UNDERSTANDING SELF-NEGLECT FROM THE OLDER PERSON’S PERSPECTIVE

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of the Ohio State University

By

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ABSTRACT

Self-neglect among the elderly accounts for the majority of Adult Protective Service referrals. However, the subjective experiences of those identified as self-neglectful remains relatively understudied and unknown. The purpose of this study was to understand the lived-experiences of those older adults identified as self-neglectful and the meaning of those experiences. The research questions for this study were fourfold: What were the lived experiences of the older persons identified as self-neglectful? What were the salient issues in the lives of those older persons identified as self-neglectful? How did these older persons experience self-neglect? What were the meanings of those experiences to the study participants?

Twelve older persons identified as self-neglectful served as subjects. Data were collected through semi-structured interviews, researcher observations, and field notes. A multiple case study design was applied to the study. The multiple cases served as basic data sources. Cross-case and cross-interview analysis was applied to answering the research questions.

Findings from the study revealed ten major themes which are presented and discussed. There was evidence older persons do not interpret their behaviors and actions as self-neglectful. Social work and policy implications are also discussed.
DEDICATION

To the memories of my father, Chief Momoh Gombeh, my son, Andrew, and my nephew, Omaru, and my grandparents.

To Mensah, my husband, Ramatu and Charles, my children, my grandchildren, Kafui and Abraham,

my mother, Haja Fatmata Gombeh,

my brothers, sisters, nephews, and nieces, especially Sitta.

To my uncle Alhaji Sheku Gombeh.
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CHAPTER 1
INTRODUCTION

Self-neglect is the most common type of elder abuse and neglect discussed in the literature (Fallon, 2006; Lauder, Anderson, and Barclay, 2005; Mosqueda, Burnight, Liao and Kemp, 2004; Pavlik, Hyman, Festa, and Dyer, 2001) and accounts for the majority of Adult Protective Service (APS) referrals (NAAPSA, 1991; NCEA, 2000; NCEA, 2006; Salend et al. 1984; Tatara, 1993; Vinton, 1992). Self-neglect is also a complex and poorly understood phenomenon (Bozinovski, 1995; Fabian and Rathbone-McCuan, 1992; Graves-McPherson, 1997; Lauder, Anderson, and Barclay, 2005; Longres, 1995; Pavlik et al., 2001). However, most of the experiences of self-neglect in the literature have been inferred from service providers and social scientists. In 1991, the National Association of Adult Protective Service Administrators (NAAPSA, 1991), based on data collected in 1990 from referrals made to Adult Protective Service agencies in 28 states including the District of Columbia, defined self-neglect as:

the result of an adult's inability, due to physical and/or mental impairments or diminished capacity, to perform essential self-care tasks including: providing essential food, clothing, shelter, and medical care, obtaining goods and services necessary to maintain physical health, mental health, emotional being and general safety, and/or managing financial affairs (NAAPSA, 1991, pp. 3-4).
In 2004, in a survey of state Adult Protective Services of adults 60 years of age and older, NAAPSA maintained the 1991 definition of self-neglect, however, it added that the “choice of lifestyle or living arrangement is not, in itself, evidence of self-neglect” (p.10, NCEA, 2006). Although many researchers have documented that self-neglect is the most common form of elder mistreatment, they still disagree on how to define it.

There is a growing body of literature suggesting self-neglect as defined in the literature does not present the true picture of this phenomenon (Blanton, 1989; Bozinovski, 1995; Fabian and Rathbone-McCuan, 1992; Lauder et. al., 2005; Lauder et al., August-2005). In fact, Bozinovski (1995) argued that self-neglect “is somewhat of a misnomer.” As the gap in our knowledge of understanding of the phenomenon of self-neglect becomes increasingly apparent, and as practitioners, politicians, and social scientists continue to grapple for a consensus on the definition, identification, and intervention strategies, never has it been as compelling to capture and document the subjective meaning of self-neglect from older adults identified as self-neglecting and the meaning of this behavior as we face diverse, ever-increasing, and changing demographic patterns.

1.1 Significance of the study

The significance of self-neglect among older persons to the service delivery system, researchers, and politicians alike is multidimensional. First and foremost, the graying of America is being accompanied by the growth of the elderly population itself. It is estimated that by the year 2020, those 65 years and over will reach 55 million and
those 85 years and over will number 7.3 million (Administration on Aging, 2006). Not only are Americans growing older, but they are living longer with multiple medical problems that increase their vulnerability for physical, financial, and emotional dependence and, therefore, are more likely to have risk factors that have been associated with self-neglect.

Secondly, self-neglect among the elderly has been linked to a diminished quality of life (Reed and Leonard, 1989) and is associated with high mortality rates among those elders reported to Adult Protective Services (Lachs, Williams, O’Brien, Pillemer, and Charson, 1998; Pickens, Naik, and Dyer, 2006). Thirdly, the broad application of the definition of self-neglect to an elderly population that is heterogeneous in nature is problematic (Griffin, 1994). Older Americans present with unique sets of circumstances and characteristics which must be taken into consideration when dealing with issues of abuse, neglect, and self-neglect. Moon and Williams (1993) expressed concerns related to service provision in elder abuse and neglect situations where the client’s perception differs from that of the professional conducting the investigation. Moon and her colleague argued that differences in perceptions between the professional and the elderly may result in “adult protective services and behavior that are mislabeled, interventions that are inappropriate and outcomes that are unresponsive to aged clients” (p. 386).

Fourth, and most importantly, elderly individuals in different communities may experience self-neglect differently and may still have meaning in their lives. How could we possibly help older adults who are identified as self-neglectful if we know little about how they perceive the problem of self-neglect?
Thus, there is a question as to the applicability of the current definition of self-neglect to the general elderly population identified as self-neglectful. The definition of self-neglect used by Adult Protective Services and others is a problem because it focuses on the individual and blames the individual instead of looking at the social structural system that causes self-neglect. This “blame the victim” definition leads to interventions that focus on the individual level rather than the social structural level. Many individual interventions will never get at the root causes of the problem. The purpose of this dissertation is to fill the gap in the elder abuse and neglect literature, contribute new information to the knowledge base in this area, and to clarify the meaning and appropriateness of the term “self-neglect.” Specifically, the intent was to determine how older adults identified as self-neglectful experience their lives and circumstances.

1.2 Statement of the problem

There is paucity of research data on the experiences and subjective meaning of self-neglect among older adults. Thanks to Bozinovski (1995), the experiences and meaning of self-neglect among the elderly involved with Adult Protective Services in seven counties in Colorado have been documented. Using in-depth interviews and grounded theory methodology, Bozinovski (1995) revealed that the actions of the elderly in her study who were identified as self-neglectful were preserving their identities as part of a continuing life goal, protecting themselves, staying in environments of their choice, maintaining control of their lives and presenting as capable individuals. The Bozinovski (1995) study has contributed significantly to our understanding of self-neglect, however,
the peculiar and complex nature of self-neglect makes for a compelling reason to conduct another study from a qualitative perspective. Aging experts argue that:

...the voices of older people themselves remain unheard... case studies written retrospectively from the standpoint of the professional and which seek to ascribe meaning to behaviors regarded as deviant are no substitute for the views of older people themselves... (Adams and Johnson, 1998, p. 551).

1.3 The research questions

The research questions for this study were fourfold: What were the lived experiences of the older persons identified as self-neglectful? What were the salient issues in the lives of those older persons identified as self-neglectful? How did these older persons experience self-neglect? And what were the meanings of those experiences to the study participants?
Self-neglect is not a new occurrence, as history would remind us that those who were isolated, lacked personal hygiene, and unable to care for themselves were referred to as eccentrics, hermits, and witches (Fabian and Rathbone-McCuan, 1992). Today, in the health and welfare system, they are known as “self-neglecters” (Bozinovski, 2000). In the United States, self-neglect did not come to public attention until the uncovering of elder abuse and neglect. The initial discussions about elder abuse originated from diverse disciplines with differing definitions: medicine, a battered old person syndrome (Anetzberger, 2000); family violence research, battered parents syndrome (Anetzberger, 2000); and social work, abuse of the elderly by informal care providers (Anetzberger, 2000). It has been documented that these reports, coupled with the 1975 publication of the article “Granny Battering and Granny Bashing” by Baker and Burston in a British medical journal, precipitated events here in the United States that prompted Congressional reaction (Penhale, 1993).

In 1978, the late Congressman, Claude Pepper (D-FL), then chair of the House Select Committee on Aging, heard testimony that elderly Americans were being abused at the hands of individuals who were expected to care for and protect them. After this
first nationwide investigation into the problem, it was deemed "elder abuse" and found to occur in "epidemic proportions" (U. S. House of Representatives, Select Committee on Aging, 1990). Elder abuse and neglect describes instances where:

individuals over the age of 65 experience battering, verbal abuse, exploitation, denial of rights, forced confinement, neglected medical needs, other types of personal harm, usually at the hands of those responsible for assisting them in their activities of daily living (Fulmer and O'Malley, 1987, p. 3).

After these hearings, people realized that elder abuse and neglect was a growing problem affecting a small but significant number of vulnerable Americans. The hearings also revealed that elder abuse and neglect was highly underreported and that only one in fourteen of elders who were abused and/or neglected were ever reported (Pillemer and Finkelhor, 1988; Quinn and Tomita, 1986).

The investigation of elder abuse and neglect by Congress necessitated the Committee's recommendation of federal assistance to state agencies. The Committee also recommended that Congress assist the states by designating state agencies to receive reports of elder abuse and neglect. What followed then were series of changes to state area agencies on aging that enabled them to receive reports of elder abuse and neglect and to help prevent, identify, and treat reported cases (Blakely and Dolon, 1991). As a result, these reports went to state agencies, and self-neglect emerged as the most frequent form of elder abuse and neglect reported.

Elder self-neglect continues to account for the majority of Adult Protective Service (APS) referrals. In another study, the National Association of Adult Protective Service Administrators (NAAPSA, 1991) found a 79% prevalence rate of elder self-
neglect among clients involved in Adult Protective Services. Based on reported cases of adult maltreatment and neglect in Texas, in 1997, Pavlik, Hyman, Festa, and Dyer (2001) documented that 87% of all the alleged neglect cases were self-neglect. In a report by the National Center on Elder Abuse (NCEA, 1995), about 818,000 older Americans were victims of elder abuse and neglect in 1994; this figure excluded self-neglectful elders. When self-neglecting cases were added, it was estimated that a total of 1.84 million older Americans were victims for the same year. In 1996, the National Elder Abuse Incidence Study (NCEA, 1998) reported that the highest category of abuse reported to APS was self-neglect. In a 2000 study, the National Center on Elder Abuse found that 41.9% (NCEA, 2000) and in a 2004 survey (NCEA, 2006), found that 26.7% of self-neglect cases was the most common category of investigated reports. It has also been estimated that only one out of every five incidents of elder abuse, neglect, exploitation, or self-neglect is reported (NCEA, 2005).

2.1 Definition/concepts of self-neglect

The data for this dissertation on “Understanding Self-Neglect from the Older Person’s Perspective” were gathered from older adults involved with APS and a home health care agency in Ohio and Illinois. The term “self-neglect” is beset with definitional “disarray” because it can be redefined based on the presence or absence of caregivers, the presence or absence of mental illness, the capacity to accept or refuse services or treatment, and by cultural or community norms (Bozinovski, 2000; Fallon, 2006; O’Brien et al., 1999).
Griffin (1999) previously argued that definitions of abuse and neglect were too broad and ignored the degree of harm and the specific cultural context. Griffin (1999) maintains that:

The role that cultural diversity plays in the definition, assessment, and intervention in elderly maltreatment has been given little attention. Although this inattention may be attributed in part to benign neglect, incorrect beliefs, and faulty theories, the complexities involved if culture is added to the mix restrict the abilities of many researchers and practitioners to consider this element fully. However, ignoring this dimension renders research misleading, and treatment ineffective (p. 30).

Furthermore, Adams and Johnson (1998) also believe that it was important to view self-neglect from a cultural perspective. These researchers made reference to Fottrell (1988), who documented the life history and social changes experienced by older adults from a working class background who grew up at a time when household technology was unknown. According to Fottrell (1988):

They grew up without many of the household items that young and middle-aged professionals regard as absolutely essential to civilized living…Food was chilled in outside meshed cupboards. Chamber pots, commodes and washing stands were common…. Milk was loose, butter was clapped, meat was unfrozen and uncovered. Flies and bluebottles congregated under blinds and in corners of rooms. The doors of tenements houses were never shut, it was usual to find broken window panes with cardboard wind stopper, and floorboards were bare or occasionally covered with linoleum… (p. 9).

In Connecticut, Abrams et al., (2002) operationally defined “self-neglect” as the “inability of an elderly person to provide for him or herself the services necessary to maintain good health” (p. 1725). In Texas, “self-neglect” is defined as “the failure to provide for (one’s self) the goods and services which are necessary to avoid physical harm, mental anguish, or mental illness” (Pavlik et al., 2001). Examples of neglect and
self-neglect (when there is no perpetrator involved) include: “malnourishment and dehydration; over-or under-medication; lack of heat, running water, or electricity; unsanitary living conditions; lack of medical care; and lack of personal hygiene or clothes” (Pavlik et al., 2001, p. 46). In Ohio, “self-neglect” is defined under “neglect” as “the failure of an adult to provide for himself the goods or services necessary to avoid physical harm, mental anguish, or mental illness or the failure of a caretaker to provide such goods and services” (Ohio Job & Family Services, 2003, p. 4). In Illinois, the legislation on self-neglect was signed into law in 2006 but did not become effective until January 1, 2007. Under this new law, Illinois defined self-neglect as:

A condition resulting from the inability to perform essential self-care tasks that threaten the person’s health. This includes providing essential food, clothing, shelter, and health care, and obtaining goods and services needed to maintain physical health, mental health, emotional well-being and general safety (Press Release: State: Illinois, August, 2006).

The concept of self-neglect remains ambiguous, and Fabian and Rathbone-McCuan (1992) assert:

There are social, physical, emotional, and economic factors to be understood, all of which in varying combinations, can produce self-neglect. It may be referred to as a symptom associated with depression, as both a physical and an environmental condition resulting from poverty, and as a behavioral characteristic emerging from mental incompetence. It is fraught with conceptual complexity and ethical ambiguity (p. 3).

They continue by emphasizing the need to:

resist the impulse to accept stereotypic and simplistic solutions to complex and multi causal problems if we are to make an impact on the issue of self-neglect, which has remained so impervious to current intervention approaches (p. 12).
Furthermore, studies have shown that “self-neglect” is not representative of reported cases (Rathbone-McCuan, 1992). In the study to explore whether services delivered to self-neglecting elderly were perceived as an unnecessary intrusion into their lives, “the label self-neglect was not used in working with such clients. Self-neglect was reframed so that the focus was on the particular presenting problem.” (Longres, 1994, p. 10). Longres (1994) said:

I think self-neglect is an important service. But they are not necessarily handled as self-neglect. We don’t get referrals that say, “we have a self-neglect case that we have here for you.” What I hear is, “We have an older woman who is not taking her medication because she cannot afford them.” It is not presented as self-neglect and that makes it easier to deal with (p. 11-12).

Some gerontologists have challenged the concept of self-neglect and argued that:

The concept of neglect should surely be limited to neglectful actions of those in a responsible position (e.g., attendants, medical caregivers, and legal conservators), whose services have been purchased by or on behalf of the older person. Abuse would apply to deliberate harm-physical or emotional-penetrated on the old by another person. Self-neglect, although a widely-used category, fits poorly into either formulation. It becomes a social concern if an individual is perceived as mentally incompetent and in need of protection; otherwise, one man’s self-neglect may be another’s exercise of free judgment. Although protective services may legitimately investigate situations where individuals seem to be putting themselves or the community at risk, defining adult abuse to embrace all protective services seems counterproductive (Salend et al., 1984, p. 66).
Pillemer and Finkelhor (1988) questioned whether self-neglect should be included in the literature on elder abuse and neglect. While some researchers argued against the inclusion of self-neglect, others argued and support including self-neglect.

It has been recognized that:

The need to handle these cases is especially critical in states which may not otherwise manifest legislative intent to support adult social services. Deleting this category from statutory definitions would condone an unconscionable neglect of vulnerable adults who lack either the capacity to act on their own behalf or the social resources to meet their needs, at a time when the size of the vulnerable population is at the beginning of a precipitous rise. The competing demands that practitioners face when asked to deal with persons found in states of self-neglect will not ebb during the discussion of definitions and the debate over the legitimacy of its classification as a category of adult abuse (Mixson, 1991, pp. 40-41).

Blanton (1989), stated:

It is not surprising that those who support the need to provide services for self-neglecting elderly do so on the grounds that protection from harm is the single, universal factor in all protective cases (p. 31).

Some view self-neglect as a private issue and fear infringing on individuals’ rights.

Others argue that self-neglect is a responsibility of the state, which should protect vulnerable older persons. According to Longres (1994):

Reaching out to those who seem unable to manage is in keeping with important values such as community, support, and concern for the welfare of others. Society-or community-is impossible if its members fail to acknowledge interdependence and fail to care for its feeble, infirm or otherwise dependent (p. 5).

Most experts conclude that we need more information about self-neglect. Gorbien (2005) stated that: “The vexing discussion of self-neglect appropriately reminds us of how little
we know about a subject even more difficult to define, identify, and remedy” (p. xii).

Despite the lack of consensus on the meaning and the definition of self-neglect, most experts differentiate self-neglect from maltreatment. For example, Longres (1994) explained that:

Self-neglect then presents a different scenario than maltreatment by others.

Allegations of self-neglect, however, well intentioned, implied a disapproval of the way elderly lead their lives while substantiation of self-neglect requires that elderly admit they have been unable to care for themselves. Unlike elderly who are maltreated by others these elderly are not, or at least have not been, dependent on caregivers. A change in their independent status in fact may put them in position of having to be dependent on caregivers that they neither know nor have confidence in. The solution therefore may be worse than the problem. Reaching out under such circumstances may be an instance where an apparently well-intentioned policy leads to unnecessary intrusion into private matters (p. 5).

2.2 Characteristics of self-neglect

2.2.1 Age

In 2000, substantiated cases of self-neglect involved 33.6% of persons 80 years-of-age and older (NCEA, 2000). In a previous study (NCEA, 1998), it was found that those aged 65-69 accounted for 16% of self-neglecting elderly, and those 75-79 year olds, who made up about 16% of the elderly population, comprised of 20% of self-neglecting older adults. Those who were the oldest were more likely to be self-neglecting; those aged 80 or older, who made up 19% of the elderly population, accounted for 45% of self-neglecting older adults (NCEA, 1998).
2.2.2. Physical functioning

The ability of an elderly individual to perform activity necessary for daily living is critical to independent living. These daily living tasks involve a series of activities ranging from activities of daily living (ADLs) such as toileting, bathing, dressing, eating, transferring from bed to chair, etc., to instrumental activities of daily living (IADLs) such as meal preparation, general housekeeping, laundry, transportation, shopping, home maintenance, medication management, financial management, etc. The ability to complete activities of daily living as outlined above is an important component of caring for oneself. However, for a small but significant number of elderly, help is often required in completing these tasks. According to NAAPSA (1991) 94% of self-neglecting older adults had difficulty with at least one activity of daily living task. Similarly, the National Elder Abuse Incidence Study, using data obtained in 1996, found that 93.4% of older adults with substantiated self-neglect had some difficulty caring for themselves, and about one-third were not able to care for themselves. Close to 60% were only somewhat able to care for themselves. Only 5% were judged as able to care for themselves (NCEA, 1998). In 2002, 52% of older adults were reported to have some disability (sensory disability, physical disability, or mental disability). Almost 37% of older persons reported a severe disability and 16% reported that they needed some type of assistance (NCEA, 2006). In a study that focused on the older person’s ability to complete specific daily living tasks, 27.1% of community dwelling residents over age 65 in 2004 had difficulty in
performing one or more ADLs and an additional 13.7% reported difficulties with IADLs (NCEA, 2006). The inability to care for oneself leaves an unmet need and can translate into risk factors for self-neglect (NCEA, 1998).

Declining physical capacity plays a significant role in cases of self-neglect (Humphries-Lynch, 1997; Pickens, Naik, & Dyer, 2006; Ramsey-Klawnik, January-February, 2006). Vinton (1992) found that one of the primary reasons older adults were referred to the Wisconsin Elder Abuse Reporting system were for medical needs. Similarly, Longres (1994) observed that in Wisconsin, 96% of the elderly referred for self-neglect had one or more impairments. In a sample of self-neglecting older adults, the NAAPSA found that 37% had diseases that limited their activities of daily living. The most common diseases found were cardio-vascular and muscle disease, arthritis and osteoporosis, and the most common physical impairments were visual and hearing (NAAPSA, 1991). Abrams, Lachs, McAvay, Keohane, and Bruce (2002) reported multiple chronic medical conditions including, but not limited to, cancer, diabetes, hypertension, history of hip fracture, and stroke; arthritis was the most prevalent among self-neglecting older adults living in the community. In a British study of community dwelling individuals who lived in squalor, Halliday, Banerjee, Philpot, and Macdonald (2000) found that 85% had at least one chronic physical illness, and 22% had at least one acute physical illness. About 46% were moderately or severely disabled, 67% were taking prescription medication on a regular basis, including 30% who were taking
prescribed psychotropic medication, 26% were determined to have a physical health problem such as incontinence, immobility, or a severe visual impairment that had significantly contributed to the squalid living conditions in which they lived (Halliday et al., 2000).

2.2.3 Nutritional Status

Another area of care that has been observed to be problematic among self-neglecting elderly is the inability to provide adequate nutrition. Poor nutrition among the elderly has been linked with increased disability and mortality (Miller, Carter, Sigmund, Smith, Miller, Bentley, McDonald, Coe, and Morley, 1996). According to the NAAPSA (1991), 66% of those aged 64, 76% of those aged 65-74, and 93% of those 84 and above needed assistance with grocery shopping. In a study by Adams and Johnson (1998), 21 (75%) of 28 nurses who responded to the question on nutrition said that poor nutrition and an emaciated older person would conjure up images of severe self-neglect. Clark, Mankikar, and Gray (1975) found little food in the house of patients; tea bread, biscuits, cakes, and tinned food were the staple diet these researchers found. Smith, Matthews, Oliver, Zwart, Kala, Kelly, Goodwin, and Dyer (2006) maintained that self-neglecting older adults were at risk for altered nutritional status.

2.2.4 Dementia and other cognitive impairments

Cognitive impairments have been shown as a major risk factor for self-neglect (Abrams, Lachs, McAvay, Keohane & Bruce, 2002). Dementia is a group of symptoms characterized by memory deterioration, and impaired cognitive functions; in its later stages it leads to impaired behavior and personality changes (Qualls, 1999). Depression
is a mood disorder characterized by feelings of sadness, helplessness, self-blame, difficulty concentrating and or making decisions, agitation, changes in appetite, sleep disturbances, and little or no interest or pleasure in engaging in any of the activities of daily living. Depression is the most common psychiatric disorder of late life with a prevalence rate of about 15% (Qualls, 1999). Causes of depression are multiple and have been attributed to internal or external events such as physical illness or loss of a loved one. Physical illness can create functional disabilities that might impact peoples’ level of activity and alter peoples’ perceptions of themselves and self-worth (Qualls, 1999, p. 315). Certain medications used to treat physical illnesses such as cardiovascular disease and anti-hypertension can cause depression (Qualls, 1999). There is high prevalence of depression and dementia found in elder abuse and neglect (Dyer, Pavlik, Murphy, & Hyman, 2000). Patients with self-neglect also may be more likely to experience psychiatric disorders (Halliday et al., 2000; Lauder, 1999).

