were stress related and I said, ‘Ya think?’”*

Not only was this experience incredibly stressful but full of mixed emotions, including guilt.

*“I knew he was not happy, but there wasn’t anything I could do about it. Because I knew I couldn’t take care of him full time myself. I felt like what he wanted, I should at least try to do it to make up for having put him in an assisted living home, because he wanted to stay home. But I thought, I did the best I could, I didn’t see anybody else running down here helping me.”*

Her narrative shows her mixed emotions, her guilt at putting her father in a facility when he wanted to be home while also justifying the logic of her decision.



Closely related to the theme of not wanting to be a burden is, *I Don't Want to Be an Intrusion*, highlights the importance to women of space and privacy. They emphasized not only their own needs for physical space, but their family's needs as well. Martha explains, "*There's always conflict in a situation like that and everybody needs their own space and their own freedom to do what they feel, to live their life the way they feel they need to live it.*" She speaks from experience, having shared a home with her parents when she was first married and later providing in-home care for her mother-in-law.

Eleanor described striking a balance between being close to her family and letting them have their space, "*I cherish every moment I have with my grandkids. But I also don't want to be an intrusion, because I know they have their own thing going too.*" Helen had a similar answer, "*I guess under dire circumstances I could live with either one of them, but if a choice can be made, I'd prefer not to, just because of knowing that they need their space. There never comes a time that you don't need your space.*" She explained that despite it being just her and her husband living in the house, she did not want to downsize, "*We enjoy it. We enjoy this, there's not that thought. We go to our little beach place and we're happy to get back to our big house.*"

Lynn's reasoning was more specific, "*I don't want to live with my sons because I don't want to live in another woman's house. I told the boys when they moved out that they could come home and visit but they couldn't move back in because my house was not big enough for two women, and that's the way I feel.*" For Lynn, the issue was not just about physical space, but the family dynamics of running a home and family. She recognized the potential for conflict between her and her daughters-in-law and wanted to evade it before it became an issue, despite having positive relationships with her family.

Space was also an issue for visiting family. Evelyn explains, "*I can't downsize more than I*

am. *I mean, I got family.*” Charlotte was in a similar situation,

*“No, I want a bigger! I got two bedrooms, I want four bedrooms. . .My grandchildren come to stay with me – they have somewhere to sleep. I don’t want a one bedroom, never. Some people downsize when they get older so their children won’t come see them. They get a one bedroom. Ain’t nobody by them. I don’t want to be like that.”*

Although family did not often stay with Martha,, she recognized the importance of having space to host family gatherings,

*“We were thinking a couple years ago that we’d go ahead and make the move but every time we go through a Christmas or a birthday or something like that here, and we have the kids and the pool table in the backroom. . .we’ll never have a house where we can have that again.”*

This need for physical space is almost metaphorical; it is a place to bring the family together. Similarly, Charlotte wants her family to feel welcome and at home so they do not stop coming to see her while Lynn recognizes that space is not just a physical necessity for privacy but could throw a wrench into family dynamics. Eleanor and Helen speak not only of literal space but of metaphorical space for their children and grandchildren to feel free to live their lives and make choices independent of them. The idea of being an intrusion was mentioned by four women, all planners (White), while the broader concepts of space and privacy were mentioned by five women: three non-planners (African American) and two planners (White).

The final theme in this cluster, *I Don’t Want to Lose My Dignity*, describes the reasoning behind the fear of dependency. Rather than an abstract concept or unknown fear, women who discussed this theme in their narratives described very real future scenarios that scared them.

Some of these were imagined while others were experienced second-hand through the people they cared for. Martha said the worst part of her experience caregiving for her mother-in-law was *“dealing with the personal issues. You feel that you take away so much dignity.”* This experience of cleaning up after her mother-in-law’s messes impacted her own preferences for her future care. Although she preferred family care and felt confident her children would care for her, she admitted,

*“I would hope that if I get to that state, I’ll be able to figure out how to be in a facility where I can have the help I need from a professional rather than putting that back on my daughters. I guess it comes down to that lack of dignity. I think that’s the one thing, more than loss of mobility or anything else, that loss of dignity.”*

While Martha would not mind accepting care from her children, she did not want her daughters to have to care for her personal hygiene. Instead, if the day came when she needed help for hygiene, she would prefer to hire it or move to a facility. For Martha, the core issue is not being a burden on her children, but rather is one of losing her dignity by having them take care of her personal needs.

Mary had a similar fear. Although she was open to moving into assisted living if necessary, she admitted that the worst part would be *“just having to have somebody to do something for me that I can’t do myself, the personal items.”* Eleanor had a terrible experience with her mother-in-law,

*“You could hear her, when you walked in the door, if they were giving her a bath or just turning her over, you could hear her scream when you entered the door*

*way. She was hurting so bad, just for them to touch her. That's hard to take, it really is. It just tears you out of your frame."*

For Grace and Ethel, the loss of dignity had more to do with losing autonomy. Ethel asked me to tell my audience, *"Older people want to do for themselves as long as they are able to do, because once you take that away from them, they begin to die. . . If you take that away, you take away that dignity."* Grace told me what she learned from her caregiving experiences,

*"You have to have patience with them because a lot of times they're not where they used to be, and you have to realize that. But you cannot – you can never, ever lose respect for them. Respect them right there where they at. They're still in those same roles, you know what I'm saying?"*

Beatrice had a very real experience with dependency after her stroke. She feared falling or experiencing another stroke that would increase her dependency and was thankful for the help she had, but still felt frustrated that she could not do for herself, *"Being homebound doesn't help things either. I guess I have to admit to getting depressed sometimes because when I want something, I can't go out and get it right then. I have to wait for someone who can come get me or go get it for me. I get irritated at that."*

The loss of dignity that comes with no longer being able to remember friends or family members was another issue that came up. Losing dignity by losing memories was described as losing personhood. Helen explained, *"I don't know which is worse, your body to be weak and your mind good or your mind bad and your body good."* Ethel spoke of her friend with Alzheimer's, *"I have no control over that but I don't wanna live with that. . . This lady that is my friend, she is very quiet now, very – nothing, just sit. To me, even though she's living, in my way of thinking, you dead already, why you living?"*

Both of Beatrice's parents had Alzheimer's, she describes the impact it had on them,

*“My Daddy was diagnosed with Alzheimer's at age 76 and he died at age 82 and he was not the same man, he was weak in his body and he would fall. He was having hallucinations and he would be hard to get along with. It just changed him. Momma is fighting to stay strong but she's not the same woman she was. Her dementia gets worse everyday and she can't even remember she has a son.”*

These women's experiences with watching their loved ones lose their sense of dignity, personhood, and self-respect gave them a picture of a concrete future where they too might lose their dignity, a future they greatly feared. Although nearly all women talked of their fear of dependency, six gave specific examples of losing dignity; of these six, four were planners (White) and two were non-planners (African American).

### **Cluster Six: Role Reversal**

The concept of role reversal between mother and child came up often in the interviews but was expressed in different forms. For some, this role reversal was closer to the theme of losing dignity while for others, it was a natural part of aging. This cluster includes viewing this role reversal with resentment, welcoming it as part of the cycle of life, choosing to turn over their decisions to their children willingly.

The first theme in this cluster relates to this resentment and is summed up in the title of the theme, *Don't Tell Me What To Do*. For women who discussed this theme, role reversal was not something that happened naturally, but something that occurred when their children lost respect for them. Cynthia had to move out of her daughter's house due to conflicts with her daughter. She explained, *“She seemed like she was taking over, she was trying to change the roles. I was the child instead of the mother and I didn't want that. So now I'm in my own house, my own*

*apartment, I can do as I want to do.” Susan had a similar issue with family care, “They feel, sometimes that they have the right to make decisions for you. What they say goes.”*

Joan saw this role reversal as the only downside to accepting family care, *“They can get all up in your business! They like to tell you what to do. That’s probably the worst of it.”* Ethel had watched this role reversal happen in other families and refused to let it happen to hers:

*“I don’t allow my kids to dictate and tell me what to do. They ask me how I feel about certain things but they do not make the decisions for me, at this point in my life. . . I’m not gonna allow my children to turn me into a child unless I’m completely unable to take care of myself and I’ve lost it up here.”*

Evelyn knew her kids could take good care of her, but feared they would limit her, *“I think that happens, even now, as their parents get older. ‘Oh don’t do that now, I’ll get that for you,’ and they don’t let their parents be who they are. They make them crippled and feeble-minded.”*

Grace talked of how she toed the line between caring for her mother and becoming her mother’s mother, *“You still have to keep that respect for them and their proper places, you know, unless she was doing something that I felt was harming her, then I would probably be a little forceful.”*

Seven women discussed this type of role reversal; three were planners (White) and four were non-planners (African American).

The next theme in this cluster, *I Took Care of Them, They’ll Take Care of Me*, was voiced by the women who saw role reversal as natural or assumed. Grace refused to see herself as a burden, *“That’s why I think I’m there for them now, because I know I’m gonna need them later, and I know they’re gonna be here. . . We’ll share this. We shared life coming up, we’ll do it now.”* Dolores had to let her daughter take over many tasks for her due to her health issues, *“To me, it has been heaven, let me tell you. Because she’s treated me the same way that I treated her,*

*when she was a baby.*” Charlotte was not worried about being left in a facility, “*Now, I always told my girls – they have teenage girls, they got their life to live. I don’t want to be a burden to them, but they already told me, ‘Ma, you’re not going to no nursing home,’ and I thank god that they said that. I don’t want to go nowhere.*” Martha spoke of letting her husband take over the personal care of her mother-in-law,

*“I remember having trouble trying to help her, in the beginning, I’d be the one to try to help her with the bath and the bathroom activities and she almost fell on me one day and my husband said, ‘Look, she did for me when I was a baby and there’s not reason why I shouldn’t do for her now.’ And he took over most of that care.”*

Four women talked about role reversal as a natural process of aging, three planners and one non-planner. Two were African American and two White, one with Hispanic heritage.

The third theme in this cluster, *I Trust Them to Do What’s Best*, was based in the view of aging and role reversal as natural. These individuals preferred to trust their families to make decisions for them. Grace, who has made no preparations, not even discussing the topic with her family, explained, “*I just, I trust what they would do for me. Because of the relationship we have. And before I would cause any confusion or anything I would just want them to do what’s best, for them too. As long as they put me somewhere where I could get proper care, I’m good.*”

Evelyn also refused to make decisions, “*No, my kids know me well enough to know what I like and what I dislike.*” Dorothy said although she had no plans for her future care needs, “*If I was unable to make a decision for myself, I would depend on my husband if he was still here, and my children.*” Cora said something similar, “*I’m sure whatever they do, I’m sure it will be what they think be best for me, because when you’re in a situation where you can’t take care of*

*yourself, you can't make those decisions.*" Ruth hoped her family would care for her, but trusted them to do what's best, *"My children, I tell them what I would like to have done and if you can't do it, you know, y'all get together and do what you can, do the best."* Instead of making decisions or plans, these women count on their families to decide for them when the time comes. Nine women said they trusted their families to make decisions for them, including seven non-planners (African American) and two planners (White).

### **Cluster Seven: No One Wants To Be In A Facility**

The final cluster revolves around preconceptions about living in a facility. The first theme in this group is *People Feel Better at Home* and expresses the idea people in need of care do better in a familiar environment, surrounded by loved ones. Grace explained that it was more than comfort, *"You're surrounded by something you built, this is a part of you – your home is part of you. If you move somewhere else, that's apart of someone else. Even if it's taking care of your needs, it's not what you did with your hands, how you kept it up, you know what I'm saying?"* For Grace, the home was a place of comfort because it embodied her memories. Her house was a physical memento of the life she had built with her loved ones and her loved ones were key to making it feel like home. *"It keeps you going when you got somebody around you. I knew that with my Dad, he did so much better when [my kids] were around him. I think if you've got a person who's isolated and to themselves, they gotta be miserable. What is it to live?"*

Susan recognized the importance of staying home, *"That's a situation that's very important to older people as they get older – being able to stay in a familiar territory."* Martha said something similar, *"Well, you're always most comfortable in your own surroundings. When you go off on the nicest vacation that you can possibly take, and it still feels good to come back to your own home. So I think there's a comfort in being in your own familiar surroundings."*



Mildred's motivation was more practical:

*“My husband and I have been in this house for almost 40 years and this is what I know, this is the only place that I know and I would rather be right here than to move in with somebody else, you know, in a new surrounding, because you know, I know my way around here. Even in the dark, I can go from room-to-room and won't bump into nothing.”*

Cora felt that being at home could actually make a person heal faster: *“I think she would get better a whole lot sooner and quicker if she was at home in her own surroundings.”* She explains, *“Believe it or not, if you're sick and you go someplace else, you're not going to be satisfied because you are not surrounded by your own stuff, by your own things. If you're 75 years old, it can be depressing, not being at home and in your own space.”*

Beatrice thought it had more to do with the people surrounding you in a facility: *“They're in a place with people so much sicker than they are.”* Evelyn also attributed it to surroundings, *“I think the benefit of in home care is people will get better quicker in home. Going to a nursing home or rehabilitation place, they automatically just figure they're gone, and they're giving up. They can't move around, they have nothing they're used to, nothing familiar.”* Ruth noted that in-home care, whether provided by a family member or a stranger, provided more interpersonal contact than a nursing home or facility,

*“I feel like you can do better because you've got one-on-one. When you go to a home, you got three, four heads to go around to. If they come to your house and stay, there's not that pressure, they can do what they need to do, y'all can sit down and talk for a while and when it's time for that person to go, they can go.”*

Eleven women in all mentioned this theme; four planners and seven non-planners; eight African

American women and three White women.

The next theme, *A Facility is the Last Resort*, was expressed almost universally among the participants in this study. Lucy noted early on in our discussion, *“No one wants to be in a residential care facility if they are coherent.”* Grace’s aversion was based on her own father’s experience, *“I don’t want to do that because my dad was in one and he hated it and I think that’s why he gave up, but there was no other way.”* She attributed his loss of hope and giving up to being in a nursing home. Charlotte had a similar experience, *“Unless push come to shove, I’d rather stay home. I worked in them, my mother and father was in one, I don’t want to go to one.”* Martha explained, *“it’s just that difference between assisted living and full time nursing care, it’s not something you want to do until you absolutely have to do it.”*

Beyond this general sense of aversion, many women complained that the care provided in facilities was inadequate. Charlotte, who formerly worked in a facility, felt strongly about nursing homes:

*“I have been in there working and how they treat some of the people. They let ‘em stay, some of them, you can tell that they’ve been wet a long time cause they smell like ammonia. It smells, and I know they ain’t bathed ‘em. No, I wouldn’t want to go to a nursing home until I had to.”*

Lucy also spoke from experience,

*“There’s not benefits in a nursing home, they treat you just like crap. I’ve been in there. Sometimes you find some people who – I just read an article, they had it on the news too, this people caring for the elderly is beating them. I would never do that. You could think about it but that doesn’t mean you have to do it. Sometimes they make you mad and you want to pop them, but I wouldn’t do it.”*

Mary attributes this inadequate care to the low pay received by care workers: *“Well, most of it is the people, the caregivers, are not paid what they should to me, what they’re worth to be able to take care of someone like that. So to me, that makes their attitude a little harsher.”*

Evelyn had a second-hand negative nursing home experience visiting a family friend and blames money for causing this disruption,

*“I’ve been visiting nursing homes and people don’t have the passion they used to have for people. I mean you can just look around this whole world, there’s no passion, it’s just money. . . there is one woman down there, every time I just look at her, she’s like, this big. She’s been in that nursing home for quite a while. And they just bring her tray in, drop it, and go. . . You know, it’s just a sad situation and I just don’t think the passion, the doctors, as far as I’m concerned, nobody has passion, for their elders for their young people, there’s no humanity. There’s not. I don’t want to be there if no one’s there to smile and, you know what I’m saying? It goes a long ways. And they’re just there for the paycheck. . . No. Let me die at home.”*

Susan admitted that while not all nursing homes are the same, there are some she would not want to be in, *“They’re not clean and they don’t take good care of their patients. They’re the ones that when you walk in the front door, you can smell urine.”* Fifteen women spoke of a facility as being the last resort, including nine planners (White) and seven non-planners (African American).

Connected to this theme and perhaps inspiring it is *Don’t Forget About Me*, the idea that people are left alone in nursing homes and forgotten. Grace felt that it was less about the facility itself and more about the individual or the family dynamics,

*“I’ve seen some of them put ‘em in a nursing home and that’s it. They don’t see ‘em – neighbors will go see ‘em or somebody else but you know, but they don’t see them, because to them, ‘I gotta work and take care of me’ or ‘he won’t be here long’ or ‘she won’t be here long,’ so you just got all kinds of mixed emotions about it so I just think it has to do with the individual.”*

Others saw it as being a byproduct of living in a facility. Ethel explained,

*“For some reason, people in senior citizen homes, people don’t visit you as much because now you’re in a home. It’s not like your home. See how my friend just rang the doorbell? But I think if I was in a senior citizen home, she wouldn’t have come. Once you go into a senior citizen home, people wanna put you on the back burner.”*

Charlotte spoke from experience, *“When you get in places like that, people don’t come see you like that should. . . It’s sad. They really don’t come visit when you’re in a nursing home. I know. I worked in one for about 17 years.”*

Others recognized the potential to be forgotten but also knew that sometimes, a facility is the only option. Ruth said, *“I’d rather be home and if the children get tired of waiting on me, they got everything on their own and they can’t do, put me in a place where they think it’s nice, but don’t forget me.”* Nine women expressed this thing, including four planners, three White and one African American, and five non-planners, all African American.