2.2.5 Alcohol and substance abuse

While only 10% of the general population abuses alcohol, almost one-fifth of self-neglecting older adults have been reported as substance abusers. While 23% of self-neglecting APS clients were substance abusers, 41% of self-neglecters under the age of 65 were substance abusers (NAAPSA, 1991). Blondell (1999), Choi and Mayer (2000), Kosberg (1988), Kosberg and Nahmish (1996), Halliday et al., (2000), Ramsey-Klawsnik, (Jan.-Feb., 2006), Reyes-Ortiz (2001) have cited alcoholism as a significant contributor to self-neglect among older adults.
2.2.6 Economic resources

Experts also have observed a correlation between poverty and elder self-neglect (NAAPSA, 1991). In a national study of self-neglect, investigators from NAAPSA found that APS clients had lower incomes than the general population. Whereas in the general elderly population only 10% had incomes below $5,000, about 57% of self-neglectful elderly had yearly incomes under $6,000, and 33% had incomes between $6,000 and $12,000. Only 10% of clients had incomes above $12,000 (NAAPSA, 1991). Halliday et al., (2000) found that the majority of participants in their study who lived in squalor were from lower socioeconomic groups. Abrams et al., (2002) found that 28.3% of the older adults in a longitudinal study of predictors of self-neglect in Connecticut were poor, with an annual income of less than $5,000.

It is estimated that 3.6 million older persons (10.1%) were below the poverty level in 2005. Older women reportedly had a higher poverty rate (12.3%) than older men. Those older persons who lived alone were more likely to be poor (19.1%) than those who lived with families (5.6%). Of those who lived alone, the highest poverty rates were documented among Hispanic women (45.9%) and older black women (36.7%) (Administration on Aging, 2006).

2.2.7 Marital status

According to the Administration on Aging (2006), the marital status of older persons 65 years or older in 2005 were as follows: 42% of women and 72% of men were married, 43% of women and 14% of men were widowed, 10% of women and 11% of men were either divorced or separated, 4% of women and 4% of men were single or
never married. Specifically, among self-neglectful older adults, Byers (1993), in a 1989 Indiana study, found that 80% (56% widowed, 6% divorced, and 18% single) of the cases studied were single, divorced, or widowed. Also, Abrams et al., (2002), in a Connecticut study of self-neglectful older adults, found that 43.6% were married, 8.5% separated/divorced, 37.5% were widowed, and 10% were never married.

2.2.8 Gender

The National Center on Elder Abuse (1998) reported that approximately two-thirds of self-neglecting older adults were female, while one-third were male. Overall, 65.6% of elder abuse and neglect victims in 2004 were women (NCEA, 2006). It has been documented that the percentage of females within the self-neglecting elder population is higher than the 58% of their representation in the total elderly population (NCEA, 1996).

2.2.9 Race/ethnicity

In a national study from data complied in 1996, 77.4% of Caucasians, 20.9% of African-Americans and 1.7% of American Indians/Alaskan Natives accounted for substantiated reports of self-neglect (NCEA, 1998). In 2000, data collected from 24 states which tracked the race and ethnicity of older persons reported as victims of abuse and neglect 65.8% were Caucasians, 17.4% African Americans, and 10.5% Hispanics. Native American and Asian/Pacific Islander represented 0.9% and 0.4%, respectively (NCEA, 2000). In 2004, 77.1% of abused victims were Caucasian, 21.2% African American, 0.6% American Indian and Alaskan Native, 0.5% Asian, 0.2% Native Hawaiian and Pacific Islander, and 0.2% were others (NCEA, 2006).
2.2.10 Living arrangement and social support

In 2005, approximately 10.9 million (71.7%) of older men, and 8.4 million (42.0%) of older women lived with their spouse. About 10.6 million (30.1%) of community-dwelling older persons lived alone. Of those older persons who lived alone in 2005, 7.7 million were women and 2.9 were men (Administration on Aging, 2006). In a previous study from data collected in North Dakota, Gruman, Stern, and Caro (1997), found that 62% of self-neglecters lived in their own home, 21% lived in their own home but shared it with others, and 17% lived in the home of another person. Abrams et al., (2002) found that 41.7% of the community dwelling older adults in their study lived alone. The overwhelming majority of self-neglecting older persons had the tendency to live alone and over half of them were found to be isolated (Gruman et al., 1997).

2.2.11 Physical living conditions

Another characteristic of self-neglect that has been identified in the literature is hoarding. Hoarding which is defined below, is considered a public health problem (Patronek, 1999) and has been linked to self-neglect among the elderly (Maier, 2004; Nelesen, 2002; Ramsey-Klawsnik, Jan-Feb, 2006; Snowdon, 1987). Hoarding is a serious problem among those 60 years of age and older. Frost (2000) defined hoarding as “the acquisition of, and failure to discard, possessions that appear to be useless or of limited value” (p. 4). Hoarding of objects poses a clinical dilemma when the clients’ or patients’ living spaces are severely cluttered to the degree that the space is not available to be used for the purposes for which it was intended (Frost, 2000). Those who hoard possessions often perceive their possessions as paramount to their identity and, thus,
losing or getting rid of those objects often results in a grief-like reaction followed by a loss of identity. Undoubtedly, individuals who hoard value having more possessions than non-hoarders (Frost, 2000; Maier, 2004; Ramsey-Klawsnik, January-February, 2006).

In addition to the hoarding of objects, animal hoarding also has been documented in the literature (Patronek, 1999). The phrase “animal hoarding” was coined by Dr. Gary Patronek in 1999. It is estimated that there are between 700 to 2000 cases of hoarding in the United States each year (Patronek, 1999). Dr. Patronek defined a hoarder as someone who:

· accumulates a large number of animals
· fails to provide minimal standards of nutrition, sanitation, and veterinary care
· fails to act on the deteriorating condition of the animals, the environment and the negative impact of the collection on their own health and well-being and on that of other household members (p. 2).

Patronek (1999) gathered data from a convenience sample of 54 case reports from 10 animal control agencies and humane societies across the United States to study hoarders who authorities identified after neighbors reported that these people were living in unsanitary conditions. The hoarders were found in variety of communities: urban, rural and suburban settings and single family homes, house trailers, apartments or condominiums and other types of housing. The majority (76%) of hoarders were female; 46% were found to be 60 years of age or older and about 72% of them were single, divorced, or widowed (Patronek, 1999).
The motivation for acquiring so many animals ranged from:

- the hoarder’s love for animals
- the animals as surrogate children
- feelings that no one else would care for the animals
- fear that the animals would be euthanized if taken to an animal shelter (Patronek, 1999, p. 4).

In the Patronek (1999) study, unsanitary conditions were found in the residences of the 38 cases that responded to the ratings. The homes were described as having large accumulations of animal feces and urine in the living areas. In addition, the clutter interfered with personal hygiene in 89.2% of the homes. In 26.5% of the cases, the hoarder’s bed was described as “soiled with human or animal urine, feces or both.” (p. 6)

Patronek (1999) revealed that the subjects in his study who hoarded animals also had the following items as part of their possessions: newspaper 25.9%, trash 38.9%, pet food 16.7%, and human food items 9.3%. Holiday decorations, paperback books, dolls, toys, pornography, milk jugs, medicines, and clothing were also part of their possessions.

Hoarding has been associated with obsessive-compulsive disorders (Maier, 2004), while Patronek (1999) argued that animal hoarding was suggestive of early stages of dementia. While the causes of hoarding behavior are yet to be understood, the tragic consequences are preventable.
Halliday et al., (2000) also documented the living conditions of the subjects in their study:

Houses were often cluttered with bags and boxes of property and possessions so that it was virtually impossible to move around, with rooms inaccessible or impossible to enter safely....floor space thickly covered with newspapers, cardboard, discarded packaging, and other rubbish. Often the occupant had accumulated or hoarded a large number of singular items such as milk bottles,...newspapers, food containers, carrier bags or fabric. Several homes were dirty and unhygienic due to incontinence or blocked and overflowing toilets (p. 884).

Clark and colleagues (1975) further documented the domestic and squalid living situations in which they found their study subjects.

All patients lived in a state of domestic squalor, disorder and extreme self-neglect. Their homes were filthy on the outside-peeling paintwork and dirty, often broken, windows with dingy net curtains serving as external markers to conditions within. Inside there was a characteristic strong, stale, and slightly suffocating smell. The patients were usually dressed in layers of dirty clothing sometimes covered by an old raincoat or overcoat, and, when confined to bed, they lay beneath a pile of ragged blankets, clothing, or newspaper. They never appeared to undress or wash, the hair being long and unkempt, with exposed surfaces of skin deeply engrained (p. 366).

Access to furniture and to frequently and expected used areas such as the kitchen and bathroom were inhibited. The homes were found in disrepair: lack of working bathroom, working and cooking facilities, lack of electricity, lack of working refrigerator and no heat. The increased risk of fall and fire posed a dilemma for service providers.
It is believed that:

...majority of the older adults have multiple chronic health conditions, but necessary home care services may be denied until hoarding is resolved. Medicines can be buried under mounds of paper or clutter, and asthmatic conditions are exacerbated by dust and mold (Cornell University, 2003).

The high incidence of clutter and hoarding among the elderly is alarming and present a challenge to the professionals who serve this population. Halliday et al., (2000) revealed that people who lived in squalor had higher rates of mental disorder and that squalor affected both younger individuals as well as older adults. These behaviors not only pose a public health issue but contribute to diminished quality of life, increased morbidity and mortality among the elderly. Aging experts must promptly diagnose and effectively intervene in the areas of mental health and those unresolved multiple losses implicated as risk factors for self-neglect, clutter, and hoarding. These issues are at best a reminder that mental health and psychiatric issues among the elderly previously left unaddressed should become a priority as the population ages. It has been suggested that intervention be collaborative in nature to involve the older adult and the family as well as other agencies, for example, mental health, adult protective services, code enforcement, building and safety, animal control, and criminal justice (Hoarding Fact Sheet, 2004, p.2).
2.3 Etiology of self-neglect

2.3.1 Social breakdown syndrome and self-neglect

Studies that have been conducted on self-neglect using the social breakdown theory have found that stressful life events such as widowhood and deteriorating physical conditions contribute to self-neglect (Reyes-Ortiz, 2001; Ungvari and Hantz, 1991). An example of self-neglect caused by the social breakdown syndrome is perhaps best illustrated by Anetzberger (2005), who documented the life circumstances of Jane, a 78-year-old retired teacher. Jane had experienced the sudden death of her partner and then subsequently the physical deterioration of her condition. Below is a snap-shot of Jane’s situation.

When her partner died suddenly and unexpectedly from complications following surgery, Jane became severely depressed, even further withdrawn, angry at the world, and bitter about her circumstances. Only the cats and home routine seemed to sustain her…The pain of her partner’s death didn’t subside as long as Jane was sober. Alcohol helped to make life bearable when nothing else did…. Jane wanders around the house clothed in many layers of shirts and sweaters and pants. Her feet were warmed by woolen socks and paper stuffed in extra-sized boots. There’s a thick woolen hat on her head, and lined leather work gloves on her hands. Jane hasn’t changed any of them for weeks—it’s too cold, not necessary, and why bother, …The sparks dance from the fireplace. Mostly they land on surrounding stone. Once in a while, however, they leap onto a mound of clutter. Usually Jane manages to crush out these stray sparks before they cause any damage. Lately, she’s missing more, because her eyesight is failing, or she’s not getting there on time, because her arthritis is more disabling (Anetzberger, 2005, pp. 47- 48).
Self-neglect is also understood as a failure to engage in self-care behavior that properly regulates functioning, such as providing a sufficient amount of food and otherwise implementing actions to eliminate, alleviate, cure, or control conditions which affect life, health, and well-being (Lauder, Anderson, Barclay, 2005; Lauder, 1999).

2.3.2 Self-care agency and self-neglect

The theory of self-care agency proposes that self-care is a fundamental preventive and health promotion measure. Among the most significant studies on self-neglect, Lauder (1999) using Orem’s (1985) theory of self-care agency, surveyed patients who were categorized as “self-neglecting” and non-“self-neglecting” from case-loads of district nurses in two geographical areas within a single Health Board Region in the United Kingdom. Lauder (1999) found that the ability to engage in self-care activities was a function of self-care agency. Self-care agency was defined as those abilities and propensities which allow individuals to employ self-care activities. Lauder (1999) conceptualized self-neglect as the inability to engage in self-care behaviors that were required to improve health and well-being. Lauder (1999) hypothesized that those patients who were identified as self-neglecting would have lower levels of self-care agency than those individuals who were in the comparison group and were not identified as self-neglecting. The mean age of the patients in the study group was 70.8 years and 74.6 years for the comparison group. The researcher’s main questions were twofold: What were the most common medical and nursing diagnoses in patients defined as self-neglecting? What was the functional status of patients identified as self-neglectful? Lauder found that the difference between the two groups differed. With regards to the
similarity of nursing diagnoses, bathing/hygiene deficit and impaired tissue integrity was found among the study and comparison groups. The differences between the two groups were the type of impairment in functional ability; continence and feeding problems were found to be more likely among the study group than the comparison group. Another difference found was that patients in the study group were more likely than the comparison group to have ineffective management therapy and demonstrate non-compliance. No particular diagnoses provided a causal linkage with self-neglect. The researcher concluded that:

it may be the case that non-compliance and ineffective management of therapy are important characteristics of self-neglect.... Nevertheless it remains the case that there are many people with self-neglect who did not have either of these nursing diagnoses....dependency and self-neglect, whilst linked, are essentially different concepts. People can be regarded as self-neglecting but may be fully independent in ADL functioning. The reverse is also true in that people who are self-neglecting may also be fully dependent in ADL functioning (Lauder, 1999, p. 100).

2.3.3 Lifestyle

Snowdon (1987) surveyed 12 community health centers in Sidney, Austria. The raters, most of whom were nurses, identified 83 subjects as living in unclean conditions. The mean age of the patients in the study was 71. Snowdon found that about two-thirds of the patients had some form of memory impairment, and 40% were or had been heavy drinkers. Snowdon found that about 15% had no obvious mental or physical problems to explain their unclean home situation. Snowdon (1987) discussed the reasons for the uncleanliness and eccentric behavior observed by the health care professionals. According to Snowdon (1987), eccentric behavior may have multiple explanations.
Uncleanliness may arise from various interactions between the client’s personality, their upbringing, as well as events and life’s circumstances (Snowdon, 1987). In some instances, eccentric behavior manifested as lifelong habit, while it varied in others. Although some people maintain a lifelong lack of interest about cleanliness, for others, uncleanliness emerged as a new behavior (Snowdon, 1987). The author believed that:

we can devise plausible explanations for the unclean conditions in which these clients lived. Individuals addicted to alcohol may have more urgent concerns than to clean themselves or their homes. Those with dementia may lose both perceptive and cleaning skills. Persons with schizophrenia may neglect themselves because of preoccupations with diminished interest or in understanding of the way their behavior affects others. Poverty, housing conditions, physical incapacity may be contributory factors. Clearly many factors lead to the uncleanliness observed by healthcare workers (p. 493-494).

In addition to the multiplicity and complexity of the causes of uncleanliness found among study participants, Snowdon (1987) revealed another important risk factor implicated in self-neglect that was subsequently reinforced: alcohol. According to Blondell (1999), those older adults who abuse alcohol neglect their basic safety and psycho-social needs. Blondell (1999) argued that alcoholism is a significant contributor to the etiology of self-neglect among older adults. Those who had problem with their drinking could:

suffer from malnutrition, develop chronic health problems, acquire unintentional injuries, become depressed, neglect their health care needs, and isolate themselves from friends and family. Premature death can result (Blondell, 1999, p. 55).
2.4 Self-neglect and ethical dilemmas

Abuse and neglect among the elderly pose ethical dilemmas for the helping professions (Dayton, Jan.-Feb., 2006; Nasbaum, 2004; Simmons and O’Brien, 1999). Simmons and O’Brien (1999) extensively discussed the ethical dilemma that helping professionals confront. I discuss, below, two cases that reveal typical ethical dilemmas that social workers often confront when investigating and intervening in self-neglect cases.

2.4.1 The Case of Ms. Mary Northern

At age 72, Ms. Mary Northern lived alone in unsuitable conditions and suffered from a life-threatening infection (Simmons and O’Brien, 1999). She was presented to Nashville General Hospital where two physicians determined she had gangrene of both feet. The gangrene was presumed to have been caused by frostbite and then thermal burning of the feet. The physicians argued the infection placed Ms. Northern’s life in danger and that they needed to amputate her feet to save her. However, Ms. Northern believed differently. Ms. Northern viewed her feet as black because of “soot or dirt” and challenged the doctors about the infection. Ms. Northern presented as intelligent and coherent, with good memory recall and no sign of dementia. Ms. Northern did not believe her feet were infected or that she would die without the amputation. Adult Protective Services went to court and argued that Ms. Northern lacked the capacity to appreciate her condition or to consent to surgery, that she did not understand the severity of her condition or the consequences of refusing amputation, and that the amputations were in her best interest. APS asked the court to permit the amputation of Ms. Northern’s
infected feet. The Guardian ad litem, however, contended that Ms. Northern believed strongly that her condition was improving, that she would recover without surgery and, therefore, the court should honor her wishes and not allow the amputation. The court ultimately ordered the amputation of Ms. Northern’s feet based on its conclusion that Ms. Northern was “incompetent to make a rational decision with regards to her infected feet” (p. 47). The doctors had argued that Ms. Northern was psychotic. The court further maintained that:

She had no wish to die but she was unable or unwilling to recognize a condition that will probably result in her death if untreated. Because she did not state her wishes clearly and extensively and because she demonstrated flawed thinking with regard to the gangrene of her feet, she was regarded as having impaired judgment…. Had she been clearer about the fact she understood that the refusal of amputation meant the inevitability of death, her wishes might have been honored. Decisional capacity is related to the ability to relate actions to consequences or outcomes (pp. 47-49).

2.4.2 The Case of Mrs. D-Diane

A patient with acute myelomonocytic leukemia, named Mrs. D., refused chemotherapy much to the dismay of her attending oncologist. Her physician had explained not only that it was confirmed by bone marrow biopsy but also went into detail about the prognosis and interventions available. It was a bleak picture. There was a 25% cure rate. The oncologist made plans to insert a Hickman catheter and begin induction of the chemotherapeutic agent. But Diane refused. She was angry that it was simply assumed she would go for the treatment. She had made up her mind against the chemotherapy. The physician continued conversations with her over a period of days, but she remained firm in her resolve to refuse treatment. The hospitalization would be prolonged and painful. She would lack control over her body. The side-effects of chemotherapy would be unpleasant, involving pain
and anguish. And, for her, the odds of 25% cure rate were not enough to justify all that she would have to endure. Further, they knew of no closely matched donor for the bone marrow graft she would certainly need (Quill, 1991, in Simmons & O’Brien, 1999, p. 49-50).

Decisional capacity is related to the ability to relate actions to consequences. Diane did just that while, according to the court, Ms. Northern lacked the ability to do so; Ms. Northern was unable to relate her actions of not receiving required medical interventions to the consequences, which would have been death. Because “adult protective services is built upon the ethical obligation to prevent harm” (Simmons and O’Brien, 1999, p.52), the authors explain that:

We can neither neglect the legitimate needs of such older persons and claim to be ethical or lightly impose care upon them that they find inconsistent with their own life values and claim to be people of integrity. ... The task is to take seriously those for whom we care and work out a collaborative and mutually acceptable plan of medical treatment. Where an agreement cannot be reached, the burden of proof must be borne by those who would impose interventions upon them.... (p. 52).

2.4.3 Refusal of services

The high rates of refusal of services among victims of self-neglect have been recognized (Byers and Lamanna, 1993; Cornwall, 1981; Longres, 1994; Roe, 1977; Vinton, 1991; Vostanis and Dean, 1992). Clark et al. (1975) observed that one-third of the patients in their study refused to let any one into their home. Longres (1994) reported that majority of the patients accepted at least some of the services offered to them but roughly 28% of all elderly refused all of the services offered. Similarly, Macmillan and
Shaw (1966) documented that 31% of the patients in their study who were diagnosed with "senile breakdown syndrome" refused offer of services. After trying offered services, some patients later refused them. In Wisconsin, 36% of the self-neglectful older persons refused services (Vinton, 1991). The need for services for older persons is, apparently, always present but whether or not these older persons perceive themselves as needing these services is unclear. Byers and Lamanna (1993) recognized the high rate of refusal of services and the frustration that many professionals felt. These researchers claimed:

Often, the elder self-neglect victim coming to the attention of adult protective services is not willing to accept offers of assistance. In other words, many are “involuntary” clients who shun the thought of anyone “interfering” in their lives. This is a frustrating reality in practice which can contribute to worker burnout. Due to the reality that many of these victims can and do refuse assistance, the elder self-neglect case is usually one of the more challenging forms of neglect the worker will encounter (p. 81).

Gruman, Stern, and Caro (1997) showed that older persons who refuse but need services were at greater risk of future harm than those who accepted help. Ramsey-Klawsnik (Mar.-Apr., 2006) believe that other factors including fear, embarrassment, and lack of understanding can prevent the older person from using necessary services. Given the severe consequences of refusal of needed services, social workers must develop effective intervention strategies that these vulnerable older adults will accept.
2.5 Strategies for intervention

Ramsey-Klawsnik (Mar.-Apr., 2006) suggests helping the client make changes gradually, maintaining respect and dignity for the client and ensuring their self-protection while at the same time providing services. Longres (1994) suggested practitioners should avoid labeling older persons with “self-neglect” and reframe their situation by focusing on “supplying resources to meet felt needs” (p. 18). Social workers should respect and value these older persons, and view them as people who still can contribute to society (Longres, 1994; Reyes-Ortiz, 2001). Mixson (1991) reinforces the importance of communication between the worker and the client and maintains that "in dealing with self-neglect the first element of good practice is a thorough understanding of the underlying factors which lead to such behavior” (p. 37). The establishment of trust has also been recognized (Dubin et al., 1988; Ramsey-Klawsnik, Mar.-Apr., 2006). Clark (1975) found “persuasion and tact was needed” to increase patients’ receptiveness to a welfare home, hospital, or home support services. Professionals must especially maintain patience when working with self-neglecting older persons because months or years may pass before they might accept help (Clark, 1975, p. 802). Care by consent should be the principle of management (Reyes-Ortiz, 2001). Dyer and Goins (2000) and Dyer, Gleason, Murphy, Pavlik, Portal, Regev, and Hyman (1999) emphasized a collaborative interdisciplinary role between APS and the geriatric assessment team. Ramsey-Klawsnik (Sept.-Oct., 2006) and Lauder, Anderson, and Barclay (2005) argued that the client’s perspectives and coping strategies must be central to intervention and early identification of potential and actual self-neglect. Lauder and his colleagues assert:
The importance of mutual engagement and commitment to a therapeutic alliance as the key to effective intervention with this group cannot be over emphasized. Working relationships develop over time. The client’s own perspective must be considered central to the development of this type of alliance. Listening to and acting upon the client’s perceptions of their problems and experiences of treatment is necessary to development of a positive, long-lasting therapeutic alliance between professional and self-neglecter (2005, p. 196).

According to Dayton (Jan.-Feb., 2006), for self-neglecting older adults who are mentally clear and alert with no immediate life-threatening crisis, intervention guidelines should proceed as follows:

- Go slowly to establish rapport, with the goal of reducing isolation.
- Be consistent and avoid transfers between staff.
- Seek information regarding long-term versus sudden changes in lifestyle/functioning.
- Recognize and respect the strong drive for independence and continuity.
- Be creative to make a connection to the client’s sense of self and dignity, knowing that the usual approaches may not work.
- Advocate with the client for assistance acceptable to the client.
- Explain when other authorities will have to intervene and assist the client in preparing (e.g., housing, health).
- Create a positive multi-agency collaboration (pp. 79-80).

According to Ramsey-Klawsnik (Mar.-Apr., 2006), the goal of intervention should focus on improving the safety and stability of the older adult and by reducing self-neglecting conditions. Efforts should be geared toward risk reduction, resolving the immediate crisis, and the establishment of long-term stability (Ramsey-Klawsnik, Mar.-Apr., 2006). Social workers must learn special skills and training when assisting these
older persons. Once again, service delivery should not rely on “practice wisdom.” Instead, practitioners must be prepared to approach potentially self-neglectful older adults from where they are, taking into account their subjective perceptions of their conditions.

One of the agencies charged with intervening in cases of self-neglect is the Adult Protective Services. Adult Protective Services were established as a result of the availability of Title XX funds of the Social Security Act of 1974; it is the state agency that investigates and responds to allegations/reports of self-neglect (Anetzberger, 2000; NCEA, 2006). APS programs differ widely across the states both in structure and administration. In addition, states vary in how they define “abuse,” the age at which people are eligible for services, and program reporting requirements (Goodrich, 1997). In two-thirds of the states, APS is responsible for investigating reports of abuse and neglect. These agencies are housed within the Department of Social Services. In one-third of the states, they operate from within the state units on aging while a “sprinkling” are located within the Department of Health and Rehabilitation Services. APS is also responsible for investigating reports of abuse and neglect in institutional settings (American Public Welfare Association, 1994). Although there are variations among state statutes, APS practice guidelines follow basic principles:

the client’s right to self-determination
the use of the least restrictive alternative
the maintenance of the family unit whenever possible
the use of community based services rather than institutions
the avoidance of ascription of blame
the presumption that inadequate or inappropriate services are worse than none (Marlatt, 2000, p. 360).
The multiple causes underlying self-neglect and the funding problems have hindered the development of effective interventions to address these problems, and Simmons and O’Brien (1999) claimed that:

The health care professional confronts a variety of scenarios each with its own distinctive factors, but all with certain factors in common. Elements of self-determination, personal independence, personal eccentricities and lifestyle choices, and conditions needing medical attention come together. To these must be added the laws and regulations of the state statutes pertaining to the protection of adults. The complexities can be so painful as to create a dilemma requiring the proverbial wisdom of Solomon (p. 34).

The remaining section of this chapter will review the legislative history of self-neglect, noting how many national efforts to address self-neglect in late life have failed.

2.6 Elder abuse and neglect and legislative history

Byers and Lamanna (1993) recognized that although self-neglect is the overwhelming majority of self-endangering cases in the practice, many states lack policies on self-neglect. For example, while the state of Illinois had no elder self-neglect statute, the many cases of self-neglect posed financial problems for the state because they lacked funds to intervene and provide services to self-neglectful older persons (Kuntz, 2003). Although the Elder Justice Act has raised hope and society’s awareness of the potential for abuse and neglect in late life, we still lack adequate understanding regarding how this social condition will unfold. Nonetheless, recent legislation, such as the governor of Illinois, Rod Blagojevich, signing House Bill 4676 into law (Press Release,
State of Illinois, August, 2006, p.1), suggests that more attention will be placed on self-neglect. This recent legislation on self-neglect in Illinois will require the Illinois Department on Aging to receive, investigate, and intervene in cases of self-neglect by seniors.

The Illinois legislation, which was sponsored by Rep. Julie Hamos (D-Evanston) and Sen. Mattie Hunter (D-3rd), became effective January 1, 2007. This is an important step in the right direction and is clearly a victory for seniors and their advocates. However, it remains to be seen how funding issues and service provision to Illinois seniors who are identified as self-neglecting will be implemented. The intent is that new services to address self-neglect will emerge as researchers examine this phenomenon in greater depth and as more resources become available to study self-neglect.

At the 2005 White House Conference on Aging, Mini-Conference on Elder Abuse, Neglect and Exploitation, the National Committee for the Prevention of Elder Abuse considered what it would take to get elder abuse and neglect on the national and international agendas (White House Conference on Aging, 2005, Post-Event Summary Report). Although it is believed that previous Congressional hearings on the problem of elder abuse and neglect raised legislators’ attention to this topic, they still minimized this issue and focused more on other family violence issues. Senators John Breaux (D-LA), Ranking Member, Senate Special Committee on Aging and Orrin Hatch (R-UT), Chairman of the Senate Judiciary Committee, introduced the Elder Justice Act, S.B. 333, in the Senate on February 10, 2003. A companion bill, H.B. 2490, was introduced in the
House of Representatives by Rahm Emanuel (D-IL, lead sponsor), Peter King (R-NY), and Roy Blount (R-MO) on June 11, 2003. What is this bipartisan bill that is known as the Elder Justice Act? It is “the right of every older American to be free of abuse, neglect and exploitation” (2005 White House Conference on Aging, Post-Event Summary Report). The Elder Justice Act proposed the following:

- Elevate elder justice issues to the national agenda
- Increase the knowledge base
- Improve detection
- Enhance intervention
- Promote prosecution and victim assistance
- Provide training
- Increase public awareness (White House Conference on Aging, 2005).

These two bills signified the beginning of a new era on elder abuse and neglect. In a statement made during the hearing held by Senator Breaux on April 23, 2003, Robert B. Blancato, an elder advocate, stated:

> Our commitment to child abuse and family violence prevention has been good. I believe we have been more remiss with respect to elder abuse prevention. The opportunity to remedy this is before us now. It may have been an emerging issue in the late 1970s, but it has fully arrived today. To not direct the same level of commitment to elder abuse as to other abuse constitutes a new and deeply troubling form of ageism (Blancato, 2003).

Despite the introduction of the Elder Justice Act of 2003, many barriers remain. One barrier that hinders successful implementation of this national legislation is funding. According to Blancato (2003):

> Senator Breaux, as you have pointed out on a number of occasions, the federal commitment to elder abuse prevention is piecemeal and inadequate. The only federal program specifically providing funds for elder abuse prevention has a total funding of less than $5 million
dollars. In fact, the program, which is the primary funding source of adult protective services, the Social Services Block Grant, has suffered cuts of more than $1 billion in recent years.... The fact that only .08-less than one percent-of all funds spend on abuse prevention go to elder abuse programs establishes the most compelling reason why we need the Elder Justice Act. We simply do not have the adequate public-private infrastructure and resources needed to be in place to prevent, detect, treat, understand, intervene in and, where appropriate.... It is critical that we recognize elder abuse for what it is-a public health, law enforcement and social services crises (Blancato, 2003).

Another barrier to successful implementation of these national initiatives is rigorous research on this topic (Voelker, 2002). For example, Sidney Stahl, the chief of Behavioral Medicine from the NIA noted the lack of research on elder abuse and neglect was substantial. He stated:

I started scrounging the literature for data, and after a day I was done...It was tragic. Much of the information that exists in the literature is anecdotal, as opposed to scientific. I was having trouble making decisions about where to go with this research. We’re talking to the major players. ...The task is monumental given the dearth of attention the problem has received to date....Elder abuse is probably where child abuse was 30 to 40 years ago, which is nowhere....This is a very difficult area to do research on (quoted in Voelker, 2002, p. 2254).

Gorbien (2005), also noted the limited research in this area, and argued “We have been limited by a paucity of data and sound scientific research on this subject” (2005, p. xi). Similarly, it has been recognized that “most elder abuse research is methodologically deficient or otherwise problematic. As a result, we know virtually nothing about elder abuse with certainty” (White House Conference on Aging, 2005, p. 5). Although federal legislation has yet to be enacted, the media has increased people’s awareness of self-neglect. When compared to elder abuse, Woolf (1998) acknowledged that self-neglect is
a controversial category issue that investigators and practitioners interpret in various ways. In her dissertation, Bozinovski (1995) asked the following questions: (1) “Why has the public remained unaware of the phenomenon of self-neglect even though cases have been served through the APS system in this country for decades?; and (2) Why does the image of physical abuse of the elderly dominate public awareness, rather than self-neglect, when the majority of ‘elder abuse’ cases handled by the Adult Protective Services System (an objective social condition) involve allegations of self-neglect and not physical abuse?” (pp. 141-143), but these questions still remain unanswered. Even today, legislators and other experts primarily focus on elder abuse and many questions on self-neglect remain. Bozinovski (1995) further argued that self-neglect “fits the description of a ‘position’ issue,” and thus has had “difficulty in becoming a full-fledged social problem” (p. 159). Blumer (1971) argued that “Social problems have their being, their career, and their fate in the process of collective definition. Downplaying the significance of the process of collective definition can give only fragmentary knowledge and a false description of social problems” (p. 305).
2.7 Conceptual framework

This study is grounded within three conceptual perspectives, specifically, compliance, ecological, and symbolic interactionism theories, which are discussed below. The first to be discussed is compliance theory.

2.7.1 Compliance theory

Compliance is the act of conforming, acquiescing, or yielding (Webster, 1989). Dracup and Melesis (1982) defined compliance as “the extent to which the individual chooses behaviors that coincide with a clinical prescription” (1982, p. 31). Compliance with health care instructions is critical to the maintenance of good health. When patients act against the advice or instructions of their physicians or health care professional, they are said to be in “noncompliance.” Researchers studied compliance in the 1890’s and 1940’s during public health movement to control tuberculosis. Patients who eschewed physician's recommendations were called "ignorant, vicious, recalcitrant, or defaulters (Steiner and Earnest, 2000, p. 926). Experts’ studies published before 1960 described these patients as "faithless" to the treatment regimen (Steiner and Earnest, 2000, p. 926), or as "trustworthy" and "unreliable" (Steiner and Earnest, 2000, p. 926). It has been estimated that between 20 to 70% of patients fail to comply, although percentages are higher when the health care recipient is female, poor, or of a different religion, race or ethnic group (Zola, 1986).

Although several compliance models have been proposed (Dracup and Meleis, 1982), in this study I focus on the health belief model of compliance for two reasons: because of the increase in the elderly population, among them individuals with multiple
health and social needs; and because of the movement from acute care to community care, necessitating the need for elderly individuals to manage their health problems amid adverse social and living conditions. These reasons make compliance an appropriate theory for the understanding of self-neglect. Originally formulated to gain an understanding of preventive health behavior, such as immunizations or prophylactic dental care (Dracup and Melesis, 1982), the health belief model was developed by Hochbaum (1956), and Rosenstock (1960) and further elaborated by Becker and colleagues (1979). The health belief model is based on motivation theory whereby motivation is used as a differential, emotional stimulant in reaction to a health problem (Dracup and Melesis, 1982).

According to the health belief model (Dracup and Melesis, 1982), once stimulated, the likelihood of an individual engaging in health-seeking behavior depends on two variables: the amount of threat perceived by the individual; and the attractiveness or value of the action in question. The degree of perceived threat then is weighed against the following variables: the vulnerability to the disease; the perceived degree of bodily harm; the extent to which the disease or illness will impact social roles; the existence of symptoms; and previous experience with the illness. The probability of compliance is increased if patients are convinced it will reduce the threat posed by the health problem, the cost and time involved is worthwhile, and if they have the emotional drive or motivation to comply. The perceived threat and the attractiveness or value of the action are affected by many factors such as how patients perceive a threat and are attracted to or value the action needed to comply (Dracup and Melesis, 1982).
There is an overwhelming body of literature suggesting that some forms of noncompliance can be perceived as the patient's objection to the health professionals’ recommended treatment (Ascione, 1994). After analysis of in-depth interviews with patients who had epilepsy, Conrad (1985) concluded that patients’ noncompliance may be a way to remain in control over what was going on with their lives (p. 25). Similarly, Nelson and Farberow (1982) maintained that clients may engage in negative interactions with health care professionals in order to feel more control over their condition.

Compliance theory is based on three major assumptions: compliance and noncompliance is a result of a health transaction in which the patient agrees to a prescribed treatment and is a partner in the care plan; the diagnosis must be accurate so that the benefits of the prescribed treatment outweigh the risks; and both the efficacy of the planned treatment and benefit of the treatment to the patient must be firmly established. Compliance or noncompliance can not be explained from the actions of the patient alone; instead, it must focus uniformly on the characteristics of both the patient and the health care professional and on the transactions between them (Dracup and Melesis, 1982, p. 33).

According to Reed and Leonard (1989), “self-neglect and noncompliance are similar concepts because both refer to the client’s lack of participation in a prescribed or necessary health care regimen” (p. 42). Although the focus of compliance is on a health care regimen, self-neglect is associated more with personal and social environmental factors (Reed and Leonard, 1989). In self-neglect, “refusal of services” is more
commonly used than reasons for noncompliance. Researchers have identified various reasons for why some older adults who need help refuse services. According to Dubin, Lelong, and Smith (1988), most older persons who refuse services are those for whom:

…family or friends provide or are willing to provide yet the elder refuses it or (b) elders living alone in poor circumstances with no one looking after them, yet they refuse outside intervention. They do not want medical attention, medication, household clean-up, sometimes even food (pp. 5-6).

Dubin et al. (1988) reported that elders who refused services or were resistant to care were: (1) older persons near death; (2) despairing older adults; (3) older adults despaired due to depression or anger; (4) those who deny the existence of a problem or had disabilities; (5) mistrusting older persons; (6) prideful older persons and care givers. Health care providers typically make most people’s health decisions and intervene at a time that self-neglectful clients are most vulnerable.

Below is case vignette of an elderly man who was cited for self-neglect:

Mr. N., a 68 year old legally blind widower, who lives in a brick home in rural Onslow County. He has lived alone since his wife’s death 6 years ago. He talks longingly of the times he shared with his wife. She was a skilled pianist and he sang to accompany her for over twenty years. He has become increasingly functionally impaired since her death. He receives home health services daily to help maintain the home. Occasionally the aide bathes him and cuts his shoulder length hair. Problems in stabilizing his diabetic condition have ruled out surgery for cataracts on his eyes. He also has been diagnosed as clinically depressed for 5 years, but refuses to take medication. His only relative, a non-kin “step daughter” lives in Maryland and calls weekly. She and her family visit twice each year. (Griffin, 1994, p. 10).
Multiple reasons could have contributed to Mr. N’s noncompliance or refusal to take his medication. Chubon (1989), and Reed and Leonard (1989) found that the side effects from some drugs caused noncompliance behavior among elderly persons. These authors argued that some older persons missed their medications because the side effects that these drugs cause reduced the quality of life:

Behavior that appears to be self-neglectful may represent an attempt to improve the quality of life; for example, some elderly patients do not comply with medication regimens to avoid side effects (Reed and Leonard, 1989, p. 40).

Another reason for noncompliance is the difficulty of implementing the plan. For many of the elderly “involved in self-care for chronic illness or health maintenance, ... compliance depends on the degree of congruence of the prescribed regimen with their usual lifestyle and goals. Where there is marked deviance, one may predict a high risk of non-compliance in self-care” (O’Rawe, 1982, pp. 1934-1935). Compliance is more likely when health care practitioners seek input from their older patients, mutually agree on a treatment approach, and implement an intervention that the older client agrees with and accepts.

2.7.2. Ecological theory

The term, “ecology,” credited to a German Zoologist and advocate of the theory of evolution, Ernest Haeckel, is a science that studies the relationship between organisms and their environment (Bubolz and Sontag, 1993). The ecological perspective focuses on interactions between individuals within their environments (Germain, 1991). The ecological perspective is rooted in the “evolutionary, adaptive view of human beings in
continuous transactions with the environment, with the person and the environment continuously changing and accommodating one another” (Brower, 1988, p. 412). The goodness of fit between the environment and the individual is at the core of the theory.

Due to the multiplicity of factors involved in and the complex nature of the phenomenon of self-neglect, ecological theory is very useful for gaining a deeper understanding of the experiences and meanings in the lives of self-neglectful older persons. Elderly persons identified as self-neglectful present with physical illness (Moore, 1989), medical conditions (Vinton, 1991), and inadequate social supports (Longres, 1994), and they underutilize formal services (Vinton, 1991; Rathbone-McCuan, 1992). For these reasons ecological theory is an appropriate framework to investigate self-neglect in late life. Below are central concepts underlying ecological theory.

2.7.2.1 Life course

The life course reflects the constant exchange between the individual and the environment but differs from previous conceptualizations by viewing human growth and development as more fluid rather than comprised of universal stages, and without social, cultural and environmental influences (Germain and Gitterman, 1996, p. 21). Furthermore, the life course perspective takes into account life stressors, stress, and coping mechanisms that are bred by difficult life transactions, traumatic life events, poverty, and prejudicial discrimination (Germain, 1991). The life course perspective is fitting for explaining the phenomenon of self-neglect with a focus on the exchange that takes place between the individual and the environment as people still develop during
their later years.

2.7.2.2 The goodness of fit/person: environment fit

Throughout the life course, individuals strive for an optimal person/environment fit between their needs, capacities, rights, aspirations, and personal development (Germain and Gitterman, 1996). The degree of fit is contingent on the availability of supportive services. Ecological theory and its focus on goodness of fit between the person and the environment have been widely applied to child abuse and neglect. Myers (2006), for example, believed that child maltreatment is caused by the interplay of cultural, sub-cultural, political, community, family, and individual factors. Similarly, Rathbone-McCuan and Bricker-Jenkins (1992) believed both personal and environmental factors such as culture, political, community, and family increases the vulnerability of the older adult to self-neglect.

As Miller and Solomon (1979) put it:

> the societal environment in which the elderly are located offers opportunities for, as well as obstacles to, successful adaption to our shared human fate of growing old. Societal values and attitudes toward and within the family, demographic trends, geographic migration, the postindustrial economy and workforce, bear for good or ill on the quality of life for all elderly people. They pose new adaptive tasks at every turn, yet institutionalized solutions, even to the more expectable adaptive tasks, are not always available (p.74).

2.7.2.3 Adaptive mechanisms

Adaptation is as a result of effective coping behavior and is central to ecological theory. These adaptive behaviors may have biologic, cognitive, emotional, social, or cultural bases and they are active efforts to change oneself in order to meet the
environment’s expectations or change the environment (Germain and Gitterman, 1996, p.9). Given the vulnerability both social and physical inherent in the aging process, it is important that the environment is “neither too demanding nor too devoid of stimulation” (Bigby, 2004). Based on the numerous changes -- physical, social, and financial losses that occur simultaneously -- elderly individuals invent different methods in carrying out activities of daily living (bathing, grooming, dressing, eating, toileting, transferring from bed to chair, etc), and instrumental activities of daily living (meal preparation, general housekeeping, laundry, shopping, transportation, financial management, etc.) (Rathbone-McCuan, 1992). Attempting to perform these activities may require some elderly individuals to engage in “adaptive compensation” (Rathbone-McCuan and Bricker-Jenkins, 1992, p. 18). The elderly person’s “inability to perform self-care tasks, combined with lack of recognition of, or admission to these limitations, is the most common personal reason for elder self-neglect” (Rathbone-McCuan and Bricker-Jenkins, 1992, p. 20).

Adaptedness occurs when the social environment provides the individual with the resources and experiences at the proper time and form to ensure the ideal biological, cognitive, sensory, perceptual, emotional, perceptual, and emotional and social development (Germain and Gitterman, 1996, p. 8). Unmet needs of older persons are believed to be at the core of self-neglect as a poor fit between the individual and the environment will result in negative adaptation.
2.7.2.4 Unmet needs and self-neglect

Using 36 subjects, Graves-McPherson (1997) conducted a study on the biopsychosocial variables of indigent African-American elderly who were reported to be self-neglectful. Her study was based on four variables: physical functioning, depression, social support, and economic resources. Though not statistically significant, Graves-McPherson found that the elderly in her study were dependent in activities of daily living: they were depressed, lacked social support, and had limited economic resources to support their medical demands (Graves-McPherson, 1997). Rathbone-McCuan and Bricker-Jenkins (1992) pursued the interplay of environmental factors a step further and maintained that environmental factors (family members, friends and neighbors, for example), may have a more powerful influence on how elderly individuals care for themselves as functional capacity diminishes. The elderly person is nested in the social support of their family and community. What happens when the family and community are unable to provide needed assistance?

In this study, Rathbone-McCuan and Bricker-Jenkins (1992) suggested that the inaccessibility of social service programs such as medical care, transportation, financial assistance, nutrition, in-home services, respite care, specialized housing, mental health counseling, adult day care programs, inpatient rehabilitation programs, affordable nursing
homes, etc., needed by elderly individuals as one of the most influential factors increasing the likelihood of self-neglect (p.21). Rathbone-McCuan and her colleague maintained that:

conditions of self-neglect may be increased or decreased and sometimes created by environmental factors that surround and directly impact the elder, so in many cases environmental conditions become a focus of the assessment and later intervention. The impact of environmental factors can often be greater than individual conditions influencing the self-neglect (p. 21).

The suggestions by Rathbone-Mccuan and Bricker-Jenkins (1992) have been reinforced in a more recent study by Woolf (1998):

Clearly, many of these individuals are forced to choose between food, housing, and medication. From the outside looking in, it may appear that the individual is choosing to self-neglect (e.g. he/she neglects to take their heart medication or are undernourished) when in fact, they simply cannot afford to adequately care for themselves (p. 6).

Self-neglect for the elderly does not occur in a vacuum; it takes place within the context of a given environment and in the face of diminished functional capacity, social, and financial resources. As people age they typically experience a series of losses, such as job, spouse, friends, physical functions, and, most importantly, financial resources.

The older persons fit best with their environments whey they have good health or, if they do have health impairments, they have adequate supports at home, churches, and communities.
Therefore, self-neglect among the elderly can best be understood from an ecological, person-in-situation, perspective. In the absence of adequate formal and informal services, the elderly individuals develop new ways of adjusting to and coping with diminished functional capacities and inadequate social resources. When services are fragmented, underutilized, living quarters and amenities outdated and unable to meet the physical needs of the elderly, the result can be self-neglect. A combination of the lack of formal and informal social resources creates a fertile ground for self-neglect. Based on ecological theory, self-neglect occurs as a result of poor fit between the elderly and their environment, caused by the unavailability of formal and informal services and the adaption that occurs as a result of the interaction between the elderly individual and his or her environment.

Whether it is self-neglect when older adults refuse social services is subject to debate. Our role as social workers and/or human service delivery personnel is to see the person within the context of the social environment and to maximize the goodness of fit. When there are no services to assist older adults that are unable to perform those activities of daily living that ensures quality of life, or when a decisional capacity is impaired, a poor fit between the elderly and the environment will result. At every phase of the aging process, assistance with adaption becomes increasingly important. As the elderly person’s capabilities change, so should the economic and social resources if
continuum of care is to be insured. Intervention must focus on and include increased social services/supports (e.g. rental subsidies, food stamps, affordable health care) (Woolf, 1998, p. 6).

The provision of adequate support services to help maintain older person’s quality of life is essential to overall well-being. It has been recognized that:

The consequences of self-neglect can be far more serious than hygiene and cosmetic problems. Those who live alone are especially liable to neglect themselves, perhaps because they have no one to remind them of their personal needs or to cajole them out of the mental and spiritual lethargy that so easily sets in with moderate depression (Simmons and O’Brien, 1999, p. 45).

The literature on self-neglect has been thoroughly reviewed and there is no denying that the elderly -- those who are disenfranchised, marginalized, the frail, the poor -- are at risk of self-neglect. It might not be that elderly persons are self-neglectful but that there are cumulative negative effects of aging: the physical infirmities of aging, chronic illnesses, lack of strong social support system, poverty, and fragmentation of social services, all of which make for a fertile ground for self-neglectful behavior.

2.7.3 Symbolic interactionism

Symbolic interactionism is a major social psychological perspective that is closely associated with George Herbert Mead and Herbert Blumer (Patton, 2002). The intellectual history of this theory began with Max Weber, a German sociologist and economist, and George H. Mead, an American philosopher. Both Weber and Mead
focused on the subjective meaning of human behavior and the social process of interaction. Although this theory is sometimes associated with Mead, it was Herbert Blumer, a colleague of Mead, who, in 1937, coined the term “symbolic interactionism.” This theory emphasizes the importance of meaning and interpretation as a necessary component in understanding human behavior (Patton, 2002). According to Blumer (1969), symbolic interactionism rests on the following premises:

1. Human beings act toward things on the basis of meanings that the things have for them.

2. The meaning of things arises out of the social interaction one has with one’s fellows.

3. The meanings of things are handled in and modified through an interpretive process by the person in dealing with the things he or she encounters (in Patton, 2002, p. 112).

Based on the three premises, stated above, which are fundamental to this theory, Blumer maintained that qualitative inquiry was the “only way” of gaining a deeper knowledge of how individuals view, comprehend, and explain their world (Patton, 2002). How older persons who had been identified as self-neglectful “construct their worlds, their realities” (p. 112) provided the rationale for the use of this theory in this study. Social scientists or social workers can not begin to understand self-neglect without going directly to those who have been identified as experiencing this phenomenon. In order to gain a deeper understanding of self-neglect, we must attempt to understand the experiences of those older persons and the meaning they assign to those experiences.
There is controversy surrounding the language and the definition of self-neglect:

The medical nomenclature of self-neglect and the language used to describe its key characteristics, such as syllogomania, desperate state of domestic disorder, troublesome behavior, and refusal of treatment, give the impression of revealing some underlying reality. In fact such language may actually define and create a reality which does not exist outside the language used to create it (Lauder, 1998, p. 2).

The question one must ask is how older persons interpret their behavior that society considers as self-neglectful and what meanings are assigned to those behaviors? Bozinovski (1995) used symbolic interactionism to explain the actions of the self-neglecting elders and the Adult Protective Services workers in her study.