The last theme in this cluster, *If it Comes to That, I Hope I Can Make Myself Happy*, was found in the narratives of women who recognize that facilities are not pleasant places to be but also recognize that they may not have a choice. Rather than resisting this possibility, they accept it as a possible outcome and prepare themselves to accept whatever comes. Alice describes her

mixed feelings about the topic,

*“I would hope that when it becomes necessary for us to go to an assisted living or nursing home, that I will go gracefully, but I know that that will be a very hard time, for anybody that has to go and leave their home. . .I have thought about what might happen in the future, but I certainly would not want to go to assisted living or a nursing home until it was absolutely necessary. But it will probably be necessary.”*

Helen expressed a similar sentiment, *“I would hope that I would be as considerate as my mother-in-law was and do whatever is necessary, whether it be a nursing home or assisted living or downsizing or having someone come in the home. I would do whatever it is that I need to do.”*

The women who discussed this theme in their narratives were more accepting of the need to plan even if they did not want to think about the topic. Nine planners (eight White and one African American) expressed this sentiment and only five non-planners admitted it was a possibility (all African American).

### ***How Ideas About Long-term Care Frame Discussions and Decisions***

Although none of the above themes directly predict planning decisions, understanding these ideas helps these women frame the issue and develop potential solutions. Themes in these final four clusters focus on the difficulties involved in anticipating and planning for uncertain future outcomes, which includes anticipating health outcomes, financial situations, family emotions and resources, and personal emotional reactions. The magnitude of this uncertainty forces some women to anticipate and plan for possible outcomes while it crushes the option to plan for others. In this particular study, those who had experienced the sudden loss of a loved one, an acute health crisis, or had watched a family member go through an acute health crisis

were more likely to see the uncertainty as necessitating planning, not negating it.

While everyone agrees that the future is impossible to predict, not everyone agrees with how to approach this unpredictability. The key difference may be these unique life experiences. A sudden health crisis, death, or accident may prompt women to see future uncertainties in a different light and plan for what they can control. For others, this unpredictability is exactly why it is futile to make plans for the future. This sample size is not large enough to say for certain but experience may be the key factor in changing this perception; however, it could just be a personality trait – some may want to have more control while others may be more comfortable relinquishing the responsibility.

The second cluster discussed in this section relates to the complex emotions of caring and receiving care. The majority of women interviewed had experienced caregiving first hand and had a mixture of emotions and experiences. These women were afraid of becoming a burden on their children, knowing how stressful it can be to provide care for a loved one. For some, this prompted them to make plans to receive formal care if needed while others preferred to ignore the topic and avoid discussing it with family members because they did not want them to feel obligated to provide care in the future.

Participants feared becoming an intrusion into their loved ones' lives and space. They spoke of their own need for space and privacy, both a need for the comfort of physical space and the metaphorical space to "live your own life." As Helen said, "*There's never a time when you don't need your space.*" Some women said they could not downsize because they saw their homes as gathering places for family members and giving them up would mean giving up times of family unity. For many of these women, there is a conflict between the desire to bring the family together and be part of their lives and the desire to leave their children alone and allow

them the space to live their own lives. Consistent with most literature regarding African American family culture, African American women in this sample were less concerned with becoming a burden on their families than White women and were more likely to worry about having space for family than their own privacy or worry about being an intrusion on their loved ones' lives.

Women also feared losing their dignity – their sense of self and autonomy. Having watched their parents and in-laws go through embarrassing situations – such as not being able to take care of personal hygiene, forgetting your loved ones, or regressing back to childhood – they were afraid of these same situations happening to them one day. This fear may prompt some women to plan but for many, it reinforced their avoidance of the topic. The thought of losing their dignity was “too depressing” to think about or plan for.

The three themes in this cluster all center around the need to maintain independence at all costs, not only for oneself, but for one's family. At the center of each theme is the need to be independent and to spare one's family the responsibility of care. Even those who admitted that family care was preferable still worried that when something happened, their family members might feel obligated to help rather than wanting to do so voluntarily.. American ideals of independence are strongly embedded in these women's narrative and they apply these to both their families and themselves. They are reluctant to make any decisions that may get in the way of their loved ones' freedom and self-sufficiency just as they are reluctant to think about or plan for a time when they themselves might have to give up their own freedom and self-sufficiency.

The third cluster, Role Reversal, addresses relationships between elders and caregivers. While some embrace the need to rely on their children or younger family and friends for help as they get older, others worry that their loved ones are trying to take over and take away their

autonomy. Ethel was particularly adamant that her children not make decisions for her, and Cynthia moved out after six years of living with her daughter because she felt she was being treated like a child. Grace had learned through her many years of caregiving for family members that you have to strike a balance between providing care and infantilizing elders; she talked about the need to provide for basic needs and gently remind elders of their limits without making decisions for them or telling them what to do.

Others, the majority of whom were African American, saw this role reversal not as something to be feared, but something that is natural and should be embraced. These women view the mother-child relationship as reciprocal; just as they once took care of their children, they expect their children will one day take care of them. Two African American women mentioned this specifically and seven said they trusted their families to make decisions for them.

Those who rejected their families' involvement in their lives connected more with the need for independence. They felt that allowing their children to help them or tell them what to do would take away their autonomy. Those who saw it as natural did not see independence as an issue when it came to relationships between parents and children. Such relationships are naturally reciprocal; there is no need to be independent or fear becoming a burden because it is not an unexpected added stressor but the logical evolution of the relationship.

Similarly, some women prefer to leave LTC decisions entirely up to their children, trusting them to make the right choice. Instead of worrying about what to do, they trust that their children know them well enough to decide what the best option would be for the situation when the time comes. Some women trusted their children because they had strong relationships with them and valued their judgment; others had discussed the topic and their wishes with their loved ones at length and knew that their children would honor these. Some women considered this discussion



as part of the planning process but many others saw it as another reason not to plan and to avoid the topic. There was no need to think ahead or make arrangements since they did not know what might happen or when.

A key difference between women who embraced family care and those who shunned it may be related to ethnic differences. More than half (six) of the African American women preferred family care and saw it as a natural progression. These women grew up in large families where people took care of their own. For most of them, family care was the natural response, it was the children's duty to take care of their parents unless they needed full-time skilled medical care. White women were more preoccupied with the possibility of becoming a burden and less likely to admit that they would prefer to be at home being cared for by a loved one. White women focused more on independence and maintaining their own and their children's ability to be self-reliant and unencumbered. The majority of White women sampled (6) stated that they preferred formal care options to informal care options.

The last cluster of themes refers to the complex attitudes towards facilities and formal care. These attitudes came from a combination of watching loved ones' health deteriorate in a LTC facility, of hearing the horror stories of abuse and neglect both in the media and from friends and acquaintances, and from watching friends and family members' requests get ignored or postponed. Participants were acutely aware of the low wages and understaffing common in many LTC facilities and felt this had a lot to do with the quality of care received. Others focused less on the negatives and more on what simply was not part of the facility experience: space, privacy, familiarity, loved ones, health, and independence. In addition to the negative reputation facilities carry, lack of familiar amenities, and loss of independence, most women recognize that most people who go into a nursing home do not come back out alive. Thus LTC facilities are always a

last resort, while home is seen as the best place for a sick and elderly person because it is familiar, comfortable, and the person is surrounded by loved ones.

Facilities – even assisted living and apartments designed for seniors – are viewed as places where families stash their aging loved ones and forget about them, intentionally or not. Moreover, people housed there are easily forgotten because these single room spaces or shared rooms are not conducive to visits. For some respondents, facilities were seen as a last resort while others were more willing to acknowledge that there might come a point when an elder would need skilled care. This idea is even less appealing to African American women who may be used to the idea of family care and prefer not to live alone.

Similarly, some women were more accepting that LTC might be in their future and they might not have control over the aging process. Most of these women were planners, which may indicate that attitude has something to do with willingness to plan. An attitude that is more accepting of multiple future outcomes – even ones that are tough to think about – may be more conducive to making some arrangements ahead of time, or at least to discussing the topic with family members. Accepting the idea that LTC care might be needed one day is a likely first step in planning for future care needs.

While the themes discussed in this chapter obviously do not predict planning outcomes, they provide some insight into how women begin to think about and reason through these complex decisions as well as helping to explain ethnic differences in planning. The results from this preliminary study indicate that personal experiences and family upbringing may play a major role in whether or not these plans are made or aging decision are avoided.

## **Chapter 6: Conclusions and Applications**

The goal of this project was to explore the factors that influence women's willingness to engage in long-term care planning as well as the actual decisions they make in this regard by interviewing a sample of 10 White and 10 African-American, independently living women ages 60 and over in Pitt County, North Carolina. Respondents completed a two-step interview process that included a more structured survey instrument and a longer, more open-ended, in-depth interview instrument. For the purpose of this research, the outcomes or dependent variables included long-term care planning (LTC) defined as advance care directives, acknowledging a preference for specific long-term supports and services or residential care, and financial planning to ensure care for the future. The factors hypothesized to influence planning include the independent variables of demographics such as age, ethnicity, and socioeconomic status; social variables like marital status, presence of children, levels of social support and the size of social networks; perceived health status and current health conditions; attitudes toward aging; and past experiences as caregivers for others.