Given the different opinions that have been expressed by those who interact with the elderly identified as self-neglectful, it is very important that we explore the subjective meanings of the behavior we currently know as self-neglect. How else can we understand self-neglect if we do not know what it means for the elderly? Unless we come to an understanding of what self-neglect means to the elderly population we serve, the best intervention strategy on the books will prove unsuccessful.

As captured in the words of Denzin (1989):

The perspectives and experiences of those persons who are served by applied programs must be grasped, interpreted, and understood if solid, effective programs are to be put into place (p. 105).
CHAPTER 3

METHODOLOGY

This study sought to uncover and document the experiences of older persons’ subjective meaning of self neglect. The research methodology used to capture these experiences was the case study method, a method classified under the general theme “Qualitative Inquiry.” This chapter describes the rationale for the method selected to understand older persons perspectives about self-neglect, and provides details related to sampling design, subjects, research settings, data collection, data analysis, and research trustworthiness.

3.1 Rationale for case study as a research method

Yin (2003), in defining the case study, approached it in terms of the scope of a case study. According to Yin,

A case study is an empirical study that investigates a contemporary phenomenon within its real life context especially when the boundaries between phenomenon and context are not clearly evident…. The case study inquiry copes with the technically distinctive situation in which there will be many variables of interest than data points and as one result relies on multiple sources of evidence, with
data needing to converge in a triangular fashion and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis (p.13-14).

The case study is preferred in examining contemporary events only when relevant behaviors cannot be manipulated. According to Yin (2003), a case study involves “direct observation of events being studied and interviews of the persons involved in the events” (p. 8).

This study attempts to use interviews to understand older persons’ perspectives on self-neglect. A multiple case design is utilized. The logic for multiple-case design is similar to that used in experimental research where each experiment is replicated in multiple experiments (Yin, 2003, p.47). Yin cautions that when using a multiple-case design, sampling logic should not be used.

This study attempts to provide insights into self-neglect among older persons, which is reported as the most common type of elder abuse and neglect but it remains poorly understood and defined. This study meets the rationale suggested by Yin (2003) for the use of a multiple case design to answer the research questions.

3.2 Designing the study

The design strategy adopted in the study is qualitative research. According to Patton (2002),

Qualitative designs are naturalistic to the extent that the research takes place in real-world settings and the
researcher does not attempt to manipulate the phenomenon of interest (e.g., a group, event, program, community, relationship, or interaction). The phenomenon of interest unfolds naturally in that it has no predetermined course established by and for the researcher such as would occur in a laboratory or other controlled setting. Observations take place in real-world settings and people are interviewed with open-ended questions in places and under conditions that are comfortable for and familiar to them (p. 39).

Hakim (2000) in her definition states:

The term qualitative research is used here to refer to a specific research design rather than as a general term for non-quantitative research methods. Qualitative research is concerned with individuals’ own accounts of their attitudes, motivations and behavior. It offers richly descriptive reports of individuals’ perceptions, attitudes beliefs, views, and feelings, the meanings and interpretations given to events and things, as well as their behavior (p. 34).

In designing the study, an in-depth interview technique was utilized. According to Hakim (2000), the

in-depth interview is unstructured (there is an interview guide but no questionnaire), of variable length (but may take up to five hours) and may be extended into repeat interviews at later dates… the depth interview provides enough freedom for respondents also to steer the conversation, for example, to bring in all sorts of tangential matters that, for them, have bearing on the main subject (p. 35).

I used Adult Protective Services’ 1991/2004 definition of “self-neglect” and reframed that definition with a focus on how participants viewed their living circumstances. An interview guide was utilized to guide the process and to obtain participants’ views of their circumstances. However, an open-ended, conversation-like interview method was utilized in contrast to pre-determined response categories. As
argued by Patton (2002), “a qualitative design needs to remain sufficiently open and flexible to permit exploration of whatever the phenomenon under study offers for inquiry. Qualitative designs continue to be emergent even after data collection begins” (p. 255).

3.3 Sampling design

A purposeful sampling technique was utilized to collect data. According to Patton (2002):

the logic and power of purposeful sampling derive from the emphasis on in-depth understanding. This leads to selecting information-rich cases for study in depth. Information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term “purpose sampling” (p.169).

Due to ethical and practical considerations (the requirement that participants be volunteer, gaining entry to settings, access to the subjects, time, and cost) most studies of this nature use purposive sampling despite its limited generalizability. While generalized outcomes are important in research, research on older persons’ perspectives are sufficiently new that the primary goal for this study of analyzing the views of older persons identified as self-neglectful was considered a significant beginning step.

The older adults who volunteered and participated in this study were identified by staff from APS and home health agencies as meeting the APS criteria for self-neglect. The unmet needs of study participants included but were not limited to lack of personal
hygiene, unsanitary and unsafe living conditions, unpaid utility bills, financial management issues, noncompliance with medical regimens, and the lack of adequate resources to support their medical and/or physical demands.

3.3.1 Sample size

Sample size in qualitative research is contingent upon what the researcher is seeking to uncover, why the study is being done, the resources and the availability of time, and what the researcher thinks will yield credibility to the study (Patton, 2002). The sample in this study (n=12) consisted of persons who were identified as meeting the criteria for self-neglect as defined by Adult Protective Services and who volunteered to participate. The study’s participants represented a cross section of the age category, ranging in age from 73 to 94-years-old. All participants solicited were identified by APS and home health staff as having unmet needs and meeting the criteria for self-neglect. The study was introduced to Adult Protective Services’ clients and home health care patients who met the criteria for inclusion - the experience of unmet needs defined by APS as “self-neglect” and the willingness to participate. The information that was needed in order to answer the research questions could only have been obtained from the older adults who had been identified as meeting the criteria defined as “self-neglect” and volunteered to participate in this study.

The use of a small sample allowed for rich, in-depth information to be gathered from the interviews. As recommended by Patton (2002), sampling designs should be “based on expected coverage of the phenomenon given the purpose of the study and
stakeholder interests” (p. 246). In the initial proposal, I had planned to interview 15 older persons for the study, but time and money were factors and would not permit me to achieve the initial goal regarding the number of participants. According to Patton (2002), “the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size” (p. 245). Thus, the use of small sample does not diminish the credibility of the study.

3.3.2 The setting

The sites for the study were homes of older persons in Ohio and Illinois, two mid-western states in the United States. Special facilities were not required. The participants were allowed to choose a time when they could complete a two- to three-hour interview with the researcher. No special equipment was required for the interviews except for an audio-tape recorder. The researcher took the recorder with her during the visits and recorded every interview. The data for this study were collected between August, 2006 and December, 2006.

3.3.3 Gaining access

This study was approved by the Ohio State University Institutional Review Board (IRB). Having previously discussed with and received support from Adult Protective Services and home health care agencies, these agencies were re-contacted following IRB approval and the administrators were provided with written materials about the study. Subsequently, separate meetings between the researcher and the administrators, APS case managers, and home health agency nurses were held to discuss the study and the
protection of the privacy of clients/patients who agreed to participate in the study.

Four Adult Protective Services’ clients and eight home health care patients volunteered to participate and were interviewed for this study. The staff at the two agencies introduced the study to their clients and patients in the privacy of their homes during their regular home visits. Five Adult Protective Services’ clients initially expressed willingness to participate in the study. Of the five that expressed a willingness to participate, three clients invited the researcher to contact them in person together with their case managers. Following these initial contacts, these clients asked the researcher to later call them to discuss the study. On subsequent contacts, the clients invited the researcher to visit them again at which time the study was privately discussed in detail. Among two of the five APS clients who asked to be directly contacted by phone, only one participated in the study. One client, who during a phone conversation expressed willingness to participate in the study and had invited the researcher for a home visit, upon arrival did not open the door. This client did not remember talking to the researcher over the phone and was not interviewed for the study.

The home health care participants who met the identified criteria and expressed willingness to participate in the study invited the researcher to directly contact them by phone. Thereafter they continued to express interest in the study, and then provided their home addresses. At every stage of contact with APS clients and home health care patients, they continued to express willingness to participate in and volunteered to be interviewed for the study. The interview dates, times, and places were set based on the convenience of the participants. The twelve (12) participants in this study from Adult
Protective Services and home health care agencies understood and voluntarily signed the consent forms and agreed to the interview. Confidentiality was maintained during and after the study, and no information about the participants was shared with the agencies that introduced the study to their clients and patients.

3.3.4 Compensation

As a token of appreciation for participation in this study, I offered $10.00 to each participant. Even though some participants said they did not participate in the study for the money, they all accepted the $10.00 gift. Some participants said they would use the $10.00 gift to buy food-related items, and others said they were glad to have the opportunity to talk. Except for those respondents who “truly need the money,” financial compensation typically does not make a difference in the participants’ willingness to enroll in a study; remuneration is mostly meaningless to the respondents experiences (Weiss, 1994). In most instances, the reward is the interview itself and the contribution the participants make to the study (Weiss, 1994). “Still a gift to acknowledge a respondent’s contribution is likely to be appreciated” (Weiss, 1994, p. 58).

3.4 Research instrument

In qualitative research, the researcher is the instrument of data collection, data analysis, and data interpretation. The human instrument was the most appropriate instrument for the study of the experiences and meaning of self-neglect among older adults. The instruments in this study included myself, an audio tape recorder, a pen and a writing pad, a computer, flash drive and printer, and a self reflexive journal. Guba and
Lincoln (1981) maintain that:

...inquirer is himself the instrument, changes resulting from fatigue, shifts in knowledge, and cooptation, as well as variations resulting from differences in training skill, and experience among different “instruments,” easily occur. But this loss in rigor is more than offset by the flexibility, insight, and ability to build on tacit knowledge that is the peculiar province of the human instrument (in Patton, 1990, p. 14).

3.5 Data collection

This study followed the format of unstructured in-depth conversations. “Qualitative gerontological research requires careful attention to the data collection process to make sure the data supply the foundation for an analysis of meaning” (Reinharz and Rowles, 1988, p. 6). Data gathering included a one time in-depth interview per participant. The important question to ask here is why use the in-depth interview as a data gathering method? While I was able to observe the participants, see and smell the environment, participants had to tell me what were on their minds and how they perceived the situations they were confronted with. The interviews lasted between 40 minutes to an hour and half. Two interviews lasted close to two hours.

Qualitative interviews were an appropriate method to gather participants’ perspectives about self-neglect while observing their behavior and circumstances. One participant asked me to pass her a glass of water and ice from the refrigerator in her kitchen. Another asked me to help her look for her eye glasses, and another asked me to help open a jar of pickles. Overall, it was helpful for me to talk with these participants face-to-face. The uncared for pets, huge flies and bugs and insects, the unbearable stench
in one of the homes, the funny odor in yet another, the open ceiling with dripping water in the kitchen and the cockroaches seen in one apartment, as well as the cockroaches in two other apartments and a house, would not have become part of my experience in the study of self-neglect had I not used a qualitative research design. While I would have been able to observe these events if I had conducted a participant observation, I would not have had the opportunity to learn as much about how these participants experienced self-neglect. My observations, in addition to the in-depth interviews, provided me with a holistic perspective that Patton (2002) explains below:

We interview people to find out from them those things we cannot directly observe...The issue is not whether observational data are more desirable, valid or meaningful than self report data. The fact is that we cannot observe everything. We cannot observe feelings, thoughts, and intentions. We cannot observe behaviors that took place at some previous point in time. We cannot observe situations that preclude the presence of an observer. We cannot observe how people have organized the world and the meanings they attach to what goes on in the world. We have to ask people questions about those things. (p. 341)

The dialogue between the participants and the researcher was audio taped, transcribed by the researcher verbatim, and stored on a flash drive. Except where there was a need to obtain specific information such as the age of the participants, most questions were open-ended. These questions allowed or provided the participants with the opportunities to share their perspectives regarding self-neglect. Patton (2002) provides four major reasons for using standardized open-ended questions:

(i) the exact instrument used in the evaluation is available for inspection by those who will use the findings of the
study (ii) variation among interviewers can be minimized

where a number of different interviewers must be used (iii)
the interview is highly focused so that interviewee time is
used efficiently (iv) analysis is facilitated by making
responses easy to find and compare (p. 346).

3.6 Data analysis

Data analysis is described as transforming data into findings (Patton, 2002). As noted
by Patton, “the challenge of qualitative analysis lies in making sense of massive
amounts of data. This involves reducing the volume of raw information, sifting trivia
from significance, identifying significant patterns and constructing a framework for
communicating the essence of what the data reveal” (p. 432). Yin (2003) describes data
analysis as the examination, categorization, tabulating, testing, or otherwise
recombining both quantitative and qualitative evidence to address the initial propositions
of a study.

This study began with cross-case analysis of the interviews conducted using
Miles & Huberman’s (1994) analytic strategy to put the data in order. The analysis of the
data for this study was based on Miles and Huberman’s (1994), and Yin’s (2003)
techniques of cross-case analysis. The intent was to identify themes among participants’
propositions, setting up a framework based on rival explanations, and developing case
descriptions. Furthermore, Yin (2003) argues that any of these strategies could be used in
practicing several techniques for analyzing case studies, including cross-case synthesis.
The frameworks developed by Miles and Huberman (1994) that were used to analyze the
data in this study included: data reduction, data display, and conclusion drawing and verification (pp.10-12). These are described below.

3.6.1 Data reduction in cross-case analysis

“Data reduction refers to the process of selecting, focusing, simplifying, abstracting and transforming the data that appear in written up field notes or transcriptions” (Miles and Huberman, 1994, p. 10). According to Miles and Huberman (1994), data reduction is a form of analysis that sharpens, sorts, focuses, discards, and organizes data in such a way that “final” conclusions can be drawn and verified (p. 11). In order for such a huge amount of data to be analyzed, it should not only be condensed for the sake of manageability, but it also must be transformed so that conclusions make sense in terms of the issues being addressed. Data reduction forces the researcher to select among the data which aspects of the data should be emphasized or minimized, which Yin (2003) describes as the first strategy in analyzing data. In initiating the process of data reduction for this study, the researcher transcribed the interviews verbatim. During the data reduction phase, I read and reread all the transcripts and became familiar with participants’ responses.

3.6.2 Data display in cross-case analysis

In an analogy to data display, Yin (2003) suggests that, “one possibility is to create word tables that display the data from the individual cases according to some uniform framework” (p.134). Analysis of entire collections of word tables helps researchers to draw cross-case conclusions. According to Miles and Huberman (1994), data display strategies for qualitative analysis goes beyond data reduction that leads to
“an organized, compressed assembly of information that permits conclusion drawing….”

Data display can be an extended text, diagram, or matrix. At this stage themes may emerge that go beyond those first encountered in the data reduction phase. The technique adopted in this study was to develop a coding system for analyzing patterns of response concerning the perceptions of the participants based on the semi-structured interview questions. “Coding qualitative data is a process of identifying bits and pieces of information (meaning units) and linking these to concepts and themes around which the final report is organized” (Padgett, 1998, p. 76). Similarly, Miles and Huberman (1994) believe that:

Coding is analysis. To review a set of field notes, transcribed or synthesized, and to dissect them meaningfully, while keeping the relations between the parts intact, is the stuff of analysis. This part of analysis involves how you differentiate and combine the data you have retrieved and the reflections you make about this information (p. 56).

I manually coded this content. According to Miles and Huberman (1994),

Codes are tags or labels for assigning units of meaning to the descriptive or inferential information complied during a study. Codes usually are attached to “chunks” of graphs, connected or unconnected to a specific setting. They can take the form of a straightforward category label or a more complex one (e.g., a metaphor) (p. 56).

Following immersion in and familiarity with the data, I labeled the texts for descriptive information. For example, passages or sentences where participants talked about medical/health conditions, I coded as “Med/Health,” and where they described a fall incident, I coded this as “Fall.” Where participants expressed issues of mistrust, I coded as “Mistrust.” Once the texts were coded, I then selected passages and quotations
that were significant to the study and presented them for the final report. Thus the older adults participants’ words were developed into themes. According to Piaget (1998):

themes … capture human experience. They may jump at you early on or they may emerge over time. Respondents may themselves offer emic themes. Emic themes have obvious salience because they reflect the respondent’s point of view (p. 83).

3.6.3 Conclusion drawing and verification in cross-case analysis

Conclusion drawing and verification involves stepping back to consider what the analyzed data mean based on the research questions and drawing implications for those questions. In Yin’s (2003) third analytic strategy, he speaks to developing a “framework for organizing the case study” (p.114). However, Yin (2003) noted that in a multiple case study the individual case studies need not always to be presented in the final report (p.149). Verification, clearly linked to conclusion drawing, involves going back to the data as often as is necessary to cross-check or verify the themes that emerge. Miles and Huberman (1994) described this as “the meanings emerging from the data have to be tested for their plausibility, their sturdiness, their confirmability” (p.11). In this study, conclusion drawing and verification involved examining and re-examining the data and noting patterns and themes that emerged, clustering cases, and making contrasts and comparisons. Responses to questions were systematically compared to determine any apparent cross-case differences. In the cross-case analysis, the research questions guided the conclusions drawn. In order to provide the reader with a clearer understanding of the experience encountered, two case vignettes were developed from the data analysis. The names were changed to protect the identity of the participants.
3.7 Establishing trustworthiness

In every research, certain criteria have to be met before the findings are judged credible. However, Guba and Lincoln (2005) alert us that “no one would argue that a single method – or collection of methods -- is the royal road to ultimate knowledge” (p. 205). They pose the question:

How do we know when we have specific social inquiries that are faithful enough to some human construction that we may feel safe in acting on them, or more important, that members of the community in which the research is conducted may act on them?… To that question there is no final answer (p. 207).

This study utilized several triangulation strategies to strengthen the study. They included triangulation with multiple analysts, theory/perspective, and triangulation of data sources.

3.7.1 Triangulation

One important way to reduce the likelihood of misinterpretation and to increase the credibility of research findings is through triangulation (Stake 2005, Patton 2002). Stake (2005) defined “triangulation” as “a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation” (p. 454). Patton (2002) argued that the logic of triangulation “is based on the premise that no single method ever adequately solves the problem of rival explanations” (p.555). Patton (2002) identified four types of triangulation: (1) methods triangulation, which involves checking out the consistency of findings generated by different data collection methods; (2) source
triangulation, which involves checking out the consistency of different data sources within the same method: (3) analyst triangulation, which involves using multiple analysts to review findings: and (4) theory/perspective triangulation, which involves using multiple perspectives or theories to interpret the data.

Triangulating data sources within this study involved comparing observations with interviews during data collection and checking the consistency of what the respondents said about their views as it related to self-neglect. As argued by Patton (2002):

"Triangulation of data sources within qualitative methods may not lead to a single totally consistent picture. The point is to study and understand when and why these differences appear. The fact that observational data produce different results than interview data does not mean that either or both kinds of data are invalid (p. 560)."

Theory/perspective triangulation in this study involved examining interviews with participants using the perspectives of compliance, ecological, and symbolic interactionism theories to understand how the different assumptions of the theories affected the findings.

Analyst triangulation is the process whereby experts are invited to assess the quality of the analysis (Patton, 2002). The principal investigator of this study, my academic advisor, provided ongoing expert review or peer debriefing. Peer debriefing is a method of ensuring the credibility of a study, and it is defined as “a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain implicit in the
inquirers mind” (Lincoln and Guba, 1985, p. 308). In this process, the debriefer(s) sort of plays the role of the “devil’s advocate” and the researcher’s “biases are probed, meanings explored, and basis for interpretations clarified” (Lincoln and Guba, 1985, p. 308). In this study, the goal was to help recognize biases, explore meanings, and clarify interpretations. The peer debriefer served three main important functions, namely, moral support, challenging biases and interpretations, and maintaining the objectivity of the methodological design (Lincoln and Guba, 1985).

3.7.2 Member check

Another important technique to ensuring the credibility of a study is member checking. In the words of Lincoln and Guba (1985),

The member check, whereby data, analytic categories, interpretations, and conclusions are tested with members of those stake holding groups from whom the data were originally collected, is the most crucial technique for establishing credibility (p. 314).

Member checking provides participants the opportunity to listen to audio taped information or to read the notes taken during the interview. Member checking serve multiple purposes, chief among them, the opportunity to add information not previously provided or recalled, to correct errors that may have been previously provided, to challenge wrong interpretations, and to reaffirm the accuracy of previous information (Lincoln and Guba, 1985).

In this study, member checks, also described by Patton (2002) as review by inquiry participants, were conducted. The stakeholders from whom the information was
collected were the older persons who were identified as self-neglectful based on the APS definition. In my telephone conversations with several of the participants before the data were collected and even on the day of interview, as well as before and after the audio tape was turned on and off, participants reiterated the same issues, which also enhanced the credibility of the study. Although three participants could not be located at the time member checks were being conducted and were unavailable for comment about the analysis, the researcher went back to the remaining participants and provided them with copies of transcripts of the findings and an analysis of the data. Participants were asked to confirm the description in the transcripts and to react to the analysis. Some participants preferred the researcher read the transcripts to them. The researcher read the transcripts to the subjects, and they commented on the findings. Other participants asked that taped interviews be replayed to them since their eyesight was not good enough to read interview transcripts. Data transcripts were then read to them for their comments.

3.8 Issues of validity

3.8.1 Transferability

Establishing transferability is a critical goal of all research. The establishment of transferability in qualitative research is parallel to establishing external validity by a conventionalist: “While the conventionalist is concerned with transferability by or in the form of statistical confidence limits, the naturalist can only set out working hypotheses together with a description of the time and context in which they were found to hold .... Thick description is necessary to enable someone interested in making a transfer to reach
a conclusion about whether transfer can be contemplated as a possibility” (Lincoln and Guba, 1985, p. 316). Denzin (1989) defines “thick description” as follows:

A thick description does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of relationships that join persons to one another. Thick description evokes emotionality and self-feelings. It inserts history into experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions, and meanings of interacting individuals are heard (p, 83).

In this study, I provided thick descriptions of older adults’ voices.

3.8.2 Dependability

Dependability in qualitative research is parallel to the conventional criterion of reliability, in that it is concerned with the stability of the data over time. According to Lincoln and Guba (1985), “there can be no validity without reliability and subsequently no credibility without dependability” (p. 316). Dependability can be achieved by overlapping the data gathering methods and leaving the audit trail. The audit trail includes the transcribed notes, the coded transcripts, the data analysis method, and the self-reflexive journal.

In this study, dependability was achieved by reviewing transcribed notes of two participants by the study’s chair and by validating the findings with previous studies to ensure the descriptions were those of the participants and were consistent with the themes.
3.8.3 Confirmability

The confirmability of a research study is the degree to which the information and its accompanying interpretations are embedded in the experience under study rather than that of the researcher’s own creations (Lincoln and Guba, 1985). “Like objectivity, confirmability is concerned with assuring that data, interpretations, and outcomes of inquiries are rooted in the contexts and persons apart from the evaluator and not simply figments of the evaluator’s imagination” (Lincoln and Guba, 1989, p. 242).

In this study the requirement for confirmability was achieved by using three techniques: a confirmability audit, triangulation, and the maintenance of a reflexive journal, which Lincoln and Guba (1985) recommend.

In qualitative research, self-reflexive journaling is a means of ensuring confirmability. Maintaining a reflexive journal is a technique that helps not only in establishing confirmability, but also enhances credibility, transferability, and dependability. According to Lincoln and Guba (1985), a reflexive journaling is “a kind of diary in which the investigator on a daily basis, or as needed, records a variety of information about self and method” (p. 327). Information such as the daily activity, logistics, personal feelings and values, interests, insights and reactions, and methodological decisions should be maintained in the reflexive journal (Lincoln and Guba, 1985).

During the course of the study, I kept a reflexive journal in which I recorded my reactions to things seen and heard, thoughts and feeling about the study, and
methodological decisions. In the section below, I report verbatim from my reflexive journal my own personal feelings and reaction to a participant’s situation. This participant had agreed to interview for the study, and she had asked that I come for the interview the following day. Although I was happy about the prospect of this interview, I wondered what it would feel like being in there, in her house for an in-depth interview. On a previous visit I was in there with her and her pets for about five minutes, and then talked an additional several minutes in the front porch. But this time I knew it would be different because the interview was expected to last longer than the previous time spent in her house. While in my car, I jotted down my reaction:

There are pets-unclean in the house. They come jumping at me. They are friendly. Client also presents as nice. Now I’m thinking of the smell. I see flies, creatures creeping on the floor, furniture, clothes. The smell. It was hard to bear for five minutes. I wonder what it will feel like for twenty minutes, one hour or longer. Will I be able to bear? Where else can I arrange to interview her? She lives in that house that smells so horrible. Does she smell what I smell? See what I see? At least she is willing to talk to me. She will contribute to my study, knowledge.

Also, I recorded a lesson learned and comment heard from an APS case manager that I believe is critical when working with seniors identified as self-neglectful. She stated:

We can’t force seniors to take their medications. We can find out why they are not taking it. We can’t make them eat. We can find out if they have money to buy food. Are they capable of grocery shopping? Preparing meals? Can refer to Meals-on-Wheels. Self-determination over safety (M. Micheals, personal communication, October, 2006).
One reason I used qualitative methods for this study was to obtain information that uncovered people’s “lived experiences.” These methods were ideal “for locating the meanings people place on the events, processes, and structure of their lives” (Van Manen, 1977, p. 210). In utilizing qualitative methodology and with informed consent of the participants, I was able to answer the four questions, restated below, that this study set out to answer:

1. What were the lived experiences of the older persons identified as self-neglectful?
2. What were the salient issues in the lives of those older persons identified as self-neglectful?
3. How did these older persons experience self-neglect?
4. And what were the meanings of those experiences to the study participants?

The results from the interviews, based on these four questions and the analysis strategies described in this chapter are presented in the next chapter, chapter four.
This chapter presents the results from a cross-case analysis of the data gathered from the 12 participants, and is divided into three sections. In order to provide the reader with a clearer understanding of the experience encountered, two case vignettes from the data are provided in the first section. The second section describes the characteristics of the participants. The third section presents the analysis for the research questions and the themes that emerged from the analysis. The names are changed to protect the identity of the participants.

4.1 Case Vignettes

4.1.1 Ms. Knight

Ms. Knight was a 79-year-old divorced woman who lived alone in her apartment with her five cats. Ms. Knight had a four-year college education, and she worked and lived with her mother after college and helped her mom buy their home. She was married for thirty years, had two children and two grandchildren. She said during their marriage her husband blocked her attempts to get jobs as a way of making her become helpless and financially dependent, and that after their marriage he did not want to give her alimony.
However, as part of their divorce settlement, she said the ex-husband provided financial assistance; otherwise, she said she would have to go on section 8 housing because her income was very minimal. She had multiple health problems including, but not limited to, high blood pressure and vision problems. She had had multiple falls outside of her home and had previously been a resident at a nursing home for rehabilitation following a fall in which she sustained fractures. Her children and grandchildren lived in the same city and she said they saw her often.

Ms. Knight had a piano in her living room, and she had some physical limitations, but she said she managed to use public transportation to visit and play piano for her friends at the nursing home. She verbalized a sense of vulnerability and believed women should have men to protect them and that marriage was a central part of human existence.

She said she was engaged and looking forward to getting married soon.

Ms. Knight says that her husband cheated on her during their marriage and that was the basis of her divorce from him. They continued to have limited contact because he was the father of her only children and grandfather of her only grandchildren.

She also was religious, and she loved animals that she felt provided her meaning because she enjoyed caring for her pets as well as people who were unable to care for themselves. She said that previously she had 12 cats but her children had taken some of the cats, so she had only five left at the time of the interview.

She indicated that she was on several medications. Ms. Knight was neatly dressed in black pants and a purple long-sleeve blouse. However, she was sitting on a couch in the middle of an apartment that she described as “dirty and cluttered up.” She
was drinking coffee from a white coffee cup that looked as dark as if it had not been washed in a very long time. There were litter boxes in the living room, pet food was strewn all over the living room area, and the apartment had a funny odor to it.

4.1.2 Ms. Clay

Ms. Clay was an 82-year-old widow who lived in an apartment with several members of her family including her grandchildren. Ms. Clay had lost a daughter several years previously, and she had promised to care for her grandson when his mother passed away.

Ms. Clay had an eighth-grade education. She wanted to become a nurse, but she did not have the money to go to school. After she got married and started a family, she forgot about going to school. Ms. Clay suffered from severe arthritis, which made it difficult for her to complete some basic activities of daily living in addition to combing her hair. She described her hair as matted and wanted a hair cut but could not afford it. She was on energy assistance, but it did not help her much. She said that once in a while they would get into a “tight spot” where they didn’t think they would be able to pay the bill, but they usually managed. Ms. Clay described the temperature in the apartment during the interview as cold, which helped her save money. Otherwise, the bill would get high, and she was unable to pay even with the energy assistance program. She was ashamed to ask for help because it made her feel helpless.

The living room was sparsely furnished but relatively clean. In the living room there were family photos of her, her late husband, and her children when they were young. Her personal appearance looked unkempt; she had on a pajama bottom and layers
of what appeared to be dirty clothing. She had on a bedroom slipper that also looked dirty. There were dirty clothes by the side of the bed in her bedroom. The rug on the floor of her bedroom looked dirty. She explained her grandson had asked to clean the rug including the other rug in the living room, but she was figuring out a way to get the cleaning supply. Physically there were family members present, but this does not “insulate” Ms. Clay from self-neglect. She explained that she thought more of her grandson than she did of herself. In her bedroom, she sat on what seemed like an old hospital bed. The consent signing and interview were conducted in her bedroom. She verbalized a strong spiritual faith, read her Bible, and found comfort in prayer.

4.2 Characteristics of participants

The participants in this study ranged in age from 73 to 94-years-old. There were seven participants between the ages of 80 and 88, four participants between 73 and 79, and one participant was 94-years-old. The average age of the participants was 81. There were 12 participants, two male and ten female. Two participants were married, 1 single, 5 widowed, and 4 were divorced. The educational attainment of participants in this study varied. Two participants had at least a four-year college education, three had some college education, three years or less, two had a twelfth grade education, two had an eighth grade education, and one, a fifth grade education. Another participant had a fourth grade education. Eight of the participants lived alone, with five living in apartments and three living in their own homes. Four participants were either
married or lived with others, while two lived in apartments and two lived in their own homes.

Overall, the Adult Protective Services’ participants had higher incomes than the participants in home health care. The incomes among Adult Protective Services’ participants ranged from $569 to $2,495 monthly, and their average was about $1,516.00. However, the living conditions of the Adult Protective Services participants generally were not reflective of their incomes. The monthly incomes of the participants in home health ranged from $523 to $1,666.00, and their average monthly income was $1,050.38.

The 12 elderly individuals who participated in this study, both from Adult Protective Services and home health care, had multiple medical and health problems. The problems included, but were not limited to, the following conditions: arthritis, lower back, leg, and foot problems, high blood pressure, gout, diabetes, chronic headaches, vision and hearing problems, and complaints of weakness. Most participants in home health care had hearing impairments, and over half had limited mobility.

The data analysis for this study identified 10 common themes that emerged from the interviews of the 12 participants both from Adult Protective Services and home health care. In the next section, I describe the themes that emerged from the data and use quotations, and, in some instances, excerpts from the interview transcripts, to support these themes.
4.3 Emerging themes

4.3.1 Experience of living with a medical/health condition

Chronic medical and/or health condition and feelings of physical weakness emerged as a major theme in this study. Participants also described the experience of falling, which will be discussed under this same theme. For example, Ms. Clay described the experience of living with arthritis:

… she (referring to her physician) tells me not to try to clean the house and stuff all by myself cause she said I know your arthritis is a hinder to you which is cause sometimes I cannot lift my arms up in the air and I have a hard time combing my hair. I have a hard time using the broom or a mop. It’s truly a hinder sometimes when you can’t do it then you get angry at yourself because you can’t do it. That’s the way I feel, you know. Like I said if it wasn’t for my arthritis I will be in pretty good health, but this arthritis, I don’t know....

Ms. Gardner shared her experience of problems with her feet:

My feet. I’ve had very bad feet. I’ve had them for thirty years… it’s at the foot doctor every other week. Uhm, I have them operated on but they say my bones shift so therefore it doesn’t do any good to have any more surgery but they’re very sore all the time. Yeah, you know.

Ms. Summer shared she had both of her hips replaced and then recently had a pace maker put in:

…I got hip replacements in both hips. I got steel in there. Now these days they put, they use plastic and you can still move your legs and all this way I can move my legs… It steel in it, you know, in my hips, both hips. And then lately I had the pace maker put in and that slowed me down some…
Ms. Roebuck previously had eye surgery, and she mentioned her concern about her eye:

I had surgery on my eye. I had what they told me was that the retina of my … eye had separated from its spot that it was supposed to be in so they’re trying to reconnect the retina to uh make it better, you know, so I wouldn’t go blind in that eye.

Ms. Peoples had a lower back problem for which she took Tylenol:

It’s the lower back, it’s the lower back, what else? When I sit up I can not stay sitting up which I can not do. I slide down. I slide down but I take my Tylenol that sort of thing. Tylenol is good.

Ms. Peoples shared that the lower back pain is awful but that people have no idea “how painful” it can get:

how painful it can be. How painful it can be. It’s tolerance. I guess you have to tolerate the pain. What else can you do? I don’t know what else to do. I don’t know…

Ms. Waters talked about the chronic headaches she had been having for years and described what she believed caused the headaches:

…I’ve had headaches, honey, for years and years, that’s nothing to be alarmed about now because I have had headaches even when I was still working at the hospital, I was having headaches. I have had them for, oh, I couldn’t tell you how long, and I will tell you what brought it on. It’s been, oh, this was still way back when I was still married to my first husband. We was going down the highway and we had a wreck. We had a wreck and the car went off the road. What caused it hit my head so hard it went off of the road down into the ditch and then it jumped back up again out of the road down so it bounced three times, going down, going up and over. But that’s been
about, oh, well that was when I was still married to my first husband, I will put it this way. It’s been any way, somewhere in the thirties or the years back when it happens. But ever since … I got banged and slammed around inside of that car when it went off the road and up down the ditch and up, I’ve been having headaches ever since.

Aside from the description of medical and health problems, some participants also mentioned physical weakness. For example, in addition to chronic headaches, Ms. Waters described her feelings of physical weakness:

…I haven’t been feeling very good for the last few years. For one thing, I don’t know what, I’m weak, I mean my body is just weak. You ever try to pick something up and you feel it kinda sliding down out of your hands? I’m weak, that’s what the problem is right now. I’m just weak and every once in a while I do have headaches too, but other than that, there’s nothing wrong with me.

When Mr. Movva commented on his experience with arthritis, he also mentioned how his hands sometimes became so tired and weak that things would drop out of his hands. He described it this way:

…then my hand be tired and weak and everything drop. Everything I take in my hand, I get in my hand, it fell out of my hand. I can hardly hold a glass of water, you know. I have to hold it with both of my hands.

Ms. Summer said that due to her feelings of weakness, she had not been following up on the recommendation to take walks in the hallway as somebody was supposed to be with her. She said if her homemaker was not there, she did not know whether to walk in the hallway or not. She stated:

… I’m supposed to take a little walk with my walker in the hallway but I don’t. Somebody is supposed to be with me
when I do that but I aren’t being doing that lately cause I’ve been weak and I aren’t been feeling like it. And if I had her to be with, by my side, she (homemaker) take me out in the hallway and walk me but I don’t know whether to do it or not.

Many participants described their health conditions and weakness within the context of falling. An overwhelming majority of the participants had experienced falls, whether it was at home or on the way home from the doctor’s office. Several shared those incidents with me.

Ms. Clay described how she rolled out of her bed and fell while she was asleep:

…I fell down, I fell out, rolled out of my bed in my sleep and I bruised the bone in my leg and it kept hurting, and hurting, and hurting. Finally, I went to the hospital and my doctor …there know it and said this: that I had bruised the bone and tore all the muscles when I rolled out of bed because I hit the floor so hard…

Ms. Lamb was married and lived with her elderly husband. During the interview, she described the fall she had at home that left her with 18 stitches. She also added that she was unable to get herself off the floor, and her husband had to summon paramedics to help her get off the floor and take her to the hospital.

…I was on my way to the bathroom and that walker caught on something, it went down, …it went down and I went down with it and hit my head on top of …once I got here, hit my knees, one person with two bad knees, this one here belongs to …hospital, this is mine but they won’t bend…I couldn’t get myself off the floor. Then I called to him (husband), this was about 5:15 in the morning. He was in bed and I said to him, ‘call 911’…then he called and they
asked me, they were so nice they asked me, “are you hurt?”
I said “I think so,” and so they came right out you know
and they said, “you got a black eye” and then the other
fellow that was looking say, “you got a black eye,” so they
took me upstairs. Again about the black eye and they put
some stitches in my eye; you know, I had 18 stitches.

Mr. Movva talked about the fall he had the weekend before the interview:

If I don’t have nobody to pick me up, I will be on the floor.
I fell on Saturday, I got dizzy and my knees get weak and
fall out. I could be on the floor for a whole night…till the
next day Sunday until he (son) come back…

When Ms. Summer fell in her apartment she described not only the fall, but her
inability to get off the floor on her own. During the interview she described the
experience of falling and not being able to get up on her own and how she had been able
to get a device that would assist her in getting help if she were to fall in her apartment
again:

…I fall like … I fell one time on the floor and every time I
tried to get up my feet will slip. My feet will slip, I
couldn’t get hold, so I was on the floor so I got to caught
this (pointing to the telephone cord) and jus luck that I, it
didn’t pull out and I pulled the phone over there and I
called the guard down stairs and he, they come up here and
helped get me off the floor. And every time I tried, they
did try to stand me up, my feet will slip out, slip out and
then finally I got up…so I felt pretty good afterward so
then that’s why I got this lifeline and this lifeline costing
me um $45.00 a month for this thing here. And if I fall on
the floor all I have to do is mention and I get help so it’s
worth me having especially if you sick and live by
yourself…

Another participant, Ms. Knight described how she fell on her way home from the
doctor’s office. Here was how Ms. Knight described her experience:
…When I broke my hand last June that was another slight fall on my way home from the doctor. One day I had packages and on the corner of … and … Street I was coming from the doctor’s office and I’m trying to balance these packages and I lost my balance and fell down and broke my hand so they put a splint on it for me and in three weeks it was healed up.

4.3.2 Perception of health and medical care seeking behavior

The perception of health and medical care seeking behavior emerged as a major theme in this study, however, participants’ experiences varied. Because it is important to understand how the present cohort of older adults perceives their health as well as when they seek medical attention, I provided excerpts from the transcript for two participants.

Ms. Gardner believed it was unnecessary to see the doctor every year because Medicare did not cover these costs. In her married life, she never went to see doctors unless she was pregnant. She stated:

…It’s not necessary to see a doctor every year. Medicare doesn’t pay for all that stuff any how so why bother if you don’t have to? You know what I mean? What the heck? Why do something that you don’t have to do? That never bothered me. Never bothers me, never bother me. Never went to doctors…. I believe, live my married life that way, never went to see doctors unless I was pregnant and that was it. No, so. I can’t say it any clearer than that. No, I mean why waste your money on something like the doctors tell you, if it’s not broken, why try to have something fixed? And thank God I’m not broken yet, so.

Ms. Waters had told me that she had not seen a doctor for five years or longer, so I asked her what she would say if somebody mentioned she had not seen a doctor in many years. Ms. Waters had this to say:
I haven’t been sick. Why go to the doctor if you’re not sick? Why agitate it? I mean, really, if you’re not sick I don’t see a sense in going. Do you? Or do you think it be just for a check up? …what if you’re not sick and don’t need to go to the doctor and you don’t even have the money to go even if you were sick? Then what? What would you do? What would you do? …. sometimes, sometimes things come up that you have to pay for something right now and you might have to let other things go for just a little while. Sometimes some things come up urgent. Haven’t you ever been in that situation?

During the interview I had the opportunity to ask Ms. Lane about her health concerns and when she sought medical attention. She said that unless the symptoms were “real bad,” she didn’t see her doctor and that she used old medications if she had some.

Ms. Lane shared that her doctor scolded her for going to see him “too late.” I have provided excerpts of the interview transcript:

(Ms. Lane) When he scolds you, he’s scolding you. He’s a good doctor.
(Researcher) So he scolds you for not going to see him sooner?
(Ms. Lane) That’s right. I always wait till the last minute.
(Researcher) During the time that you’re waiting when you have a symptom what do you do? Between the time you feel the symptom and the time that you go, in between what do you do?
(Ms. Lane) Sit down and wait till he examines me.
(Researcher) No, I mean when at home what do you do?
(Ms. Lane) I just sit down and turn on the fan and breathe fresh air from the fan so I can get more air in my lung.
(Researcher) So you really don’t go see the doctor when you have symptoms?
(Ms. Lane) Not if it comes down bad. If it comes down bad and I know when it’s gonna come down bad I’m on my way. When I do then I’m on my way, I just take my time walking up there and when I get there I got time to sit down and rest and then when I see him I’ll be smiling ear to ear. He say, “there you go again, what is it?” I say, well, you
know I can’t lie to you doc and I tell him what happening and he checks me out and then he gives me some medication. He ask me if I still got some of that whatever medicine he gave me. I say, yeah. And if I don’t tell him no, he be sure I get plenty of them then he tell me what can’t, what am not I supposed to do. He say, “you know better not to run, not to overexert yourself.” I say I’m just taking it easy and that’s it.

(Researcher) But you mentioned if the symptoms don’t come on hard you don’t go?

(Ms. Lane) No, I don’t go cause I know how to take care of that but when it get hard, real hard, I just put on my coat and go.

(Researcher) How do you take care of the symptoms?

(Ms. Lane) If I still get some more left over medication I use it. If I don’t, I just sit quiet in the house and I be very quiet. If I lock my dog and out there in the back so she don’t come and play with me and I lock her up in the back there then I sit up here and just breath until I come down normal again and that’s it.

(Researcher) So you’re saying that a lot of the time when you feel sick you’re going to treat yourself, do you know how to treat yourself?

(Ms. Lane) Yes, he told me what to do. He say “don’t try to walk out of the house with that thing on you already cause you won’t get that far away you be puffing and huffing and having a hell of time walking,” cause he know I don’t have my car now. He also know that I have to walk up there and something I didn’t lie to him.

(Researcher) What is it that you have? What medical condition is it that you have with your lungs?

(Ms. Lane) Bronchitis, asthma and they think I get uhm some kind of lung trouble but they haven’t told me what it is yet so I just take one day at a time.

(Researcher) So you have bronchitis, asthma and they think you have lung trouble but they haven’t told you yet?

(Ms. Lane) No, they haven’t found it or whatever. They haven’t told me yet so I just take it like that. I don’t do no strenuous work like I used to.

Ms. Summer shared that she was surprised she had pneumonia and then went on to describe her beliefs and history of seeking medical care. At first, she said she was
unsure whether to believe the doctor when he said she had pneumonia. I have provided excerpts of the interview transcript as a way of gaining a deeper understanding of how older adults perceive not only health and illness but when and how they respond to a given medical condition. For example, Ms. Summer, who was African-American, shared her perspective:

(Ms. Summer) … I was just surprised I had the pneumonia… I didn’t know it worked like that. Did you know it worked that way? I thought I had a cold cause I always had the cold maybe once a year or something like that and then I take my own home remedy medicine and it will go away.

(Researcher) What home remedies do you have?

(Ms. Summer) Oh, well, my mother always used to give castor oil, it has a bad taste but now they make it tasty castor oil. Take a dose of castor or take a dose of Tylenol and something like that and … drink hot tea and finally the cold go away. And what this time I was coughing and spitting and wasn’t good and the day care nurse didn’t want me round the other peoples at the day care by me coughing too much and that’s when she say, “I’m gonna send you to the hospital, and send you to the doctor” and she send me over there and that’s what they found and the doctor wanted me to jus rest, rest…

(Researcher) When you mentioned home remedies, um, so your mother taught you?

(Ms. Summer) Yeah, yeah my mother used to give me when I was little and all, and now I did that all the time at home and I have a lot of my friends, we all, we do the same thing, take care of our own medicine and then we get better, but this time it was jus something different.

(Researcher) What is it like you take it and what happens, you wait out until? When do you see the doctor?

(Ms. Summer) Most time we didn’t go, jus take your own remedy and until you get better and that was it. You know, very seldom I went to the doctor when I come along in my age. People jus didn’t go to the doctor but nowadays they stay in the doctor’s office. Every day, everything they have to go to the doctor, go to the doctor. So things have jus
changed, everything changing. And we drink tea, hot tea, two or three times a day, take that hot tea, take that castor oil and that castor oil make me so sick that first day. You feel so sick and the next morning you get up your bowels move, you have a good move and you start to feel better and you okay. We did that once a year but it’s all together different, uhum. All together different.

(Researcher) So you’ve got a different experience about seeing doctors, is that what you saying?

(Ms. Summer) Yeah, yeah, you go to the doctor now a day they give you something different. Like when I come along, was coming along we didn’t know what antibiotics is nothing like that, we didn’t know. But now they give you that, and they give me the pain pills and they told me to take them but not to take it if you don’t have no pain don’t take it and so I do like the doctor say, so. Um. And they gave me a letter to take to my doctor when I go back I got a letter to give the doctor and they was telling him about what they had cause they give me so many different tests. Oh, they give me lot of tests…

(Researcher) So even in old age there have been times when you’ve had a health problem but you didn’t go to the doctor?

(Ms. Summer) Right, you’re right, we didn’t go to the doctor then and I know when I was down south when you fall down and hurt your leg and your knee be bleeding and you know what they did? They put red mud on it till it feel better with that red … and now people, “oh, no don’t, don’t do that, don’t get no germs in it, put your gloves on, do this, do this.” We didn’t do nothing and got along fine and didn’t go to the doctor. But things have changed, things have changed, things have changed.

Although only one participant in the study had pets that were uncared for, I include this information here. Ms. Waters talked fondly about her pets and described them as her protectors, companions, and family. However, the pets were scratching and
appeared sick. When I asked her if she would see why people might say that the pets had been suffering because they had not been taken to the veterinarian, she stated:

But they haven’t been sick. The dogs have not been sick. They have been eating good.

Ms. Waters, however, retracted her initial statement a few minutes later and then restated the reason she hadn’t taken the pets to the veterinarian:

…I didn’t have a penny to my name to take it to pay the bill. I didn’t have it. I did not even have the money in the bank. No money was, no money was even in the bank that I could have got to take that little thing to the Vet, and he won’t, you can’t go in there and charge it. At least he never did let me you know, go ahead and take care of it later. I don’t think he does that …

4.3.3 Sense of mistrust

Another major theme revolved around the mistrust of health care professionals. This included skepticism about prescribed medications, recommended medical regimen, and a related subtheme focused on relationships with friends and family. Finally, many participants felt vulnerable and tried to protect themselves and maintain control in their lives. This theme is divided into three different areas: (1) participants’ mistrust of healthcare professionals and how this contributed to lack of adherence to recommended medical treatment and/or therapy; (2) lack of trust in friends, family or relationships, such as wondering if people were stealing from them or picking on them; and (3) feelings of physical vulnerability.
From the description provided by the participants, various reasons contributed to their lack of faith in health care professionals and the recommended treatment. Some reasons included, but were not limited to, not trusting the judgments of physicians about their diagnosis, misunderstanding adverse side effects from the recommended medications and/or therapy, and perceiving the recommended treatments as unhelpful or as worsening their conditions.

Ms. Summer said she remained unaware of her diagnosis when the doctor told her she had pneumonia. She stated:

…I didn’t know whether to believe when the doctor say that it was pneumonia. I said you got to be kidding, he say, “no, I’m not, you got pneumonia”…

Mr. Movva had arthritis for which he was previously receiving physical and other therapies. He had, however, stopped the therapy because he questioned whether the therapy was helping. This was how he described his situation:

…They come out here whole year taking therapy…therapy don’t do nothing either and the people say, I don’t want to do therapy. I want to do therapy but they ain’t going to help nothing …”well you get therapy, the therapy help you.” I say, “man, therapy aren’t do nothing for me, a whole two years.”
…I had to go to clinic for four, five months, going to the clinic…come pick me up, every week, every week. They come here for four months take me to the clinic; they give me therapy in the clinic. They put hot, hot pain, hot bag in my back and make me get on the bike and do exercise. That exercise aren’t gonna do nothing to the hurt. And when I went to the clinic, really, really when I went to the clinic for the first time, I wasn’t like this… I wasn’t that bad…when I went and make that …get that exercise, that’s when it get worse and worse. See, before I go to the clinic I
was walking good, do everything here. Go therapy, I started going to clinic, I get therapy, get exercise… The arthritis start getting worse and worse and worse. ..