This chapter distills the key conclusions gleaned in the research and makes recommendations for how these ideas might be applied by community organizations that work with older adults to facilitate planning for LTC needs. The discussion is organized in terms of this project's specific research objectives.

The first half of the chapter reviews key conclusions related to the research objectives. The first part of this section reflects on the methods used and their utility while the second part reviews the results in light of the research objectives. The first of these was to try and determine if older women in the sample were actually thinking about and making future plans or if they were avoiding doing so and why. Of particular interest in this consideration is a closer

examination of the type of decision-making that is involved in LTC planning and how women cognitively process relevant information to reason to outcomes.

The second key objective was to try and delineate the major factors that influence both the willingness to plan and the actual decisions made by eliciting information on demographic, social, attitudinal and health status variables and correlating those with both the action of making plans/decisions as well as the choices made. A more in-depth analysis of key themes in the interview data helped to identify the overall cultural frameworks that frame women's ideas about aging and to delineate the types of long-term residential and medical care elderly women prefer and why. A final research objective was to explore the extent to which the choices (outcomes) considered as well as the factors involved in decision-making vary by ethnicity (African American and White elders) since a consistent theme in the literature is that these two groups differ in key ways with regards to LTC plans.

The final section of this chapter outlines more specifically how these findings could be applied to help seniors think about and plan for their potential future care needs. This includes advocating for policies that would provide funding to LTC facilities and agencies to increase staffing and pay for caregivers, broadening Medicaid and Medicare's LTC benefits, and on a more practical level, helping local community centers develop workshops that might aid seniors living in the community and their family members to begin to think about and work toward LTC planning.

### ***Reflections on Research Methods and Objectives***

Research objectives were attained through the use of two separate interview instruments: the first, a structured interview instrument with an open-ended section based on a vignette about LTC decisions, the second, a semi-structured interview instrument with open-ended questions.

The interviews were performed several days to two months apart and although they required more from each participant, making recruitment more difficult, the sequential interviews allowed the interviewer to develop a deeper understanding of the participants, aiding in the coding and interpretation of the qualitative data. This also allowed for the interviewer to build rapport with each participant, making it easier for them to open up about their thoughts and experiences.

The first interview was structured but rather than administered as a written survey, the questions were read aloud to participants and their answers were checked off. This format allowed for participants to expound on their answers to the extent that they were comfortable. In addition to collecting basic demographic data, this initial interview allowed for myself, the interviewer, to develop a better understanding of each participant's background and their experiences with other family members, health, caregiving, and LTC prior to the second, more in-depth interview. The survey's inclusion of a vignette telling of a woman who suddenly required LTC after a health crisis but had no plans in place was particularly useful for discovering participants' views about LTC and experiences. Although the first interview contained no questions about caregiving, many women opened up about their caregiving experiences after reading the story or admitted to knowing someone in a similar situation. Some offered their own stories or opinions after hearing the story before any specific questions were asked. This vignette provided rich data on attitudes towards LTC decisions and opened up the topic in a non-threatening way. After discussing the story, women were more open to discussing their own LTC plans (or lack thereof).

The second interview was more open-ended and in-depth, discussing family situation, past and present health issues, caregiving experiences, and attitudes towards growing older, LTC, and making plans. The information acquired during the previous visit and interview helped to

target the questions and question wording, allowing for more in-depth answers. While the second interview was good for diving deep into attitudes about growing older and LTC, the first interview was more useful for attaining the research objectives. Although the first interview was written as a survey, because it was conducted more like an open-ended interview, it collected more data regarding attitudes and experiences than expected. In future assessments of LTC plans and attitudes, this type of survey instrument – with a few tweaks – may make a more effective tool. It's shorter, requires less commitment from informants, and is easier to transcribe and code.

### ***It is Possible to Plan for Long-term Care Needs?***

Many of the non-planners in this study did not see LTC needs as something that could be planned for; in their eyes, there was no decision to be made until the time came when (or if) they required care. In the literature review for this research, three different approaches to decision-making were evaluated (stages of change health readiness theory, barrier theories, and schema theory). While each approach has its merits, they all neglect to ask first if people are actually making a decision. The issue of whether women actively plan for aging or avoid it altogether was a major focus of this project.

While some of the women interviewed had made some decisions regarding LTC, many avoided the decision and did not make any plans, preferring to wait until something happened or a loved one took over the decision-making process. Others planned in some areas but avoided others or made concrete arrangements, but avoided talking about their decisions with friends or family members.

Although eleven women could technically be identified as planners according to the survey design, the overall attitude of avoidance expressed by nearly all participants and lack of

any concrete ideas about what could happen in the future and how to arrange for these unanticipated outcomes shows that very few women in the sample are actually prepared for future outcomes. Legal arrangements such as ACDs do not require women to envision or plan for LTC needs; rather, they designate what would happen if they could not make medical decisions for themselves. In addition to ACDs, some women mentioned that they had designated a power of attorney, last will and testament, and paid for their funeral arrangements. Designating a power of attorney and healthcare power of attorney can help women transition into LTC arrangements, however, it really does not help women plan for future care needs or prepare themselves psychologically.

The psychological toll of the transition has been noted as one of the biggest consequences of not planning for LTC arrangements before a crisis. These decisions are commonly made by unprepared women and their children in hospital rooms with a lot of pressure to make a quick decision (Nakashima et al. 2005). These sudden decisions can create resentment between mothers and children and cause problems during the adjustment period (Chen et al. 2008; Groger 1994).

The results of this study indicate that the majority of the women are not psychologically prepared to make or adjust to sudden LTC decisions, in spite of their planning scores. After interviewing each participant twice and discussing LTC decisions and attitudes at length, it is questionable whether or not LTC can be planned for in any concrete way. Some decisions can be made ahead of time – such as purchasing LTC insurance or setting aside savings for LTC or preparing legal documents – but no concrete decisions about LTC can be made until the elder can no longer live independently or feels that she should no longer live alone. Downsizing or moving in with a loved one are options, but many women are reluctant to give up their space;

their homes are havens of comfort and privacy and gathering places for families. Another option is to move into a staged retirement home, however this also requires giving up space. Continuing care retirement centers are also very expensive, making them inaccessible to all but the richest women, making hard and fast decisions about LTC difficult for many women.

Still, having discussions about preferences and possible future outcomes may help prepare elders and their families psychologically to make the decision when the time comes, yet seven of the women interviewed had never discussed the topic with loved ones. These factors show the complexity of LTC decision-making and planning, thus it may be useful to consider the extent to which this decisions resembles others, in addition to how this decision may be unique. In the next section, I will discuss how the three decision theories discussed in the literature review frame LTC decisions and how well they explain participants' approaches to decision-making.

### ***Health Behavior Theory on Readiness to Change***

The public health decision-theory, Stages of Change, posits that the individual goes through a set of stages of readiness or action (Prochaska & DiClemente 1983; Prochaska, DiClemente, & Norcross 1992; Prochaska & Velicer 1997). The Stages of Change model states that health interventions can promote change but must be targeted towards people in in each stage of readiness. This study exposes the limits of this model by pointing out how the stages of change do not easily conform to LTC decision-making stages. The stages of change include contemplation, preparation, action, maintenance, and termination – these are discreet and sequential stages (Prochaska & Velicer 1997:39). According to Prochaska and Velicer, the stages of contemplation and preparation refer to when people are aware of the reasons to make a change but may not be ready to act, and when people intend to take action had have a plain to do so,



respectively (1997:39). These two stages seem to apply to LTC decision-making and planning. Many of the women in this study appear to be in a stage of preparation, where they are aware of why they need to make arrangements for future care needs but are also swayed by other influences, such as the idea that the future cannot be predicted or planned for. The preparation stage was also noted in women interviewed for this study, where some women plan to take action but have not done so yet (such as Mildred, Lucy, and Grace). The action stage is where a person has made changes recently and applies to many planners in this study, however, the maintenance stage refers to when a person has taken action recently but may still be tempted to revert to past choices or behaviors (Prochaska & Velicer 1997:39). Martha, Mary, and Joan seem to exemplify the maintenance stage; each has made preparations for LTC but doubts the usefulness of their choices. Martha pointed out the futility of attempting to anticipate future care needs while Mary and Joan emphasized their reluctance to discuss LTC planning, despite having planned concretely for it.

The final stage, termination, is when a person is no longer tempted to reverse their decisions (Prochaska & Velicer 1997:39). This stage does not easily apply to women in this study making LTC decisions. Even women with extensive plans for possible future LTC needs admitted there was no way to know what would happen or when, so there is only so much one can plan for. Because this decision is based largely on what changes occur in health, mobility, and living situation as a woman ages, it cannot be predicted and planned for with any certainty, leaving all planners stuck in the maintenance stage, questioning their decisions. LTC insurance is expensive, and savings and property investments could more easily be cashed in for enjoyment or current needs rather than long-term health needs, making this decision a tedious one.