Also, Mr. Movva had a walker and a wheelchair, but he shared he did not like to use these devices.

Mr. Wells relayed that the exercises had not been helpful nor had Tylenol helped his arthritis. He stated:

I had a nurse here to exercise you know but it don’t do nothing. When you reach a certain age, you can’t, there is no limit to cure arthritis, it’s the age. The doctor tell you take Tylenol, Tylenol don’t cure no arthritis. It’s the age; you know what I’m saying? They say take Tylenol. Tylenol not gonna do nothing. It’s the age…

Mr. Wells had multiple health problems, and he told me he was on at least 12 different medications. During the interview Mr. Wells shared his experience of taking multiple medications simultaneously:

…When you take too many pills, you get constipated. When you take a lot of pill, and some pills you take it, let’s say, … it’s good for the sugar but it affects your kidney. It affects different parts of your body, did you know that? That’s what I was told. Like I have one pill I was taking three times a day for the sugar and the specialist at the University… I used to take three pills when I was with …and this specialist you know what he told me? … He said, I don’t even want you to take none of them … you know. He said, you know what that does? Your kidneys go, don’t, won’t function. You see what I mean? They help with your sugar but affect different parts of the body…
Ms. Lamb shared with me how a doctor withheld important medical information from her:

...And there was a woman doctor...she was very nice but she held back on so many information I thought I should have had and she said on the last day she said, I know when you came in you lost a sight in your eye, she told me that...

Ms. Peoples shared she disliked relying on people because she doubted their sincerity:

...I can not participate as far as church, I cannot go. Several members have offered to come and take me. I don’t like to rely on people. I wish I could but I don’t know how to do it...how sincere are we? Do we really mean I will come and pick up everyday, today?...

During the interview, Ms. Peoples described a broken promise where someone had said he would bring her cokes but never followed through:

...There was a gentleman that’s been here three days ago he told me he was going to come here and get me some cokes. He hasn’t come here. He called me and he said he was broke. I said you are? That’s good, so am I.

Two participants mentioned that people stole from them.

Ms. Knight stated:

...the other thing there that kind of gets me is gone on in my whole life, stealing. People used to steal my clothes when I was a child, be in the drawer one day the next day it was gone. I had a cousin, my mother’s cousin she’ll come in our house when the door was unlocked and steal things...
Ms. Lane had forgotten to pay the utility bill, and then the heat was shut off at the time I met and interviewed her for the study. Ms. Lane relayed she forgot to pay this and lost the bill. Ms. Lane described that she usually put the bills on the table when they arrived in the mail, but because her house had been robbed recently, she lost the bill:

...See, my house was robbed. Everything was on all over the floor, everything. The drawers off of my dresser that was pulled out, everything was pulled out. I don’t know what they looking for and was scattered all over the floor. I always put my bills one place and I just leave everything like it is when I come in I look at it and I get my pay check and right then and there I get to stop at the post office or some place to get my money order. I sit here and I write them all out, put a stamp on it and set it right there and the next morning I put it out. But there are times when I come in the house I can tell somebody is been in my house because everything is moved around and then when I go look around for things sometimes it’s on the floor and sometimes it’s not here and sometimes it’s thrown up here, thrown over there. That’s the only thing I can tell, I don’t know what’s going on...

Two Adult Protective Services participants referred to their deceased and ex-husband’s unfaithfulness during their marriages. During the interview, Ms. Knight reflected on how her husband’s cheating affected their marriage and the decision she made to divorce him:

...we were happily married for thirty years but when we came back from...and he had some heart attacks and we get him through that alright. And then I found out he was playing around on me and he was unfaithful and he deserted me. So, I just decided to divorce him which turned out to be a very bad decision because I was left penniless. He didn’t want to give me alimony. And all through our marriage he blocked my attempts to get jobs so
I had had money on my own, uhm.Apparently he’s one of these husbands who want to keep the wife helpless and dependent for money, apparently.

Ms. Knight further described why she was still bitter towards her ex-husband:

…I had been bitter at him. He was so mean to me after the divorce…I’m still bitter at him because I was a good wife to him and I never was unfaithful. So the minute we got divorced, all his people: his mother, his brother, two of his sisters went over …and said I was unfaithful and I wasn’t. He was the one who was unfaithful during the marriage.

During the interview, Ms. Waters shared with me that for a while her husband was great and treated her well, but about one year or so before he passed away he started running around with some of the young ladies in the neighborhood. This was how Ms. Waters described her experience:

… probably a year or so before he passed away but there was a lot of tramps in that area too, in the… There was a lot of should I say, whores? … Yeah, but he was getting pretty sick, you know. When he started that I think maybe about three months he got the running around with some of the neighborhood young ladies. Young, good looking ladies there in that area and he sort of fell for some, for some of them and I think they jus pretended to fall for him. I think all they wanted off of him was his money.

… for a while he was jus great I mean he was real good to me, and he was jus great you know for a long time and then there was real pretty girls that lived in that area down in the … and some have been married and divorced and some was married and still running around and that’s jus the way it went…

In addition to her second husband’s cheating on her during their marriage, Ms. Waters said she had a problem with the mother of her first husband. Ms. Waters shared
that she was “never good enough” in the eyes of her mother-in-law. This was how she described her experience with her mother-in-law:

…she, just everything had to be so, so. And if she didn’t want to tell anybody something, she wouldn’t tell them, or she’ll tell somebody else get up and go outside until I talk to so and so and to me that was rude. And just things like that and she never really liked me because uhum I, nothing was good enough for her son. Nothing was never good enough for him in her eyes and she held him to high heaven. And me, I was nothing but a piece of dirt...

Two Adult Protective Services participants felt that people were either picking on them, or trying to boss them around or get into their business. Ms. Waters described it this way:

…they’re trying to dig deep down in, you know, picking at me. Picking at me. Picking at me…where did you go yesterday? What you gonna do tomorrow? And what have you got in the house and this and that, and that, you know. I call that nit picking…

In addition to feeling picked on, Ms. Waters said that several people had been trying to boss her around by telling her what to do:

Well, some of the people, there’s been several people that’s been trying to boss me around and tell me what to do and…that makes me angry very, very quick. And I think that I’ve got enough sense to take care of my business and I think I’ve got sense enough to do the things that needs to be done… But I said there are some things that I don’t consider as anybody’s business …that’s what I told them.

Ms. Lane said that everybody was trying to get into her business:

I’ve been through a hell of a lot with family and everybody else. Everybody trying to get in my business, want to know this or want to know that…then I had uhm in-law troubles
and I tell them, look? Just leave me alone, I ain’t got nothing to do with it.

Two Adult Protective Services participants described feeling vulnerable. Ms. Knight noted that she had told her son that living alone made her feel like somebody had written a large target on her back and when I asked her what that target said, she replied:

This is a woman living all alone, nobody to protect her, victimize her. Victimize her, victimize her till your heart’s content. Kill her if you want to.

Ms. Waters told me that she rarely used the bedroom upstairs and slept downstairs on the couch in the living room because:

Honey, I sleep on that couch downstairs for a reason. I will not sleep upstairs if I had a golden bed. I will not sleep upstairs because somebody could come upstairs and knock me in the head and I couldn’t even get out.

Three participants had pets, and although all talked fondly about their pets, two participants mentioned their pets provided them with companionship, and most importantly, a sense of protection. I included participants’ descriptions of and feelings about their pets in this category because during the interviews and data analysis, participants’ sense of vulnerability and their attempts to protect themselves were in some ways linked with pet ownership.

Ms. Lane described not only her feelings of companionship she experienced with her dog, but also the sense of protection she gained from her dog around the house:
I feel good. At least I have somebody protecting me because she growls at things that I don’t hear and she be hearing people walking on the street that’s when I hear it. There’re times she be lying on my legs watching TV with me and then all of a sudden she jumped up and she turns her head towards the door. I say, I didn’t hear nothing, what you hear? And she looks at me and then she gets off my leg and go to the door and push the door open and look because many times when she done that there was somebody standing in the door…. And I get up and I say, oh, I say wait a minute. I say go, move, move, this is so and so, come on, move. A friend, you know that I didn’t hear knocking but I just took a chance and go to the door to see what the dog barking about. There are times I don’t see anybody. I know people think I’m crazy but I’m not crazy, I know what’s going on. I try to keep a tab on my own house.

Ms. Waters also described feelings of protection from having the dog:

… especially with me been alone, and you know what? Another thing about them dogs, they let me know on the double when anybody is fooling around. That is the one thing why I keep my dogs because they let me know if anybody is messing around the house, they let me know…

4.3.4 Difficulty with activities of daily living/instrumental activities of daily living

Many participants’ struggled to complete activities of daily living and instrumental activities of daily living. First, I discuss participants’ perceptions regarding difficulties they have had completing their daily living tasks, such as ambulation, personal care, and housekeeping. In the second section I focus on instrumental activities of daily living, such as financial management.

Participants both in Adult Protective Services and home health care described
their experience of feeling weak and too tired to complete activities of daily living. Some participants referred to daily living tasks they used to do when they were younger but now found difficult to perform or complete due to their increased age and physical limitations. Others had difficulty with ambulation and only left the house to see their doctor. Ms. Clay stated:

…but I don’t leave the house except to go to the doctor’s and that’s just about it. And so I don’t, um go shopping like I used to, you know. It’s hard on me getting down these steps any way…

Ms. Peoples lived on the second floor of her building that had no elevator and, like Ms. Clay, she went out only when she needed to see her doctor. I asked her to describe this:

I call an ambulance service. I get ambulance service for a ride to leave this place. I have to have an ambulance service because I can never; I don’t think I can walk on the steps. I don’t know but I don’t think…I don’t walk the steps…I don’t think I can do that but the ambulance service is nice. It’s costly but what isn’t costly…

Ms. Waters described her experience of feeling weak at her age and that sometimes she felt too tired to do housework. She described it this way:

Well, sometimes I let it go like that because I just don’t feel like doing it. There’s times when I jus don’t feel good, I don’t feel like doing things like lifting stuff around. Being seventy-three years old you keep getting weak, you don’t get strong, you get weaker. I’ve tried to lift things up and I couldn’t do it or get it picked up and dropped it. I do the best I can about lifting things, you know. There’s some things I can do and some things I can’t.

About washing dishes Ms. Knight stated:
…Dishes I get around to them eventually but I’m only one person it seems I got dishes for three or four people. It’s part of the last thing I get to because I’m too tired at night.

Ms. Lamb described her difficulties completing chores:

It’s depressing, it’s depressing, because I can’t. I want to do and I can’t, that’s the thing. I sit here and see the dirt and the mess. I would like to jump up and do it but I can’t. . . .The sores on my feet are stopping me. The sores on my feet are stopping me…

Ms. Clay described the experience of what she could do when she was younger but didn’t do the same any more:

…When I was younger I will sit down on the floor and scrub my rugs. I can’t do that no more because my arms get too tired and I, my body starts aching all over. I get angry at myself and I have to stop what I’m doing so I don’t even try to scrub the rugs no more myself…

Ms. Clay shared that the night before the interview she took a shower and had this to say:

…just like last night I took a shower. I have no rails for the side of my bathtub. I have to hold on to the sink cause I’m afraid of falling…I held on to the sink to get myself out of the tub. I can’t get down in the tub; my arthritis won’t let me bend my legs far enough to get down….
Ms. Clay also described having difficulty with combing her hair and how her legs would give way when she tried to do something she was not supposed to do. She stated:

…I have trouble combing my hair, getting my arms up in the air, you know. Sometimes I have to take one hand that push my arm up like this to get to comb (laughter) my hair…I got awful bad up here, my shoulders here…and um, my back and my legs give way on me if I try to do something I know that I’m not supposed to do…

Ms. Roebuck described some activities of daily living that she was unable to perform:

The things that are limited when you get older is, you can’t put yourself in a position where you can’t get out of it so you don’t put your self in that position. Like I will not go down on my knees on the floor unless I know I can get up by holding on to something because I found that if I get down on the floor to scrub it with my knees like I used to, I will not be able to get off the floor. So you don’t get down on the floor to scrub the floor. You don’t get in the tub if you can’t get out of it without help. So you don’t do those things if you know you can’t do it and that’s it… So you got to be smart enough not to do it…

Some participants stated that their previous lifestyles were different from the situations they found themselves in now. Ms. Flowers said she enjoyed straightening up her house, but that she had become lazy and that things had gotten a little disorganized,
but she was going to straighten things out. Ms. Flowers described how she felt about the condition of her house at the time of the interview:

… I enjoy, I enjoy straightening up my house any way because I know this is terrible for you to see like this, you know what I mean? But I guess in everybody’s house or sometime or another things get a little disorganized until they straighten it out, you know…I just get lazy and didn’t straighten it out…I know I live by myself … might be a day that, I am a human being like everybody else you know, sometimes feel like, they feel like doing nothing so they don’t do anything, you know. And I know that I live alone and I know that I have to keep my place sanitary and I have to keep my place in order. If it takes me two or three days to do that then I have to do it so there’s no problem because I’m not gonna live in no filth…

During the interview Ms. Roebuck described her house cleaning and other chores and how her mother had completed those activities based on a set schedule:

… usually when I was growing up too we lived in apartment building and my mother on her day because there were other people that had their day to do laundry and other days that other people did laundry, so when you down to doing your laundry you had from the morning till the afternoon to do your laundry. Somebody else had the afternoon to or later in the day to do their laundry, but mostly everybody wanted the morning cause then you hang your clothes out, you bring them in and then the next day you do your ironing. Okay, then on Saturday, um you will do your shopping for your grocery. On Sunday, you will do all your cooking and baking you know, for your family. But all during the week you would have everyday chores of dusting, vacuuming, and cleaning, doing dishes, cooking um, you know you did your dishes and what not, so all of these things were kind of a schedule. One day for laundry, um another day for ironing, another day for uhum, if you were a baker and you bake your foods and what not or you made out a list for your uhmm chores for uhmm the house cleaning you wanna do. You gonna do your windows
today, and um you gonna do your kitchen floor, you gonna scrub that, you gonna clean out your pantry or clean out your refrigerator, you don’t do that everyday, but you have a schedule, now I don’t have a schedule for that …

While several participants shared their circumstances at the time of the interview were in part due to age and physical decline, Ms. Peoples described she never did chores when she was younger. She shared this with me:

I can’t wash and iron, I never did that when I was coming along. My mother did all the washing on Monday and ironing on Tuesday. Her mother said to her before she died, she said, I don’t have to die on Monday because you got to wash on Monday. We had to wash on Monday and iron on Tuesday so I can die on other days. Do you know my grandmother died on a Monday? Yeah, she died on a Monday.

Most participants talked about their eating habits and food preferences, in various forms. One participant said she could have Meals on Wheels, but added, “I don’t care for their food.” Another participant asked me if I ever had Meals on Wheels. When I responded that I know about Meals on Wheels but had never eaten anything from them, she said to me, “You haven’t missed anything.” Another participant who suffered from gout had several cans of tomatoes in his apartment. This participant told me he had been trying to eliminate the use of canned tomatoes because of how the acid content affected him. He stated: “I am trying to eliminate the cans of tomatoes you know, for the acid …tomatoes…anything with acid, it builds up the pain you know, …it affects the gout….

Some participants said they were eating once a day because they felt no hunger. One participant said she could go all day until evening before feeling hungry when she would “open up some real good can soup….or cook potatoes, or some things that’s quick,
quick to get done. Something’s that you put in the microwave oven and cook.” This participant also stated, “Well, for another thing, I missed not having someone to eat with, you know. You get tired of eating by yourself all the time.” One male participant expressed preference for his native dishes. He had previously switched homemakers in order to have a worker who could prepare his native dishes, which he preferred. When given the gift of $10.00 for their participation in the study, about half of the participants told me they planned to use the money to buy food-related items. One participant said she would share the $10.00 with her friend: give her friend $5.00 and then buy food with the remaining amount. Another participant shared she would use the $5.00 to buy food for her cats and then buy Danish pastry for herself with the other $5.00. Another participant would use the $10.00 to buy cleaning supplies.

Multiple factors affected these older persons’ decisions about diet and nutrition. Some lacked an appetite, perhaps because of psychological and/or emotional reasons as in the situation of one participant who had lost a significant amount of weight, which in part she attributed to the change in her appetite, not feeling hungry and not having a good appetite. This participant was facing foreclosure on her home and said this was the first time she had to face such a challenge alone: “not eating and then having this thing on me that’s bogged me down…what happened to me right now. All of this I never had to face anything like this by myself alone.”

Others had denture problems. One was a participant who said she disliked Meals on Wheels. The food she fixed was “with mainly vegetarian and … eggs, lots of cheese, lot of potatoes, lot of cottage cheese and stuff rich in calcium and salads. ..I don’t have
any lower right teeth …I can only eat on one side …I can only chew on the left side…”

When asked how she had had this dental problem, she said that “ever since a dentist
in…broke my dental plate and I didn’t realize it couldn’t be put back in.” The
participant said she had had her last dental cleaning about one year and half prior to the
interview, and added, “I need it cleaned badly then he (dentist) can concentrate on
making … moral for a lower dental plate.”

In addition to problems completing activities of daily living, many participants
also referred to difficulties handling instrumental activities of daily living, such as
finances. For example, Ms. Lane was behind on her mortgage payments and faced
foreclosure on her house. She also had many other unpaid bills. Because Ms. Lane failed
to pay her gas bill, she had no heat in her home when I interviewed her. As documented
elsewhere, Ms. Lane was confused about her finances because in the past, she relied on
her husband to pay the bills. Since his death, she has felt incapable of managing money.

Ms. Waters said she was unsure who was with her the day that she withdrew a
large amount of money from the bank. This was less than a week before the interview.
However, she mentioned a gentleman who she thought was with her on the day she
withdrew this money, but she was unsure. Shortly after the interview and while Ms.
Waters and I were standing in front of her house chatting, a man matching the description
that she had given appeared from the back of the house. Ms. Waters introduced the
gentleman as just a friend who helped and ran errands for her. At one time, she told me
that the bank was taking her money but she didn’t know why or what was going on at the
bank. Ms. Waters appeared physically unkempt; she lacked hygiene; and she neglected to
care for her home or pets. When asked which basic necessities she needed help with, Ms.
Waters mentioned those that were most basic for survival. She stated:

Well, right now I’m in need of food and uhm I don’t need
clothing, I get plenty of that and maybe a little bit of cash,
just a little bit for necessary things, you know like a little
extra food, or something like that, you know. Not a whole
lot, just a little and uhm. Then I’ve got my animals here, I
have to keep them fed, and uhm that just about it, basically
for what I will need... umh There was a rug here about a
year ago and when the city came in here and cleaned
everything up. They took the rug out and they didn’t
replace it or anything you know, and it makes this room
terribly cold coming up through the cracks of the basement
you know and that’s why it’s so cold in here now and uhm
other than that you know… if it just wasn’t cold in here and
if I had some heat in here I would get along great, fantastic.
I wouldn’t have no wishes no wants or no nothing, just
warm, that’s all. That’s all. I need a rug in here to put down
to keep it warm, and umm a little bit of heat and a little bit
of food and money, I’m happy. I don’t want the world
(laughter). I just want a few bites, bites of food you know,
and that’s about it. I mean I don’t, I’m not a person that
wants, and wants, and wants, I’m not like that …

Both Ms. Lane and Waters stated that they were unable to manage their finances
and that handling money was a task they disliked. I asked Ms. Waters what it was like to
have the experience that she was confronted with, such as the situation with the bank, the
checks, and many unpaid bills to which she replied:

…I’m hardly interested in writing out checks. I mean I
know they have to be done. I know the bills have to be
paid and all that and I’m not complaining about that. What
I’m saying is, it’s the check thing that I don’t like to bother
with. You know, like you sit down and so, so, is this, so,
so, is that and don’t make mistake on there now and you
know.
(Researcher) Has it always been like that for you?
(Ms. Waters) No, not at all, not all like that. I have wrote checks out there before, but is just not my, what do you call it? Something that I jus don’t care about do?
(Researcher) At this time?
(Ms. Waters) Yeah, at this, this is something that I jus don’t care for it really. I never was down on writing. It’s something that I guess I took after my mother because she hated to write, too. Yes, she could write, she could write good, but she just, she just didn’t like to do it and I guess I took after her, after her, you know. I don’t like to sit down and have to write, write, and write, and write and write either (laughter). To me it’s kind of gruesome…

Financial management remains a difficult issue for many Adult Protective Services’ clients and one that is difficult to resolve, but obviously needs more attention.

Ms. Waters described the experience of previously having had a case worker come to her home to help with sorting out the bills and making sure they were paid on time.

However, this arrangement was short-lived. Ms. Waters shared her experience with check writing during the time the case worker was helping her in the following way:

…But now I wrote checks there one whole winter but the case worker was there. She was in there sitting on the sofa but you know that was the way it went. I mean, I will talk and she would hold and we get along great. We get along real good but I don’t know it was just sort of lapsed you know and she just didn’t, she stopped coming back cause one of them told me that she had to go back to another state, and of course that took that and just one thing and another you know, but I don’t know what it is about the checks…
4.3.5 Lack of adequate resources/services

Another major theme focused on participants’ inadequate resources and lack of services to help them maintain their support systems and to pay for heat to keep the homes warm, their prescription medications, and home repairs. I first focus on participants’ comments regarding inadequate financial resources, after which I discuss their problems with social supports. Finally, I identify factors, such as widowhood, that have affected these participants’ social networks and interactions.

Although Ms. Clay said she was on the energy assistance program, she claimed that the program hardly helped her. She also wanted a haircut, but she was to pay the $7.00 it would cost to have this done. She explained it this way:

The heat bill. It was 224.00 dollars, I’m supposed to be on the budget, I don’t know the way that keep on getting higher. The heat bills I don’t know whether I am … I’m supposed to be uhuu on the heat bill budget… …Well, 144.00 dollars don’t help much. That’s my budget, 144, so I don’t know.

… generally like I like to get me a hair cut I can’t afford so I don’t get a hair cut. My daughter once in a while before she took sick, now she cut my hair, but she’s sick herself so I don’t ask her to do it no more. Uhum, she had her hair cut two weeks ago and she told me that it cost her like 7.00 dollars for a hair cut and she say mamma when you’re able, when you feel like it she say I’ll take you up there and have you umm get a hair cut. I said, I tell you, I say, I can’t afford 7.00 dollars. She said she’ll pay for it. I said no, you’ll need it; you have trouble of your own…

Ms. Summer’s also referred to the cost of her medications and other bills:

800 dollars, that’s what I get for a month. I got to pay for my rent, light, phone, everything get to come out of that
800.00 and then for 98.00 dollars a month for medicine, I don’t know how long I’m gonna be able to do it. I don’t have no more income. And so you can see the bills there…

(Researcher) Yeah, I see umm with the printout $93.98 cents.

(Ms. Summer) uhum, that’s right.

(Researcher) So what happened then do you have the medicine or what happened with the prescription? Were you able to pay for it this time?

(Ms. Summer) Yeah, like I said I got the money but I have to let something else go and get the medicine cause the medicine and them more important. I should have that cause I’m supposed to take that thyroid pill everyday and I’m supposed to take the eye drops every day and the nose drop everyday, one. And I jus don’t want to go without the nose drop and …

(Researcher) So in order to get the medicines that you have to take everyday you said you have to let something go?

(Ms. Summer) Yeah, like um I missed paying the light bill this time, I missed paying something else and been trying to get it up next month now and this is the nose drops that I have to take (participant reached over the table and brought out the nose drop), did you get that? And so, and this is my prescription that my doctor gave me (showed researcher the script) to get the medicine, and then but I don’t understand why, they one time they say uhuu that I have to pay $7.50 for the medi, $7.50 for one, $7.50 for the other one and now they come up with something else. So I don’t understand, so she gonna go over there Monday, or Tuesday and talk to the pharmacy and see what happened. And now I have insurance, umm a group insurance where they, and they say I didn’t have to pay that much so but the pharmacy say like I have to pay it. So is some misunderstanding somewhere, somebody is making a mistake or something but I don’t know what it is. So she gonna go over there and take all my cards, everything with her and see what happened.

(Researcher) What is the experience been like for you having to let paying your light bill go?

(Ms. Summer) Yeah, I had to let something else, I just said the light bill maybe it was another bill, whatever it was I let go and didn’t pay that month so I can get the medicine.
(Researcher) What does it feel like when you let some other thing go?

(Ms. Summer) Well, it don’t make you feel good but I catch, try to catch it up the next time you know, maybe if I got, like I’m suppose to pay $30.00 maybe I try to pay $25.00 and then it keeps till I catch it back up like that, that’s the only way. For this I jus can’t pay it every month like that. ..

Some seniors who were home owners had inadequate funds to make needed repairs. For example, after Ms. Gardner said that she did not have money to pay for repairs on her home, I asked her to tell me what repairs she needed. She replied:

Like I said, I need new basement windows, and I have a large crack on my foundation that runs from the roof way down to my cement and I have no idea how much that is gonna cost. And I jus cannot do it right now. Well, with the holidays coming, too. I’ll have to wait till January and call somebody then if it’s too expensive I won’t have it done. Have one of my kids climb out the ladder chu, chu, chu. And my basement, oh, God, my basement is really bad. I’ll love if somebody could come in and jus seal my sides of my basement so it wouldn’t seep all that water. All this water seeps in. I get a lot of seepage and that will be both things that I would like to have done. But you just don’t. When you’re raising kids and everything you just don’t think about these things happening. Who knew that my husband and I would still be alive after fifty-two years of marriage? Years ago it was unheard of people been married for fifty years, so you know, that’s about it.

Those seniors considered ineligible for services because their income and or/assets disqualified them from receiving formal services suffered self-neglect because their personal finances or informal support system inadequately addressed their needs. It has been documented that those elderly who have had negative experiences with service providers were less likely to ask for or seek help in the future (Rathbone-McCuan and
Hashimi, 1982). Ms. Gardner was the primary caregiver for her elderly husband; however, she also has had multiple medical and health concerns. Ms. Gardner said she had previously asked for assistance but was told she was ineligible for services because she was considered middle-class. I asked Ms. Gardner what it was like for her at her age of 74 to be a caregiver to her husband, to which she responded:

… I am the only one or if there’s somebody else here that helps. But otherwise, you just do it. I don’t really think, I just know I have to do it, there’s nobody else there. And when he was first so bad we were looking for caregivers but they are so expensive. Seventeen dollars an hour to come in and sit with him for an hour but you had to tell them two hours so that will be thirty-five dollars for two hours for a caregiver to come in and sit with him if I have to go some place. So that’s why we rely on the kids. That’s just too much money. That’s one thing if they ever have a program for senior citizens, and what it relies on how much money you got in the bank or if you got a house, if you got a car, whether or not you get this free aid from the … If you got this much, you can get it. But if you haven’t get this much how are you gonna buy his diapers for him? How are you gonna buy his pills? I will like to see where it was regardless of how much money you had, you could call the… and say, okay, could you send somebody over here today? I’ve got to go here, I’ve got to go there and not cost anything. But no, that’s not the way it works. If you want to write a book about something, write about that. I mean to get help, like they told me once when I had social services here. If you’re very, very poor, you can get everything. But if you’re very rich you don’t have to ask for anything. But if you’re middle-class, forget it and that’s what we are considered, middle-class, so we can’t get all this help. No, social services came right out and told me that. So, I guess it’s true. But it would be nice for senior citizens or even for people with problems that they don’t have to worry if you get a penny keep in your bank account, don’t worry about this because you can still get help. But that’s not the way the system works. You have to be very, very poor. In fact you have to be so poor that
you can’t imagine how people could even survive on what they tell you, you make before you get all that help. So, I don’t ask for anything. I have a couple of social workers come (oh, I’m getting a headache) and this is exactly what I have been told.

One participant stated that his “legs tights up” after walking two or three blocks and then he had to “stop” walking. However, he was previously determined to “not qualify” for transportation assistance because during the evaluation process he said they made him walk a little in front of a building and they concluded he walked fine. However, this participant reported that for “most of the people you see on a wheelchair,” they automatically qualify. This participant told me he used public transportation for doctor visits.

Five women were widows in this study, and two had had multiple marriages. Although one widowed participant expressed bitterness at the extra-marital affairs her husband had prior to his illness and death, the majority of the widows stated they had experienced good marriages, but that their current circumstances were due in part to their husbands’ deaths. They felt that more needs would be met if their husbands were still alive, but these women’s bereavement experiences varied. Some widows missed their husbands’ physical presence, but also confronted reduced social and economic resources and lifestyle changes. Some had to relocate; these were major challenges that they had to face alone for the first time in their lives.
Ms. Summer described what widowhood had meant for her after her husband died almost twenty years ago:

I didn’t have to go through with this (financial hardship) when I had a husband (giggle), but that’s been almost twenty years now I didn’t have no husband. You know I lived on the … close to the University…, I lived there and umm and when he was living and he had a stroke he died so I didn’t have no body else and then I moved here and I’ve been living here about seventeen years in this building.

…

… when he was living things was a little bit different cause he was working but he got sick. He was sick for five years, he had a stroke and he was sick so he passed away and then that’s when I left, moved in this small apartment and is okay.

Widowhood had profoundly changed Ms. Lane’s life because her husband had always managed their finances. He had set up a trust fund before he died that directly deducted their mortgage payments every month to pay for their house. This system had worked well for several years until recently. Now Ms. Lane faced foreclosure on the mortgage that had not been paid for several months. Ms. Lane was unaware of why this problem developed and remained uninformed about how to resolve this problem. Ms. Lane also was behind on other bills, including her gas bill. Ms. Lane had five children, but she was closest to one child who was helping her solve her financial matters, but this child went to jail, which was another trauma for Ms. Lane.

I include excerpts from the interview with Ms. Lane below to provide the reader with a more detailed depiction of Ms. Lane’s situation:

(Ms. Lane) The mortgage payments was supposed to be paid when my husband, before my husband died. He was paying it from wherever it come from; wherever that come
from I have never seen it. It never came to me. Never. And it being paid through straight to the mortgage people so now I don’t know what’s happening. I don’t know how to contact. I don’t know nothing. That’s what I’m, and a friend of mine, Mr. he says he’s gonna try to see what he can do because he’s a business man. I say, “Find out what’s happening cause I think I got two or three more payments on this house here before … I own it.” I’m not sure but I’ve been trying to keep checking my head and uh the mortgage money was supposed to be going out to uh this company here uhm after he died. Before he died he made it possible for them to get it from his, whatever it was …and then recently they’re telling me that I am behind. How can I be behind if I don’t see nothing? So, I’ve been after them about it and I can’t, so I asked a very good close friend of ours, please run a check on it and see what’s happening, I need to know. I say it’s almost time to say that the house is paid in full so he doing that for me to find out what’s going on. He says… “I don’t know you was in trouble.” I say, “I didn’t know myself.” I say, “All I know is either find out or get out.” ...

(Researcher) So you either get the mortgage or get out. What does that mean?

(Ms. Lane) Well, I don’t know who’s paying it. I don’t know.

(Researcher) Are you going to be moving, leaving the home?

(Ms. Lane) Well, if they pursue me like that uhm I don’t want to leave it. I have been established enough to sit here and wait for some kind of something from them to let me know that the mortgage is being paid but no one has showed me anything this time. I’m gonna sit here until I find out what’s going on. See, my husband did all this calculation by himself. He never once brought me into it and I say, well come on now let me know where this is going and where that is going. He says, “I don’t want you having new problems, you got enough problems.” I say, okay. Now look at me, I’m still having problems, so he’s gone. I don’t know … I don’t want to leave really, I really don’t. I love the place and everything here. I’m not just gonna walk out, I’m gonna try to find out what’s going on that’s what I want to do. I want to find out what’s going on, who’s getting the money and why haven’t I heard from
them. They haven’t even send me a notice of, we received last month and this month payment, how do I know? I don’t know. I don’t know what company got it. That’s ridiculous.

(Researcher) What does it feel like to be in a situation like this?

(Ms. Lane) Hell, you worry about it twenty-four hours but you don’t know where to start looking for it.

Three primary caregivers participated in this study, and while two cared for their elderly husbands, one watched over her grandson. These participants were more committed to their care recipients than to themselves. In the face of inadequate resources and services, many elderly caregivers to spouses and/or family members sometimes lose their sense of self and inadequately care for themselves, which, in turn, increases their risk for self-neglect.

For example, Ms. Gardner had personal health concerns, specifically vision and foot problems, but when I asked her how caring for her husband had affected things that she used to do like going out or going to see the doctors, she responded:

… I don’t think about it…. Now this is the truth, I don’t think about myself. I think about my husband. God has given me the health to be able to do for my husband so therefore that’s what I do.

… It’s just that you don’t think about your needs, you think of the needs of the person you’re taking care of more than yourself.…..

4.3.6 Pride in self-sufficiency

Sometimes it is difficult for professionals and service providers to understand why some seniors who need services are reluctant to ask for help and hesitantly accept assistance. One reason for their resistance is due to their sense of pride, which was
another theme in this study. In this section, I discuss three major issues: (1) values learned from their parents such as “don’t be scared and don’t go out and beg”; (2) doing a good job and maintaining self-sufficiency; and (3) avoiding assistance from agencies and other service organizations. The first issue, i.e., values learned when young, is best exemplified by Ms. Lane who described it this way:

... That’s the way my mother brought me up, don’t go out there and beg. You don’t beg for nothing unless you really down and out ... I got all of this from my mother before she died. She took me out with her to go shopping for grocery... we go through that market place to get to the market and I used to be so scared I grabbed my mother’s hand and she tell me don’t be scared and I say, well, I don’t know mama. And I was a little girl growing up at the time too but I listened to her but mama told me, don’t let anybody hit you first. If you think you gonna get in a fight you should hit first and I learned to do that.

Ms. Peoples illustrates the second issue regarding pride about one’s work below:

When I go to the VA Hospital and the Department of Justice, I don’t think there is a place in the United States that they did not send me to talk. I have speeches down there included and I have letters from doctors and judges where they congratulated me on my speaking, how well I conduct the task. So I guess we have this ingrained in us from my father, “do something and do it well.” I don’t care what it was...

This sense of pride is significant to understanding self-neglect, and Mr. Wells also shared his feelings about this. He mentioned how he never missed a day of work, and when he was laid off, he never collected money from the government. Mr. Wells believed it was wrong to beg for money from anyone. He said:

...I never missed a day’s work. When I worked I never missed any day’s work and I never collect from the
government when you get laid off. Yeah, as long as you can make it I guess I don’t want to beg anybody for money. Yeah, I’m not got money, don’t get a lot of money but I get along. Whatever I got, you know, that’s what it is…

Finally, Ms. Clay’s comments, below, showed her reluctance to seek help.

(Researcher) I was wondering, you know we talked a lot today and some of your worries you said were maybe when you worry not being able to pay the bills? Have you always needed help to pay your bills or what has happened to change that for you?
(Ms. Clay) Well, I never had help before and then uhuh.
(Researcher) What has changed about your financial situation?
(Ms. Clay) My, my uhuh, my other grandson, he doesn’t live here, his wife told me about this place that may put you on a budget, so I went up there. Usually, I don’t like asking no body for help at all but I had to because I couldn’t pay all the heat bill. Now, I still have trouble paying it all but I get it paid. Somehow or other, I always try to pay it but the only worry I have is the heat bill. It gets up to five hundred dollars is, they just have to take payments because that’s all I can do and so far they haven’t cut it off so I’m praying to God they don’t…
(Researcher) You mentioned that you don’t like asking for help? (Participant did not hear the question the first time so researcher had to repeat same question)
(Researcher) You mentioned that you don’t like asking for help?
(Ms. Clay) No, I don’t like asking for help but sometimes in the situation you have to. I didn’t really want to go up there and find out about it but my one grandson say, grandma? Go up and find out, is not gonna hurt, maybe they won’t help you, maybe they will. So I went up and um they put me on the budget because I had to have my rent receipt, phone bill, light bill and uhuh the gas bill, I had to have all that, so. I think it’s a hundred and forty-four, they allow me.
(Researcher) What does it feel like to ask for help?
(Ms. Clay) I feel ashamed. I really do, I feel ashamed asking somebody for help. Maybe I shouldn’t feel that way, but I do.
(Researcher) Can you talk a little bit more about feeling ashamed asking for help?
(Ms. Clay) That’s because I never had to before. When my husband was alive I never had to have anybody for help. After he passed away I always lived in an apartment where the heat was furnished you know. Everything was furnished except for the lights and the rent and now I have this big apartment, uhu the rent is … hundred dollars a month. I try my best to pay the heat bill and I feel ashamed because I had to go and ask for help. I really felt ashamed but I didn’t want people to think that, oh, here comes another helpless person… I try my best but I jus couldn’t pay five hundred dollars. I didn’t have it; all I had was two so they put me on the budget, one hundred and forty-four, that’s it. But I still feel ashamed because I had to go ask for help. I don’t know…I’m not different from anybody else. There’s a lot of people don’t like to ask for help and if they like me they probably feel ashamed too, but when it come down to it sometimes you have to whether you want to or not, so I did…

An overwhelming number of participants in home health were mindful of the needs of those family members who would provide or were providing personal or financial assistance, and their comments below reflect their desire to contribute to their own care. Ms. Clay described her experience of saving up quarters in order to contribute towards the laundry and why she did this:

She does all the washing. We split the money, you know for the washing. Sometimes I don’t have the money for my washing and I tell her to leave it alone till I get the money. She says, “No, I’ll do it.” So she does it all. That’s a great help to me, it is. And then when I get my quarters all saved up I give them to her. So she does the laundry, so I may not have the money, what she put out, but I’ll give her about eight dollars, nine dollars I saved up in quarters towards the laundry. I give it to her because she does the laundry without asking for any money from me. And that makes it hard on her too, so that’s why I do that. I’ll save all my quarters (reached down to the side of the bed), and
my bank and then when I get about eight dollars, nine dollars, I give it to her, so that’s it.

Ms. Gardner shared that when she was younger she “did so much” for her parents, but she herself would not like to ask her children for help and have them do the same for her. When asked why she reluctantly asked her children for help, she stated:

Nothing, just the fact that I know how busy they are. They all work. They all have got jobs, they all got kids, they go to school, they’ve got grandchildren, you know what I mean? You just don’t. When I was younger I used to do so much for my mom and dad and ran so much for them that I don’t want my kids to have to do that for me. I don’t want them to.

Similarly, Ms. Roebuck mentioned why she would not want to ask her sons for financial support:

It was only my husband that worked in my family, in our family. But now my kids are. …they work …So everybody seem to have two salaries to live nowadays and that’s why I feel as though I don’t want to ask my sons to do anything for me if I can manage to live the way I have been living all these years since my husband died without asking for any financial assistance…

In the face of inadequate resources, financial and social, and physical limitations, most participants described putting forth their best efforts to clean their homes, locate resources and pay their bills.

Ms. Peoples said she preferred the use of a walker to that of a wheelchair because with the walker she could walk and cook and not have to ask anybody what they were having for dinner. She further compared herself to her friend:

…I have a friend who is sick and the same age as mine but she’s like me; she’s gonna do it, you know. She can’t walk
any amount of steps at all but you know what she does? She bumps all the way downstairs and then she turns around when she gets there and she bumps up the steps, that’s what she does. She’s like me, too independent for your own good. Too independent for your own good.

When asked what Ms. Peoples meant by the above statement, she added:

That you want to do it your way. She (her friend) has her grandchildren come, “I will help you down the steps, grandma.” “Leave me alone. I will get down here,” and she does. It takes time. It takes time.

Ms. Waters described how cleaning the house, caring for the dogs, etc, placed her in a situation in which she was unsure what to do first. When asked to describe the condition of her house and what she felt she was going through at the time of the interview, this was how she responded:

Well, I’ve been trying to keep the house clean along with all the other problems that I’ve been having along the way. So you take trying to clean the house and with all your problems and other things to think about, and knowing that the dogs are sick, it kind of puts you in a bind, don’t it? You don’t know which one; you don’t know which thing to do first… But as far as the house, I try to keep the house clean. I have no rugs on the floors and naturally they gonna get dirty with animals walking over them and everything but I do sweep them and I do try to mop and try to keep things clean. I try. I try to do my best that I can. But sometimes you can go so far because I have days when I get down sick myself and with no body here but me, I mean, I just, you know, I just do the best that I can do and that’s all that I can do. ...

Ms. Clay described her worries about the heating bill and how she sometimes turned the heat on low or off in order to keep the monthly payment to a minimum. Ms. Clay had applied for and was accepted to the energy assistance program, however, she still worried
and struggled to pay her bill each month because the help she received was “not much.”

She described doing her best to get the heating bill paid:

Yeah, the heat bill is the only one I really, really worry about, you know. Like I said we don’t have it on all the time because I’m afraid it will get too high and then I won’t be able to pay it then they might shut it off and I can’t have that … Myself I’m not so worried about cause I can go to bed and cover up, but uhuu I got umm the last one was two hundred and twenty-four. I paid a hundred and forty-four, no, hundred and eighty-four and then the following month it wasn’t so high and then I finished it off, I got it paid off. That’s the only thing I really worry about though is the heat bill because I don’t like I said I don’t have the heat on all the time and it does get cold in this apartment but then I went up last, was it last year? Yes, last year, I went up on L… and K… and um they helped me get on a budget, but the budget only a hundred and forty-four dollars so I can’t go over that but sometimes we do because it get, this is a big apartment and you see how it’s arranged: It’s mostly all halls and the bedrooms this way and the heat that’s already big and that’s the only thing I really worry about though is the heat bill but like I said, we get it, I get it paid somehow or other I get it paid (giggle). But I wish I had a little bit more help on it but there’s nothing I can do about it, you know. So, I do the best I can and when God’s help I’ll make it. I have made it for eighty-two years so I will make it again.

Ms. Summer also shared how she did her best to make ends meet:

Well, I jus do the best I can. I can buy what I have to and jus … do that, buy this and leave that out, buy this and leave that out, do that to make ends meet. It’s kind of hard to explain it to a person if they never…

…I get what I have to have, what I need or what I can get; I get that um, next time I get something else. You can’t get everything that you want at the same time cause everything gone up, you know and so you jus get what you can, um.
4.3.7 Good and helpful to others

Participants perceived themselves as good and helpful to family, friends, and others who were in need. Some participants shared their experience of having been helpful to their parents when they were alive. One participant described the trip she sponsored to Europe as a graduation present for her niece, while others described how they had helped others who they perceived as more needy. For example, Mr. Wells commented that he bought a lot for his mother when he was young:

When I was young I used to buy my mom a lot of stuff. I used to you know, go to the store and what she likes, I used to bring stuff like that. You can tell a person how they take care of their parents…

Mr. Wells also considered himself a “giving person” and one who “got along with everybody”:

I gave today; I gave a nice shirt to a friend of mine down there, you know. He can’t walk too good but he lives on …He lives there, he likes me, you know because I get along with everybody…

Ms. Peoples described the graduation present she gave her niece in the past:

…went to Europe. In fact my niece, yes, when she graduated from the University of…I took her to Europe for her vacation, for graduation present, not vacation. We stayed there and she majored in French. Well, I shall never forget the time we sat down in front of the restaurant in France and we ordered her a dinner. Oh, I said, “Whatever you wanted to” and she did and when the dinner came back the hamburger was raw and I said, “I don’t know why but lets ask him” so we asked him why this hamburger was raw and he said, “that’s what you ordered.” She said, “No, I didn’t,” and he showed her, showed it to her what she ordered, and she did not know that she had ordered this raw hamburger.
Ms. Knight said that she previously made good money and before she got married, she stayed with and helped her mother pay for the mortgage on their new house:

…I made it. Was back in the sixties before I got married and I had, I made good money for those days, hundred and fifty a week. That’s nothing now but in 1960 it was a good wage. I helped my mother pay the mortgage on our new house that we bought. I stayed with my mother till I got married.

Aside from helping her mother buy their house, Ms. Knight described herself as a “good-hearted” individual, a reason she felt was why God put her and others like her on earth:

…I feel that God put me and others like me, good hearted people that believe in God and their Christian religion, he put us on earth to help people less fortunate than ourselves in every way …

Ms. Lane similarly shared that she had been helpful to others:

…All my life I have been helping others and now I’m down. I’ve helped a lot of other people that were down from one thing to another and I was by their side. They needed strength they need to get back on their feet and I was happy for them. I don’t know where they are now but somewhere in this world I hope and I hope they doing better but I haven’t regret it, offering my help to people because somehow, somewhere, I always get a payback and I will say, no, never mind, I’m all right. When I come to you for your help that’s when you ready to offer me your help, if you can’t do it at that time that’s all right too, I can understand it.
Ms. Summer described herself as a giving person; that is, she received from others, but at the same time she shared with those she knew were in need. Ms. Summer believed things would work out for her:

...and when I buy, get something uhum like Christmas my nephew down in ... may be he send me something. And if he send me $20.00, I give away $10.00 to somebody else that I know need it and always did that and I always get more. I’ll divide whatever I have. Like my girlfriend upstairs she come down here and she says, “Can I have two eggs? Can I borrow two eggs from you?” And I say, “Oh yeah, go get it.” And she go get it, she don’t never payback but that’s all right. I don’t want no payback, she could have them. And I do things like that for people and they do good things for me and so it will work out. Something will work out...

Ms. Gardner relayed that she donated to charities:

... were’re in a lot better position than a lot of other people are I will say that...You know, when I watch TV and listen to people...I give to charities. I give to the ones I think that really needs like the St. Jude Hospital in Tennessee, we donate there. The Salvation Army, we will donate. We will donate to our Church when they have those collections, you know for...

Hospital...

Two participants not only considered themselves as “good” people but also felt that there were evil people in the world. For example, Ms. Peoples said it was good to be kind but also believed there was evil. She then asked me if I had heard of the man who had killed a little girl:

It’s good to be kind...when we continue in our longevity, there is evil people. It’s good to be kind. You heard about the man that killed this little girl. Why? What are they gonna gain?..
Ms. Knight also talked about evil in the world:

…I don’t believe in the beginning when God made the earth, I don’t think he meant any of these terrible things to happen. But I will come right out and say I attribute the evils of the earth to Satan, Lucifer the fallen angel and to the satanic cult that exists here on earth very much right now. As you and I try to do good deeds not because we expect any credit or reward, they do bad deeds expecting to be rewarded with pleasure or use or money. But of course they don’t get any rewards from bad deeds like the man that shot the little Amish girls. They are not punished here on earth with prison. They will be punished by God because they forget God sees everything and overlooks nothing.

4.4.8 Unfulfilled dreams

Most participants experienced unfulfilled dreams, although they varied in the descriptions of their unfulfilled dreams. One participant, for example, mentioned the assassination of late President John F. Kennedy, and how this devastated her. Overall, the participants’ dreams varied from wishes about getting a good education to working well-paid employment. For example, Mr. Wells described a job he worked at when he was younger and how he made little money:

…I was younger I had three jobs: I worked for the city I was a tree trimmer, they eliminate job tree trimmer. I worked at sanitation and I worked at hospital, a custodian …at that time we didn’t make a lot of money, you know, custodian, very little money and when you don’t have an education…

Similarly, Mr. Movva described his employment history:

I work in a lot of jobs. I had a lot of jobs when I was young. When I was about twenty-four, twenty-three. We
use to make chairs. I worked in one factory for five years, and in another factory for a year and half, I was making stove, cooking stove. I was in another place two weeks, another place for about one year. I had a lot of jobs before but don’t make any money, they only pay you a dollar an hour that’s all that was too many years ago, about forty years ago. The only place that I’m making, that I was making three dollars an hour that was in a factory where they making chair, I was making chair...