Criticisms of this model include its assumption that individuals are capable of making coherent and logical plans of action and its sequential and fixed stages (Rakowski, Dube and Goldstein 1996). Due to the nature of LTC planning decisions – based on the anticipation of future needs rather than concrete realities – the Stages of Change model does not easily fit the LTC planning process. Because LTC decisions are not based on concrete realities, the stages of the decision process are not necessarily discrete, sequential, or predictable. This model does, however, point out some stages where women could use support and encouragement. The key stages that seem to inhibit women from making LTC decisions are those of contemplation and maintenance; these are stages where women need to know that making a decision is better than a non-decision and more information about of local resources available might help persuade them. Targeted intervention at these stages may enhance decision-making and planning for LTC decisions; however, this model does not explain how women come to these stages or what order they move through each.

### ***Modeling Barriers to Health Decision Making***

Public health barrier models assume that people will make a decision and take action unless prevented from doing so (Urban, Anderson and Peacock 1999; Young and Severson 2005). These “barriers” are usually external environmental conditions that restrain individuals’ choices. While this study certainly points out the potential for barriers to interfere with LTC planning (such as low income and low levels of education or negative stigmas around nursing homes and formal care options) it also suggests that removing these barriers does not automatically result in a decision being made or any advance care planning: having higher income and higher education did not make women plan any more than having low income and

little education prevented it. The connection between socioeconomic barriers and planning is there, but it is vague and needs further research.

Socioeconomic or psychological barriers alone do not explain why older women do not plan for their own future care needs; rather it seems there is a complex interplay of variables that factor into these important LTC decisions. For example, African American respondents were least likely to plan but also more likely to have lower incomes and lower levels of education. Additionally, African Americans in this sample were more likely to live in large extended family units and place a higher value on family cooperation. These variables interact in complicated ways and it is difficult to say whether the removal of socioeconomic barriers would change their decisions or increase their planning in any way. The results from this study indicate that knowledge of and experience with the long-term health care system may contribute to planning; however, examining knowledge of resources was not a goal of this research and this interpretation cannot be adequately supported by the data. This angle needs to be fully fleshed out through further studies.

While barrier models (rightly) focus on how to tear down structural barriers and address issues of healthcare access, they do not paint a full picture of the decision-making process or tell us how to address the issue on a more local and practical level. Barrier models are helpful for tackling big issues in healthcare behavior such as enhancing access to preventative care and insurance but they do not explain how people make decisions about their healthcare. This study shows that there is a complex interplay of variables that is not entirely dependent on resources available, but on family and personal values, attitudes, personality traits, and specific life experiences.

Both the Stages of Change and Barrier Models to health decision making assume that if a person has knowledge of an issue and is motivated to take action and if barriers to action are removed, the person will act. Such an approach would suggest that if older women recognize and learn about the likely issues she may face as she ages, and if barriers (i.e., lack of financial resources, education, or knowledge of resources, etc.) to taking action (in this case planning) are removed, then she will make plans.

On the other hand, empirical studies of some common medical decisions reveal that people do not make intentional choices to have tests or procedures. Instead, they go through with a procedure because a physician or authority figure recommends it. Despite studies identifying numerous barriers to mammography including high costs, fears of pain and of cancer detection, and lack of education, the single factor prompting women (regardless of socioeconomic status or ethnicity) to actually have a mammogram remains receipt of a physician recommendation (O'Malley et al. 2004) which suggests that women are not consciously weighing criteria to make an informed choice; they are following a recommendation so that it becomes a non-decision. Similarly, Press and Browner (1997) found that women attending a prenatal clinic in California agreed to have the maternal serum alpha fetoprotein (MSAFP) test for the detection of neural tube defects and other developmental disabilities even when they had no intention of aborting a fetus that tested positive for these disorders. When asked why they had the screening at all, these women responded that the physician recommended it. Clearly, they were not thinking through what the decision meant – they were following orders.

The one component of planning that women in this study appeared willing to carry out involved the legal domain. Thirteen women interviewed had completed advanced directives and health care powers of attorney. But they did so largely because authority figures recommended it

and made the forms available. Much like women's decisions on mammography and FAP screening, they did not really think through the implications of the documents, much less use the process to begin to envision life as a disabled, older adult.

### *Schema Theory*

Schemas, as defined by anthropologists and psychologists, are generic version of (some part of) the world built up from experience and stored in memory (Strauss and Quinn 1997:44). To the extent that experiences in a group are common, schemas may come to be culturally shared. Because they provide frames against which people come to understand and interpret the actions of others, schemas are often highly motivating because they help establish goals and often contain strategies for action (D'Andrade 1992:29). The application of schema theory to studies of aging would suggest that idealized and culturally shared scenarios about how people expect the aging process to progress or expect life to unfold as they age might impact they anticipate and make decisions about their own future needs and circumstances. Nardi's (1983) examination of reproductive decision-making in Samoa provides an example. Although she was not focused on later-life aging, she did ask her younger respondents how they were deciding about whether or not to have children. She found that Samoans greatly valued children for many reasons: they provide love and affection, they aid in burdensome household work and more importantly, they are expected to care for parents as they age (1983:689). When people discussed their actual decision making with Nardi, she reports that they did so in terms of these imagined, simplified pictures of how life would be with children, constructing scenarios where they could picture children caring for them as they aged. (1983:703).

This study uncovered several hints at culturally shared scenarios regarding retirement and marriage in old age; however, most of these schemas were vague. While many included ideas such as independence, increased free time, and travel, these scenarios were not as detailed, fleshed out, or as widely shared as those of Nardi's study. Instead, many respondents claimed that they never pictured what it would be like to grow old or retire. Some mentioned that they felt their children would take care of them if they needed it; however, like the women of Groger's (1994) and Girling's and Morgan's (2014) studies, they did not discuss this with their children, nor did they have any detailed or shared scenario of what this would look like or how it would happen. Women in this study certainly did not picture disability or dependency, poverty, or caregiving – a common predicament for older women – but saw their life as older women full of independence, autonomy, and enjoyment.

If these vague scenarios had anything to do with decision-making, they dissuaded women from making decisions or plans for a time of declining ability. It may be that the broader value frameworks found in the thematic analysis, ideas about aging gracefully or notions that the mind could control the body, may derive from larger, shared cultural schemas about the importance of independence, self-sufficiency, optimism, and continuity of self, notions that certainly underlie the culturally shared ideal of the "American Dream," and that may act to prevent the formation of specific scenarios of decline, disability and dependence. Respondents in this study avoided thinking about aging but when they did, were predisposed to view it as a time of independence, freedom from earlier responsibilities and something to be dealt with in the moment, not planned for. It was only when forced to consider the negative aspects by experiencing a health crisis that women began to consider possible options, although not always concretely or realistically.

### ***Factors that Influence Planning***

Of the factors examined in this study, several emerged as potentially associated with LTC planning: ethnicity, socioeconomic status, caregiving experiences, attitudes and values, and social support levels. Ethnicity was the strongest predictor of LTC planning for women in my sample, with African Americans being less likely to plan than White women; however, African American women were also more likely to have lower incomes, lower levels of education, and stronger preferences for family caregiving. The White women sampled were more likely to have higher incomes, higher levels of education, and were more likely to have experienced making LTC arrangements for others, rather than just providing direct informal care. Attitudes and values affected the decision to plan, the decisions made, and the types of care preferred. The extent of the role of social support was unclear, however there was a significant association between planning and lower levels of social support.

Socioeconomic factors such as income and education played into the results, with those lacking socioeconomic resources being less likely to plan, however this relationship was not as strong as expected given the results of prior studies (Pope 2012; Sorenson and Pinquart 2000; Broyles et al. 2015). Given the strength of the relationship between ethnicity and planning, family values and upbringing may be the key factor in willingness to plan. As noted in the previous chapter, several of the women in this study expressed a strong preference for a tight-knit family structure and are very proud of being close to their families. Most of these women also prefer to stay at home or move in with a family caregiver. These attitudes are especially prominent among African American women in this study. African American cultural values include strong extended family networks and a reliance on family caregiving for childcare as well as eldercare (Bailey 2002). Thus, it is not surprising that these social and cultural factors

may outweigh demographic factors, caregiving experience, and health status in LTC decision-making. This confirms findings from Mitchell, Mathews, and Hack (2001), suggesting that African Americans were less likely to make plans than Whites.

While family values are important in American culture, White Americans are more likely to live in nuclear family units and African Americans are more likely to incorporate the extended family into their living arrangements (Bailey 2002; Groger 1994). Planners, the majority of whom were White, did not want to burden their families and interfere with their lifestyles, prompting them to make alternative care arrangements. Non-planners, all of whom were African-American, saw elder care as potentially burdensome but were more likely to interpret it as a natural part of reciprocal family relationships, suggesting that their lack of planning could be based on the expectation of family care in the future. This finding coupled with the thematic analysis suggests that value orientations toward long-term care derive from specific family life experiences and not broader cultural themes.

The desire for independence was a strong undertone throughout the thematic results. Going to a nursing home was viewed as the ultimate blow to autonomy; thus many women preferred to stay in their own homes until it was absolutely necessary to move. Some of the literature suggests that this emphasis on independence and individualism, especially when combined with similar cultural ideals such as optimism and avoidance of negative thinking and the idea of a static self (i.e. Mind over Body), may create psychological barriers to planning for LTC (San Antonio and Rubinstein 2004; Sorenson and Pinquart 2000). These psychological barriers make it difficult for American individuals to imagine a time in their future where they may be dependent and disabled. This imagined future scenario violates the way they view the self – as constant and self-reliant – leaving little room for a positive outlook. These culturally



created psychological barriers do not let individuals picture a time when they will need LTC and thus, create the illusion that planning is unnecessary or futile.

Negative stereotypes of nursing homes and in-home medical care also create obstacles for thinking about long-term needs, both for women in my sample and elders surveyed in prior studies (Chen et al 2008; Nakashima et al. 2005). The women interviewed in this study expressed a general negative attitude towards and avoidance of nursing home care. Some women did not go into detailed descriptions of why they did not like nursing homes, but many referenced the experience of friends or family members and one mentioned her experience working in one. Those who did mention specific reasons for their dislike cited the lack of independence and concern that elders would suffer once placed in a facility. They talked of the psychological and emotional trauma of moving an elder out of their home and into a facility, saying that these elders would suffer heartbreak or depression, and may give up sooner. They also suggested that elders in a nursing home do not receive the same amount of attention from their families; they believe that nursing homes are places where elders are forgotten. Others mentioned concern for the quality of medical care and support from the staff of nursing homes. These attitudes and expectations of nursing homes and in-home care work, alongside the American preference for self-sufficiency, prevent elders from making arrangements for a time where they may need nursing home care. Elders justify their reluctance to make plans for LTC by citing examples they've witnessed or stories they've been told about paid medical care and its rumored negligence.

The survey results show that knowledge and resources play a role in ability to plan, while life experiences, personality traits, attitudes, and values may have a stronger impact on what decisions are made. Although most participants noted that the future is unpredictable, survey

data suggest that those who have experienced a health crisis or helped a relative navigate one are more likely to plan and having a family history of Alzheimer's or dementia also seems linked while those who did not have these intimate experiences with dependency were more likely to view future planning as futile, as noted in Pope (2012) and Sorenson and Pinquart (2000). These patterns are understandable because first-hand experience of illness and disability is a prompt difficult to ignore as one ages. Alternatively, having larger social support systems was associated with not planning. Having a larger support network may mean more people to lend a hand when needed while having a smaller support network may prompt women to have a plan in place for when they may need assistance.

Certain types of caregiving experiences may prompt women to plan more proactively for their own future needs; those who had helped a loved one navigate a health decline and the need for LTC were more likely to plan for their own needs. Pope (2012) found a similar pattern among caregivers in her sample, with watching loved ones experience a LTC transition not only providing knowledge but incentive to plan, as did Girling and Morgan (2014), Clark et al. (2012) and Broyles et al. (2015). Having watched a loved one experience the mixture of emotions and conflicting desires that comes with needing LTC and helping them navigate this without a plan in place for how to proceed is a difficult and formative experience that appears to prompt women in this study to make arrangements for themselves. Having watched what happens when one does not plan ahead may motivate women to plan, or the motivation may be more practical: those who had helped a loved one navigate LTC needs have more knowledge of the resources and supports available and what legal and financial arrangements must be in place. The knowledge of the long-term health care system acquired along with higher education and

financial resources may be the magic combination that makes some more likely to plan for future care needs than others.

Of the two concrete planning dimensions (legal and financial) legal plans were the most common. This may be because death is a more acceptable outcome to anticipate and plan for than disability or dependency. It may also be because issues of end-of-life care planning get more attention than issues of issues of LTC planning; highly publicized court cases revolving around life-support systems and the right to death with dignity have made topics of death and dying more acceptable dinner conversation with loved ones than conversations regarding who will take care of an elder who can no longer live independently. Living with the need for constant (or even intermittent) care is a very different issue than dying. Death is an accepted, inevitable outcome but many women feel they can avoid the need for LTC supports and services by taking care of themselves and keeping their minds young despite estimates that up to 70% of elders will require LTC at some point. Legal arrangements are also pushed onto elders in health care settings and community settings alike. Local community and health organizations team up to host workshops for women to complete ACDs, making it easy and convenient to put basic legal documents in place for a time when women may not be able to make decisions for themselves.

Due to the United States' focus on production, aging is generally feared in this country (Buhler-Wilkinson 2003; Cruikshank 2013) and the course it will take is fraught with uncertainty, the women in this study tended to resort to larger cultural themes when forced to speculate in the course of an interview on what the process of aging might be like. Yet in doing so, they espoused general beliefs about aging that in some ways contradicted one another. For those who were healthier, the idea that you could age gracefully by using your mind to control

your body made sense. Yet probably because they had seen other older family members suffer and decline, they also recognized that the body could control the mind and sometimes you had to give in to your limitations.

For many women who do not plan for future healthcare needs, Medicare, Medicaid, and Social Security are the only fallbacks and LTC funding available through these outlets is limited. Models such as “Successful Aging” and the US’ signature attitude of “Rugged Individualism” contribute to this mindset, putting people in charge of their own health and healthcare. In other words, successful aging is something that is a life choice. This sounds like a great idea, but for many poor and working class people, especially women and people of color, there is only so much to be done with few resources.

Successful aging, rather than being a useful conception of aging, then becomes a way to redirect responsibility for the public health of America’s aging population and market more anti-aging products and services (Cruikshank 2013). This mindset reframes Social Security funding as an entitlement, often used in US politics to refer to a “selfish demand placed on taxpayers and the government” (Cruikshank 2013: 27). Cruikshank goes on to suggest a different term,

“deferred compensation, to acknowledge that people over sixty-five are both contributors to the system and its beneficiaries. And if Social Security were seen, correctly, as an earned benefit, a way to preserve living standards, or a program that shields families over the life course, attempts to reduce confidence in it would appear destructive” (Cruikshank 2013: 27).

The US also does not offer any type of universal health care system and there is very little spending for preventative care, causing more chronic health problems for our elderly population as they age. Recent changes in the health care system (such as the Affordable Care

Act) and pushes from public health organizations are beginning to change the focus from treating illness to preventing it but this is comes too late for many middle-aged and older Americans already suffering from chronic disease. If things do not change soon, politicians will continue to cut the already scant funding for supports such as Medicare, Medicaid, and Social Security.

Under these conditions, how can the findings of this project assist those policy makers and social service personnel working directly with older adults to help empower them to plan more effectively for their futures? The following section addresses potential applications of these data.

### *Applications*

It was clear in the interview process that informants were more comfortable discussing funeral arrangements, end-of-life care preferences, and advance care directives, than speculating about a possible future where they would be unable to take care of themselves independently, possibly because of the deeply ingrained American cultural values of independence and self-sufficiency. Topics about preparing for a life with illness, disability, and financial limitations – possibly without caregivers – remain taboo for most families who prefer to avoid them.

Increasing people’s knowledge of how to navigate the LTC system might lead to more future planning. At the same time, the lesson from the policy push for advance care directives suggests that providing contexts where people can gather to discuss the more taboo topics associated with LTC might help them and their family members think through future scenarios in a less threatening way.

Data from this exploratory study show the importance of knowledge and resources and

could be used to develop a workshop for seniors that would offer concrete information about the LTC process and local facilities, services, costs, and details on insurance options. In addition, the workshop should include a session with family to discuss hypothetical situations with different LTC options in order to open lines of communication. Stories, such as the vignette included in the survey portion of the study, may help open up elders and their caregivers to difficult topics of LTC. Discussing different health crises and their potential outcomes – for example, a car accident or a fall that limits mobility, a gradual decline due to chronic conditions, or a sudden health crisis such as a heart attack or stroke – may help elders think about what might happen and what types of decisions regarding LTC they may need to make. Including caregivers (and potential future caregivers) in these workshops could help families navigate these conversations and prompt them to discuss their expectations of one another. In addition, the workshop could provide information about local resources, including residential facilities, support groups, financial resources, and professional counseling.

In addition to opening the lines of communication with family members, we need to open the lines of communication between elders, their caregivers, and government authorities to increase funding for Medicare and Medicaid, rather than cutting it, and to prompt policy makers to come up with more creative solutions to LTC issues. These solutions may include reforming the structure of nursing homes and considering new building and layout innovations that may help dispel and dispute stigmas carried by facilities.

Integrating senior homes and senior centers with preschools (Jansen 2016) or assisted living facilities that also function as dormitories for college students (Reed 2015) are two solutions that have been proposed in other areas that could change the face of LTC. Other solutions include providing more direct funding to LTC facilities to correct issues such as

understaffing and underpaid workers. Education initiatives to encourage more care workers to go into the field of geriatric care and to provide more specific education to care workers currently in the field may help fix these issues as well.

As noted in this study, many times, ethnic groups have their own models of eldercare usually involving more direct and hands-on eldercare, dictated by their own culture, rather than the overarching culture of the so-called “American Dream,” nursing homes and assisted living facilities. Hispanic and Asian caregivers spent more hours, on average, than White caregivers on direct care for elders (Miyawaki 2016) and an earlier study showed that African American caregivers provide more direct caregiving hours than White caregivers (White-Means and Thornton 1990). Gaugler et. al suggested that African Americans were more likely to delay institutionalization, as evidenced in their avoidance of institutionalization or the topic in the two interviews used to collect data for this study (2004). Although the results are mixed, many studies on ethnic differences in caregiving have shown that African American caregivers report lower levels of burden and role strain, anxiety, and depression than White caregivers (Dilworth-Anderson, Williams, and Gibson 2002). Additionally, the cross over mortality of African American and Hispanic elders (Preston et. al 1996; Ruiz, Steffen, and Smith 2013) may be evidence that family support models are a more effective way of providing care; at the least, it warrants more research.

Although many studies have shown that paid home health services do not necessarily reduce the cost of care or hospitalizations overall (Buhler-Wilkinson 2003:206), this view is limited in scope and does not take into account the long-term costs to caregiver’s physical and mental health and wellbeing, the financial costs to caregivers and their families, and hours of lost labor. Taking inspiration from ethnic models of caregiving used by minority groups living the

United States, policy makers could save money in the long run on health care costs for the aging by financing paid home health care and allowing Medicaid and Medicare to reimburse informal family caregivers for their time and labor. Policy makers should also consider changing laws and policies regarding family and sick leave in the workplace, allowing for both men and women to take time off work to care for a sick, disabled, or chronically ill loved one without losing their jobs or their financial stability. These changes could reduce dependence on federal and state funding for care, reduce burden on caregivers, and enhance the health of caregivers and care recipients alike, saving money in the long-run.

There is certainly much work to be done and many angles with which to approach the issue. The results of this study indicate that while state and national level policy pushes are needed, intervention can start in the local community by providing resources to seniors and caregivers and sparking conversations between them. Regardless of the approach, action must be taken now while elders are still in a position to anticipate and plan for future care needs.

Anthropologists have a unique part to play in advocacy and in designing creative solutions to LTC arrangements. The anthropologist's commitment to discovering and presenting the emic perspective puts her in a distinctive position to provide solutions that meet elder's needs – both physical and emotional. In this short-term, exploratory study, I have exposed several key components of LTC decision-making using an anthropological perspective: knowledge, resources, and comfort. What elders really want is to be taken care of and for their families not to be burdened with their care. For some, this means allowing Medicare and Medicaid reimbursements for informal caregiving while for others, this may mean a change in the structure of LTC facilities, making them more spacious and leaving elders independent in as many aspects as possible. Other solutions involve providing more information about LTC options and how to



plan for LTC needs and providing more funding for LTC facilities to increase wages and staffing to improve the quality of care received in facilities. In order to create sustainable, long-term solutions, we need to talk to elders and their caregivers and listen to their needs. Anthropologists listen to people and use a holistic perspective to examine problems faced in particular communities; the complexity of LTC decision-making requires an anthropological perspective. Mixed methods approaches, holistic perspectives, and insider views are essential to developing sustainable policies and solutions. More research needs to be done on this topic, but in the meantime, anthropologists can partner with community workers to produce local changes in knowledge, attitudes, and resources to increase preparedness for LTC.

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# Appendix A: IRB Approval

5/23/16, 9:52 PM



**EAST CAROLINA UNIVERSITY**  
**University & Medical Center Institutional Review Board Office**  
4N-70 Brody Medical Sciences Building · Mail Stop 682  
600 Moye Boulevard · Greenville, NC 27834  
Office **252-744-2914** · Fax **252-744-2284** · [www.ecu.edu/irb](http://www.ecu.edu/irb)

## Notification of Initial Approval: Expedited

From: Social/Behavioral IRB  
To: [Lindsay Cortright](#)  
CC: [Holly Mathews](#)  
[Lindsay Cortright](#)  
Date: 4/29/2015  
Re: [UMCIRB 15-000653](#)  
Factors that Influence Long-term Care Decisions Among Elderly Women

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 4/29/2015 to 4/28/2016. The research study is eligible for review under expedited category # 6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
code book 4-3-15.xlsx	Data Collection Sheet
data set 4-3-15.xlsx	Data Collection Sheet
interview questions 4-3.docx	Interview/Focus Group Scripts/Questions
Questionnaire 4-1-15.docx	Surveys and Questionnaires
Revised Informed Consent_4-12-15.doc	Consent Forms
thesis proposal 4-3-15.docx	Study Protocol or Grant Application

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

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IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418  
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

## Appendix B: Interview One

1. What is your current relationship status? 0 – Single
  - 1 – Partner
  - 2 – Currently married
  - 3 – Separated
  - 4 – Divorced
  - 5 – Widowed
  - 6 – Other
2. If currently or formerly married, for how many years?
3. Do you have any children?
  - a. If yes, how many?
  - b. What gender?
  - c. What ages?
4. Including yourself, how many people live in your household?
5. Can you tell me a little bit about the medical history of your family?
  - a. Diabetes
  - b. High blood pressure
  - c. Stroke
  - d. Heart trouble/heart disease
  - e. Obesity
  - f. Asthma or Respiratory Illness (chronic respiratory disease episode or flu, pneumonia, bronchitis)
  - g. Cancer (what type)
  - h. Other (specify)
6. Have you been diagnosed with any of the following in the past five years?
  - a. Diabetes
  - b. High blood pressure
  - c. Stroke
  - d. Heart trouble/heart disease
  - e. Obesity
  - f. Asthma or Respiratory Illness (chronic respiratory disease episode or flu, pneumonia, bronchitis)



- g. Cancer (what type)
- h. Other (specify)

7. What would you say your overall state of health is...?

0 – poor

1 – fair

2 – good

3 - excellent

8. Who can you count on to help with daily tasks like grocery shopping, house cleaning, errands, repairs, etc?

- a. Relationship to you?
- b. How many?

9. Who can you really count on to help you out in a crisis situation, even though they would have to out of their way to help you?

- a. Relationship to you?
- b. How many?

10. If you couldn't drive yourself or were without transportation, who could you count on to give you a ride?

- a. Relationship to you?
- b. How many?

11. Who would help you if you could no longer take care of your house and yard on your own?

- a. Relationship to you?
- b. How many?

12. Who could you talk to when you need help making an important decision?

- a. Relationship to you?
- b. How many?

13. Who could you count on to support you in any major decision?

- a. Relationship to you?
- b. How many?

14. Who would come to see you in the hospital if you have been in an accident?
- Relationship to you?
  - How many?
15. Say you come home from the hospital after an accident and you need help around the house, who could you count on to help you at home?
- Relationship to you?
  - How many?

16. Are you involved in any clubs or organizations that are particularly important to you?
- 0 – no                      1 – yes                      2 – don't know
- Can you name these clubs or tell what type of club they are?
  - How often does this club or group meet?

17. I'm going to read you a story and ask you a few questions about it. Here is a copy for you to read along:

*Mrs. Smith is 75 years old and has recently been hospitalized for a stroke that has left her cognitively impaired and with limited functional mobility. She is weak on her left side, has difficulty gripping, cannot walk without a walker, and is not able to lift her left arm over her head. These disabilities will make it difficult for her to get around her two-story house without help, bathe, dress, and complete routine household and personal care tasks. The doctor has recommended that she would be better off in a skilled care facility, but Mrs. Smith does not want to leave her home. Her three children have discussed hiring in-home help or taking turns checking in on Mrs. Smith at home and aren't sure where to look for information on long-term residential care facilities. Her children want her to be safe and cared for, wherever that may be but Mrs. Smith insists on staying in her own home. The doctor, Mrs. Smith, and her children cannot agree on a plan for her discharge*

- Where should Mrs. Smith go when she is discharged from the hospital?
- Who should make the final decision?
- How should Mrs. Smith and her family pay for her care?
- What other information would you need to make this decision? What would make a difference?
- What would you prefer if you were in Mrs. Smith's situation?
- Any other comments?

Have you executed a living will or other orders about how your medical treatment should proceed in a crisis? 0 – no  
1 – yes

2 – don't know

- What orders?

18. Have you designated a health care power of attorney?

0 – no

1 – yes

2 – don't know

a. What relationship is this person to you?

19. Have you purchased long-term care insurance or set aside savings for long-term care needs?

0 – no            1 – LTC insurance            2 – Savings for LTC            3 – other            4 – don't know

20. Have you discussed your own preferences for long-term care with anyone?

0 - no

1 - with partner

2 – with family

3 – with friends

4 – with a doctor or health care professional

5 – other

6 – don't know

22. Modified Lubben Social Network Scale

a. Question 1: How many relatives (including in-laws) do you see or hear from at least once a month?

0 – none            1 – one            2 – two  
3 – three to four    4 – five to eight    5 – nine or more

b. Question 2: Tell me about the relative you talk to the most. What is your relationship?

How often do you see or hear from this person?

0 - < monthly            1 – monthly            2 – a few times a month  
3 – weekly            4 – a few times a week    5 – daily

c. Question 3: How many relatives do you feel close to? And by “close to,” I mean how many relatives do you feel comfortable with, can talk to about private matters, or can call on for help?

0 – none            1 – one            2 – two  
3 – three to four    4 – five to eight    5 – nine or more

d. Question 3b: How satisfied are you with the amount of support from your family members?

1 – very dissatisfied            4 – a little satisfied  
2 – mostly dissatisfied            5 – mostly satisfied  
3 – a little dissatisfied            6 – very satisfied

- e. Question 4: Do you have any close friends? And by “close friends” I mean how many friends do you feel comfortable with, can talk to about private matters, or can call on for help?  
 0 – none                      1 – one                      2 – two  
 3 – three to four            4 – five to eight    5 – nine or more
- f. Question 5: How many of these friends do you see or hear from at least once a month?  
 0 – none                      1 – one                      2 – two  
 3 – three to four            4 – five to eight    5 – nine or more
- g. Question 6: Tell me about the friend you talk to the most. Where did you meet that person?  
 How often do you hear from or see that person?  
 0 - < monthly              1 – monthly                      2 – a few times a month  
 3 – weekly                  4 – a few times a week    5 – daily
- h. Question 6b: How satisfied with the amount of support you have from your friends?  
 1 – very dissatisfied              4 – a little satisfied  
 2 – mostly dissatisfied            5 – mostly satisfied  
 3 – a little dissatisfied            6 – very satisfied
- i. Question 7: When you have an important decision to make, how often do you have someone to talk to about it?  
 0 – never                      1 – seldom                      2 – sometimes  
 3 – often                      4 – very often                      5 – always
- j. Question 8: When others in your life have important decisions to make, how often do they talk to you about it?  
 0 – never                      1 – seldom                      2 – sometimes  
 3 – often                      4 – very often                      5 – always
- k. Question 9a: Is there someone who relies on you to do something for them everyday, such as shopping, cooking, doing repairs, cleaning, providing childcare, etc?  
 0 – no                      1 – yes
- l. Question 9b: How often do you help out someone else with things like shopping, paperwork, repairs, childcare, cleaning, or cooking?  
 0 – never                      1 – seldom                      2 – sometimes  
 3 – often                      4 – very often                      5 – always
- m. Question 10: Do you live alone or with other people?  
 0 – alone                      1 – spouse/partner              2 – parent or parents  
 3 – siblings                  4 – children                      5 - other  
 6 – combination (define:)

23. How do you identify your race?

- 0 – White                      1 – black                      2 – Asian                      3 – native  
 4 – mixed                      5 – other                      9 – prefer not to answer

24. Do you consider yourself Hispanic or Latino?

- 0 – no                      1 – yes

25. What was your age on your last birthday?

26. How much schooling have you completed?  
 0 – none      1 - <4<sup>th</sup> grade      2 - <8<sup>th</sup> grade      3 – some high school  
 4 – high school/GED      5 – some college/associates      6 – college      7 – graduate school
27. Do you currently or have you ever worked outside the home?  
 0 – no/homemaker      1 – current full time      2 – current part-time  
 3 – retired      4 – unemployed disability      5 – unemployed  
 6 – other (please specify:)
28. What is your job title?
29. Do you currently have health insurance?  
 0 – no      1 – yes      2 – don't know
30. What is your yearly income?  
 0 – less than \$15,000    1 - \$15,000 – 24,999      2 - \$25,000 – 34,999  
 3 – \$35,000 – 49,999    4 - \$50,000 – 74,999      5 - \$75,000 – 100,000  
 6 – over \$100,000

Notes:

## Appendix C: Interview Two

*Opening:* Thank you for fitting this interview into your schedule. I just wanted to remind you that everything said here is confidential and though it is being recorded, once the recording has been transcribed, all personal identifying information will be removed and the audio will be destroyed. If you are uncomfortable or wish to stop, you can do so at any point.

### *Personality/Family/Background*

1. How did you come to be the person you are today? (What life experiences made you who you are today?)
2. How has your situation changed over the last 5-10 years?
3. Where is your family?
  - a. Do you hear from them often?
  - b. Who in your family do you talk to most?
  - c. Tell me about your children, how often do you talk to them?
    - i. Visit?
4. *(if currently or previously married)*

When you were first married, how did you picture retirement?

  - a. Did you ever think about growing old together?
    - i. What did that look like?
    - ii. How has that picture changed in recent years?
      1. *If widowed*, how did he die?
        - a. How has your life changed since becoming a widow?
        - b. What's the most difficult part of being a widow?
      2. *If divorced/separated*, can you tell me a little bit about why you're no longer together?
      3. Why not remarried?

*(if never married)*

Why not?

### *Caregiving Experience*

5. Have you ever provided care for an elderly person for an extended period of time? (have you orchestrated care for another elderly person? Or watched someone provide care?)
  - a. Who was this person?
  - b. What did you do for them?
6. What was the most difficult or worst part of caring for the elderly?
  - a. What was the best part?
  - b. How has caring for the elderly changed or shaped your views on aging?
7. How is caring for the elderly different from raising children?
8. *If they worked in a "caring" occupation:*

- a. What did you do?
- b. How did you decide to choose this career?
- c. Did you like what you did?
- d. If retired or unemployed, do you miss working?
- e. If not, do you want to retire?

*Attitudes towards aging/experience with aging*

- 9. What do you think it means to be elderly?
  - a. How old do you have to be?
  - b. What are some of their physical and mental characteristics?
- 10. At what moment did you realize, I'm getting older, or "I'm not as young as I once was?"
  - a. How old were you?
  - b. What happened?
- 11. What do you think it means to age gracefully?
  - a. Is it possible?
- 12. What's the best part about growing older?
  - a. What's the worst part?

*Health Status and Abilities*

- 13. Have you experienced a serious health crisis?
  - a. What was it?
  - b. What's the worst health problem you've experienced?
  - c. Why?
- 14. Have your abilities to complete daily tasks changed over the last few years?
  - a. Do you experience pain on a regular or daily basis?
  - b. Has your mobility (ability to move around, walk, drive, climb stairs, etc) changed over the past few years?
- 15. What concerns you most about your health right now?
  - a. What worries you most about getting older?
  - b. Do you ever fear growing old?
    - i. Or becoming disabled?

*Future Plans and LTC attitudes*

- 16. When you think about your future, say in the next 10-20 years, where do you see yourself living?
  - a. Have you moved recently or thought about moving?
    - i. Why?
    - ii. Would you consider downsizing?
    - iii. What would be the biggest obstacle?

17. Let me give you a scenario: Suppose you had an accident or health crisis in the next week and could no longer take care of yourself and your home without help, what would you do?
- a. Walk me through what happens, what would you want?
    - i. What could you realistically afford?
      - 1. How would you pay for your care?
  - b. If the doctor recommended an assisted living facility, would you go?
    - i. Why or why not?
    - ii. What do you think of when you think of assisted living?
      - 1. What are some of the benefits or drawbacks?
  - c. What if your doctor recommended a nursing home?
    - i. What do you think of when you think about nursing homes?
      - 1. What are some of the benefits and drawbacks?
    - ii. Would you hire in-home care?
      - 1. Would you prefer someone to stay with you or to come in during the day?
      - 2. What do you think of in-home care?
        - a. What are the benefits and drawbacks?
    - iii. What do you think about family care?
      - 1. Would you feel comfortable with a family member caring for you? Why or why not?
      - 2. Would you prefer to move in with family or have them move in with you? What if they came during the day to check on you and bring things?
      - 3. What are some of the benefits and drawbacks of family care?
18. Have you discussed your plans or preferences with anyone?
- i. With who?
    - 1. How'd it go?
    - 2. What was said?
  - ii. Why not?
    - 1. Who would you talk to?
    - 2. What would you say?
19. Have your children or family members ever brought up the topic with you, either for yourself or about themselves?
- a. Have they offered to help?
  - b. What did they say?
20. If you were given the options of in-home hired help, in-home family care, assisted living, and a nursing home, with no financial restrictions, how would you rank these in order of preference?



- a. Can you rank them again according to what is financially and logistically feasible for you and your family?

*That's it, thank you so much for your time!*