Two participants shared that when they were growing up, they wanted to become nurses, but for various reasons were unable to realize those dreams. Ms. Clay said she wanted to be a nurse when she was growing up, but then she was unable to accomplish this. She shared the reason she was unable to fulfill her dream of becoming a nurse:

Well, I really didn’t have the money to go to school then and uhm. I then, well, I got married and had two children and I jus kinda slipped away from my mind about becoming a nurse…now I wish I had…

Ms. Summer shared that she lacked the opportunity for formal education, and while she had the desire to become a nurse, she explained that she would have been able to have a good job, help others, and make more money. She described that she was unable to help patients as she would have liked because being a housekeeper limited her in what she could do. She explained:

I just wish that I could have went to school and …I would have a better, I would have had a good job. I would have made more money, would have made money and things like that. And I always wanted to be a nurse, I liked that field. I wanted to be a nurse that’s when I wanted to help sick people. I wanted that job but I couldn’t do it because I didn’t have the education…that’s what I wanted to do. I wanted to be a nurse, I wanted to help somebody.
I asked Ms. Summer how the lack of educational opportunity was affecting her life. In her response, she described that she could have passed the examination and reiterated she could have had a good job at the hospital where she worked. Here is how Ms. Summer described her experience:

It been bad for me cause I could have got a good job at the hospital when I was working there but I couldn’t pass the examination and that hurt me awful bad cause I could have got the job but I couldn’t get the job cause I couldn’t pass the examination cause I didn’t have the education and this when I know is very important that you should have the education. If you had the education you should get any kind of job, but if you don’t have the education you can’t get it and now you got to have the proof …

After having one son, one participant shared that she had a miscarriage while four other participants were unable to have children. Ms. Knight shared her experience of having had a miscarriage about forty years prior to the time of the interview for this study. Ms. Knight relayed that she had told her son he was going to have a brother, but he did not. Ms. Knight was emotional as she talked about the experience of the miscarriage she had when she was about ten weeks to three months pregnant with her second child.

And I told my son he was gonna have a little brother but he didn’t. Later on he had a little sister. Children are funny, they always want the new baby to be a girl if they are a girl or a boy if they are boy. They are funny but the parents only want a healthy baby.

...He can be born again if he wishes to. A lot of people that go to
heaven don’t want to be born unto the earth again. This is spiritual knowledge that I received from my spiritual guidance.

Four of the ten female participants never had children, but they all mentioned something about children during the interview. Out of the four participants, two were African-American and two were Caucasian. Ms. Summer, who did not have children, described, below, how badly she wanted to have a baby but she never got pregnant:

…never had no children and I always wanted them so bad, never got pregnant, uhum. So well I had two aunts, they never had no kids, just like my cousin she never had one, the rest of them had six and seven kids and all like that. We never had any. Just one of them thing, I guess because we wanted them so bad. I always wanted a baby. I wanted to rock a baby, baby, but never have them. …

Although Ms. Summer said she badly wanted to have children, she added she also knew that a lot of people had trouble with their children:

…cause it’s always nice to have children. I know a lot of people have trouble with their children. Their children come soon as they get their check every month. The children come and take the money away from their parents… and all that stuff. So a lot of them have difficult… so just one of them things.

Ms. Peoples, who also did not have children, shared she was married but divorced after about fifteen years. She relayed her husband remarried and had children:

But he remarried and I understand he had three children. They say they were nice kids; he was entitled to this. Because we didn’t get along that doesn’t mean he … couldn’t have nice kids.
When Ms. Lamb described their life (she and her husband) as a very simple one, she mentioned that they had no children coming in as if there was a void without the expectation of children coming into their home.

…our life is very simple…we don’t work…There’s nothing in it. There’s no future. We not planning anything. There’s no children coming in. Most of our friends are dead. … I have a sister in …I haven’t seen her, maybe when somebody dies she might come up here, so we don’t see anybody…

When Ms. Waters described the love she had for her pets, she mentioned she never had children so she got dogs instead:

I mean, I don’t, I never did have any children so I guess I got dogs instead and I do, I just love them to death. And that little Bran I know he loves me too cause he will come right up to my face right up here and touch my nose and his eyes is right up against my eyes (laughter) and he just glares right at me… Now he’s not dumb by no means, but that’s why, you know, and I’ve had him for so long that um, they’re just like family and I’ve heard so many people say that their animals are family and you know after you have them for so long…Well, they’re not like family, they are family. I’ve heard so many people say that they are family and I know mine is… …yeah, they are family, absolutely. I mean I wouldn’t know what, if I didn’t have them, honey. I wouldn’t know what to do because at least I can pet them, I can put fresh food down to them, and hold them, sometimes I hold them and they will get right up in my face and try to rub my face and try to rub my nose. They’ve actually tried to rub my nose (laughter), you know how sometimes the cat will try to get up in your face, rub your cheeks or I guess that’s because they love you… I do love my animals though. I do love them and every time I lose one I just practically go with it. I just cry myself to death when I lose one of them…

While only four (33%) participants in this study were childless, two of the participants who had children were not without problems or concerns about their children, which was
reflective of parents whose dreams for their children had been denied or largely left unfulfilled.

Ms. Lane had a son who was in jail at the time of the interview. When asked about her son she provided this response:

…is in the county jail right now. … I don’t know. I didn’t get the scoop on that. They told the people not to tell me anything. So, whatever is, I don’t know.

Even though Mr. Wells had two other children, a seventeen-year-old daughter who had a two-year old child and another daughter who maintained phone contact with him, he talked about his son who he said had become addicted to cocaine and disappeared. Mr. Wells described what had started out as a promising dream but one that had thus far been left unfulfilled.

…And he took up some engineer; he went to some college here. He learned a trade and he earned engineer, pluming stuff like that. He learned everything. He took the test and guess what? He passed them all. He could have got in any hospital, he was in the union but he passed the test but he never liked to work in hospitals you know. So what happened? I used to see some guy, I don’t know what he was, I don’t know. He used to come over the house, they used to live upstairs. First, he was living with some girl and then they can smoke third floor in the attic. I can smell there’s something. I can smell it you know, they went out for a long time because I know what he was doing… So then he was in charge of the elevators in downtown city hall before he took the test. You know what did he got? He got on cocaine...and disappeared. He can’t face his mother, he can’t face me.
During the interview, Ms. Summer recalled one of America’s historical moments by describing where she was when she heard the news of the assassination of late President Kennedy and her feelings about his assassination.

…When I was working there when President Kennedy, Kennedy, yeah, when he got killed in um Dallas, Texas…He got killed and she (the nurse at the hospital)…put a plastic up there, no body to go in there, no body to go in that room because she didn’t want them to tell the doctor what had happened. And as the doctors come out when they went through the surgery and then she will tell them what had happened and they called up and made reservations at …(airport). The doctors went to Texas to see what they could do for him but he died any way. And I remember so well when they told me I went to the washroom and I just cried, cried, the tears just running my eyes. Oh, I felt so sorry, so sorry but that happened. And I think of them kind of thing that was really something to happen, he got killed. They killed him down there because he was really for black people. He was a good president…

4.3.9 Connectedness to places and things

The participants’ connectedness to their environments was a major theme in this study. Some participant’s wanted to remain in environments where they had always resided even when their safety and well-being were at risk. These participants did their best to care for themselves and their family members in order to stay where they were. They avoided relocating to institutions like nursing homes because they perceived such places as either the last stop or where they would only receive poor care. Quotes supporting these themes follow. For example, Ms. Roebuck described her home as the perfect place to retire:

…I have been here since …, so but everything needs, you know now, not improvement but just uhm, keep it from falling apart, you know……I can’t go and live anywhere

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else than where I’m living at now because everything is so convenient for me, this is the perfect place to retire. I have one bath, I have my laundry room next to here downstairs, I have my kitchen, I have two bedrooms and everything is easy for me so I don’t want to move…

Similarly, Ms. Waters said she will not give up her house because she had lived there for 50 years:

…I’m not gonna give up my house as long as I don’t have to. I’m not gonna do it because that is my house. I have lived in that house for over fifty years, can you see where that’s home? Fifty years, my animals here, why should somebody take me out of my own house? As long as I’m able to get up and get around and do something…

Ms. Summer said she will keep on trying and will not give up because she wanted to stay in her house and avoid entering a nursing home:

…I just do the best I can and I will make it. Like I said I don’t give up. I will keep on trying, trying to do cause I’ll never gonna, never, never. I may have to do it but I don’t never want to go to a nursing home, no. I want to stay in my own house that’s why I jus keep strong, doing things for myself, try to do the best I can…

When I asked Ms. Summer what it was about nursing homes that she didn’t like, she responded:

… The way the people treat the people there. What they tell me about what they do and then they don’t know like the people soon they go to the nursing home they gone that quick…Cause we don’t have no control over that, we never know. But it just seem like something about it, people don’t live long when they go there. Well, one thing, we already old when we go there so you can’t look for nothing else. ..
Ms. Gardner talked about the bedsores that her husband had developed while admitted to the hospital, and she said she would not put him any place where he would not receive the care that he was getting at home.

…my husband was in the hospital for six days, a month and a half ago. My husband never had a bedsore. He was in the hospital for six days, came home. We still have not been able to clear up the bedsore from the hospital so there is no way I will put him any place that he wouldn’t get the care that he’s getting here. Yeah, no, uhuh, I can’t, I don’t like that, so.

Ms. Clay did not want her grandson in a nursing home because she said before her daughter had passed away, she had promised her that she would not put her grandson in a nursing home. Ms. Clay described the reason for her decision:

...my daughter passed away… and um there was no one else to take care of him and I did promise her in case something happened to her not to put him in a nursing home and that promise I have kept. And I won’t put him in a home, not the condition I’ve been hearing about over TV, about these nursing homes…

Hoarding was an issue that emerged when discussing connectedness to things. Hoarding is a serious public health problem among many elderly persons and has been linked to self-neglect (Nelesen, 2002). Two participants hoarded things and objects in such ways that created health and safety risks. At the time of the interview, Ms. Waters had so many objects in her house that it looked as if it had never been cleaned. The condition of this house was deplorable. The pets were scratching a lot and it smelled. Because I wanted to understand how Ms. Waters experienced this situation, I listened to her story regarding what happened the previous year when the city cleaned out her
house. I included excerpts from the interview to show the reader how Ms. Waters viewed her condition. Ms. Waters felt attached to some objects in her home and stated that she had wanted to get the things that she never had in childhood. Below is our dialogue about this:

(Researcher) Going back to the things in the house you seem to have a lot of things that maybe you don’t need? I don’t know like the old lawn mower, the plastic bags, and cans of food, and things like that, you seem to have a lot of stuff there?

(Ms. Waters) What do you mean plastic bags?

(Researcher) I see a lot of things there but you know it could mean different things to you. I don’t know but you said the city code was here before, was it last year?

(Ms. Waters) Well, yeah, they just about cleaned the house South end…

(Researcher) Tell me how did all that start with the city code coming in?

(Ms. Waters) Well, for one thing, the house was overloaded.

(Researcher) Overloaded with?

(Ms. Waters) Well just everything. Like you said the lawn mower was there and I think I had another table in there and eh, oh, I don’t know all what I did have, I had a bunch of stuff in there. I mean a bunch, but ehh it’s just about everything is gone now, and really, I’m glad it is. I feel better. I feel better but now the only thing that I, I didn’t get nasty with them honey, I know you can’t do that and I wouldn’t do it anyway but it really hurt my feelings when they took the rugs up off the floor because those are wooden floors and they have the long cracks in between each board and the cold comes right up from the basement in the winter time it gets cold in that middle room and I pleaded with them to leave that one rug down in the front room. If they didn’t take, you know, if they would only leave the one, take the other two but leave that one in the front room but you know they wouldn’t do it. They took it up and after that one of the workers that was working in here was parked right over here and don’t you know he got another guy to help him and they rolled that rug up and
took it out and tied it on top of their car and took it home? Why didn’t they let me have it because it was mine, it belonged to me but they got it. They got it instead of me and it was a good rug, it didn’t have a break in it no where and it was about that thick. That’s why I wanted it because it kept all the cold air coming out of them cracks as wooden floor, but they wouldn’t let me. They got it. The city got a lot of things in there that they took to their homes that they wouldn’t let me have.

(Researcher) Describe some of the things that they took to their homes?

(Ms. Waters) Well, some of my fancy glass ware, some of my dishes, they took the rug up, they didn’t threw that rug out…And among other things, smaller items and things, some of my beautiful dishes that I had of china ware, china glass ware, fancy glass plates and everything in my china cabinet that’s there in that middle, they took a lot of that stuff out. Oh, they took the best of everything …

(Researcher) So are you saying that you really weren’t happy about the things that they took from you because they took your good things?

(Ms. Waters) They took my good things, honey. And not only that but it was desperately things that I needed. Now that front room in there gets real cold in the winter time because the air comes up through the cracks in the floor but when that rug was down about that thick, it was just toasty warm. I stayed warm in there but I don’t stay warm in there now, the air is coming up through the floor. A lot of that cold air is just coming right up. ... They took the best of everything that I had. I had beautiful crystal glasses, all of them went. Everything I had was nice, it went, it went…That was my stuff...

…They did, they did, they took a lot of good stuff but my pictures when they come around my pictures they jus tossed them out in trash. Pictures that I had taken and wanted of my friends and some of my relation that I had took you know, and my cameras. I had two of them, old boxed cameras they were real good camera boxes. You know the one I’m talking about? I don’t think you can get them anymore, at least I haven’t seen any but any way they even took them, took my two cameras. …

…I thought I was the boss of my own home but they jus, they jus literally took over jus like you know like they was
the boss of the house. What ever they wanted to throw out, they throw it out. They throwed out a bunch of clothes.

(Researcher) They threw out a bunch of clothes?
(Ms. Waters) Yeah, well, before they even get started in the house, one of them great, big oversized dark yellow dump trucks, great big ones, they pulled one of them up in the back yard and let it sat there for two or three days and the reason that they let it sat there was what they was gonna throw the trash out in and they did. They throw a lot of good stuff out in that truck, it had a great big square… on it, you know what I’m talking about, don’t you? The big yellow ones.

(Researcher) Did you say they took a lot of trash out?
(Ms. Waters). Well, what they will call trash, but to me it wasn’t trash but what they called trash was clothes that ... was good clothes and then other little items, I had a VCR, they took that cause they kept that and I, just had all kinds of, I had a real nice radio, VCR, all of them, I had everything. I had bought everything, I had stopped working, saved up money and I made up my mind that I was gonna get things that I wanted that I never had in my childhood which I never and all of that stuff. ...There’s a lot of nice things in there that real nice people had given to me over the years, and it’s all gone. It’s all gone.

(Researcher) What does it feel like for you now?
(Ms. Waters) It hurts. It hurts because some of them things was special to me. They was special from special friends. I mean I have a lot of good friends and they gave me things like around Christmastime, Thanksgiving or whatever you know and I had little what now sat around on the mantle there in the front room and stuff, it’s bare ever since. They jus took everything they wanted, they didn’t ask me nothing. ...He got my black Polaroid camera you can’t even hardly get them anywhere, you jus click them down you know, he got that and he got two bran new packs of film that was with the camera, he took all of it. So the house is just practically bare.

(Researcher) Even though I see a lot of things in there still?
(Ms. Waters) You talking about what?
(Researcher) The lawn mower, the old chairs, the plastic bags you have?
(Ms. Waters) Honey, I can’t leave the lawn mower and
stuff like that outside, if I did the people will steal it. My garage has been torn down for few years now. I don’t have a garage, it’s been torn down at least getting around eight or nine years. I had to keep them in the house. I couldn’t drag that heavy stuff down in the basement I probably fall down and burst my head. That’s why that lawn mower is upstairs, it’s heavy.

(Researcher) How about the encyclopedias, the other books, the newspaper, the plastic bags?

(Ms. Waters) And plastic bags?

(Researcher) Yeah, you have a lot of books in there on the floor but looks soiled, is that something you gonna use later?

(Ms. Waters) Probably not.

(Researcher) Do you keep things that you’re not gonna use later?

(Ms. Waters) No, but there’s certain books that I like to read. Don’t you like to read once in a while? Just to relax?

(Researcher) I do like to read. I do like to read. Do you have any safety concerns in your home because you have so much stuff there even on the couch, does it concern you?

(Ms. Waters) Well, no, that mess right there, in that room there about the fire place that is gonna be cleaned right away. I know it’s a horrible mess right there, the clothes are in front of the mantle in the room?

(Researcher) I did see that.

(Ms. Waters) Yeah, the clothes, I’m gonna get them out desperately. Yeah, desperately, I am gonna get them out right away, because I can’t even get around in there myself, hardly. You know walking around that fireplace and around through there I can’t even hardly get in there myself and I do want to get all that cleaned out. And in that fireplace, I don’t know if you’ve noticed it or not, is probably pretty well covered up. I have got a real nice little heater that’s sitting back in that furnace and it’s one hundred percent legal. It sits back in the fireplace, it burns nothing but kerosene and it’s one hundred percent safe and the little stove that I was telling you about is completely covered all over with real heavy metal fronting, clear across the front of it, real heavy and there’s no way that any sparks at all can come out, come through it or anything or anywhere. It is one hundred percent safe and it only burns kerosene, nothing else. ..it’s one hundred percent safe and I
used it. It’s been sometime ago now but I used it one whole winter and it kept me nice and warm there in the front room and I never had any trouble with it at all. Not at all.

(Researcher) So yes, I may see a fire risk but you say you don’t see that?

(Ms. Waters) No, you don’t see a whole lot of them anymore. You don’t, but it just like this honey, if you know how to work with it, you’re safe. You’re safe but I said now them sparks that would ordinarily fly out they can’t do it because that cover, that real heavy thick cover is over the front of it and the sides of it all, it’s all covered. Nothing can get out.

For many hoarders, the decision as to what needs to be discarded may not come easy. While one participant noted that she was trying to throw the papers away, another participant, Ms. Lamb, talked about the pile up of papers she had brought home from rehabilitation and for which she had even bought a shredder, but she was yet to sort them out. Ms. Lamb described her experience of the decision-making process of what to keep and what to discard:

…There’s a lot of papers here that I got from rehab. There’s so much to keep and so much to discard. I got a shredder and one of these days I will sort it all out and I will shred it. The papers that I don’t need and start filing this stuff away and of course, I got to clear up the file cabinet so there’s room for new stuff going in but all that takes time. It just takes time. I have time but not that kind of time. See, everything is piled from this to here. I’ve got to get rid of all that, that makes the place looks messy and I don’t want the place messy.

In contrast to Ms. Lamb, Ms Roebuck said the following about getting rid of paperwork:

…now of all these papers and stuff like that I have to go through to see what I can throw away because I’ve got so many things that I have written on little pieces of scrap paper and some of those things that look important and they’re not; you don’t want to throw them away and yet if you keep them
they’re gonna just stay there, and stay there, and stay there until
if you wanted to find them and the information that you need is
not gonna be there and there’s another way of getting the
information that you’re saving. So what I’m doing too is I’m
trying to do is throw everything out so I don’t get overloaded
with too much paperwork…

4.3.10 God, prayer, and coping mechanisms

Spirituality came through as a significant theme for almost all of the participants.
While some participants did not perceive their health and life circumstances as bad and
actually described other people as being worse off, 9 out of the 12 participants
overwhelmingly expressed having a strong sense of spirituality and of perceiving God as
helper and provider, sustainer of life. Many participants prayed to cope with their
circumstances. Even those participants who were not very vocal about their spirituality
mentioned God. For example, two had religious symbols mounted in their apartments.
One participant, who said he was Catholic, had the religious symbol mounted in his
apartment, although his son said the crucifix belonged to him. Mr. Wells described other
people as worse off than himself and added that he was satisfied with his life.

Here was how Mr. Wells compared his situation to other people he perceived as
worse off:

… lets say, I walk from here to…there (pointing toward the
street) I stop couple of time because this tightens up, the
legs (holding onto his legs and back)…well, I got to be
glad I don’t have to be on a wheelchair least I feel sorry for
the people in wheelchair. You know what they got to go
through? On the wheelchair is a handicap. See, you don’t
have somebody to help you out when you’re, you know,
it’s a hardship. You know if you get money you can be in a
home where people will take care of you, nurses, staff, or
whatever, you know. In a place like this you got people on
a wheelchair they must suffer quite a bit you know what am saying? They got...all day long on a wheelchair. I don’t know what happen when they go to the bathroom, when they got to take a shower, when they go to do a lot of things. It’s a hardship. You know what I mean?

… My thinking is, I think because you see people, you got to figure in life there’s always somebody worse than you are. You know, never complain because another person got more problems than you got. That’s the way I look at it maybe I’m wrong, am I right? In other words you complain that you got a lot of this, a lot of bad life, or you’re broke, you this, do the best you can that’s the only thing you got to figure…

…Be satisfied in life. I told you the next person got more problems than you got. So you got to...keep your mouth shut...because the next person got more problems than you got. Right? Didn’t you mam, dad tell you all these things?..

Ms. Lamb shared her spiritual beliefs:

I believe in God, in prayer, that’s the only thing that will take us through. The good Lord won’t give you any more chores, any more than you can bear.

Ms. Clay described why she believed God was her helper:

Just like when I was sick with my leg and I was so sick in my stomach all the time. And it juss seem like everything was against me, everything was going wrong, you know. And I um cause I read my Bible and I read a verse in there about don’t give up hope or your faith so I said, okay. I read my Bible over, and over, and over and over. Finally, I brought myself up out of the condition I had ... you know,... nervous. I say, finally get yourself together here and start all over again, so I did. I did it but that's why I say, God is my helper.

When I asked Ms. Peoples what kept her going, she stated:

...And what keeps me going is God. I guess who else keep me going at ninety-four ...? Who else will keep us going but God, I don’t know. I don’t think there’s a man on earth who will keep us cause doctors can’t keep us here when we
get sick. There are times when they can not help us, when they can not save us, and I say that’s our time to go. We are to go at that time so I don’t know what makes us live… I don’t know what keeps me going, I don’t know what keeps other people going other than the grace of God. And grace is the only thing that will do it. I miss not a morning or night, now I don’t say my prayers religiously like I did when I was younger but I ask God for his grace every night, every morning, and I thank Him every morning and night. When we were younger my father will get up in the morning and he will say, “Good morning Lord” and my, I say to my mother, why does he say that? And my mother say, “Because he wants to,” and then she says, “Because that’s the way he feels, that’s all.” I don’t ever remember him getting up without saying good morning Lord because that’s the way he felt. You know there’s a silly kid asking why did he say that. That’s the way he felt…

Ms. Lane also believed that God kept her going:

…I know that much is no body else keeping me going but God. I believe in Him cause he can turn off my windpipe in a hurry and I will be lying out there gasping and then let me go, keep on going. He’s the only one that is in my corner, keeping me from one day to another and I am blessed for what little I got and I thank Him very much for everything that he has bestowed upon me.

Ms. Gardner shared that while providing care for her husband, she had run into so many people who did not understand what she did for her husband and did not think that she could adequately care for her husband. She added that people kept saying to her, “Gee, you can put him in a nursing home.” She said it became frustrating to her when people said that but what kept her going was her “inner strength.” She felt that this strength
helped her not to worry about what others thought of her situation.

During the interview Ms. Gardner described the experience of having

“inner strength” in this way:

Being able to do what has to be done. Not worrying about yourself all the time. Not worrying about what other people will think, you do what has to be done. You don’t worry about it, you don’t, you just don’t. And I’m not saying that you don’t get depressed, sometimes you do get depressed. I mean when you’re in a house like I am, there are sometimes you say, I wish I could go out, I wish I could just hop into the car and take a drive out, go out and visit the cemeteries even, or go out to the store, or go you know, any place. But you just go along…

Ms. Gardner further described similar feelings below:

Inner strength is what I think every person has, it’s just that you have to draw on it. That’s why I have my Communion every week because I rely a lot on my prayers and God. I figured this is what he gave me to do so therefore it’s coming from His teachings inside of me. That’s all I can say, I mean I don’t know how else to describe something like that. You either have it or you don’t.

Ms. Summers also prayed and praised God a lot. She believed that God was a “way” for her and that things would work out for her:

Um, I just, one thing, I pray a lot. I praise a lot and um I have my Jesus Christ picture on the wall right over there and I always look at that every day and I pray the Lord will make a way for me. The Lord take care of me and then I believe in that, God. That keeps me going. He say anything that you need ask Him and He will give it to you. Things will work out for me somehow and I believe that too, uhum.
Ms. Flowers was no different from the other participants as she shared during the interview that she prayed and read her Bible. I asked her what she asked God for in her prayers, to which she said:

I ask Him for guidance, I ask Him for patience, I ask Him for uh just a good day to live by you know and guide me as I try to make that day and He does, you know. And my serving God is not just wrapped up with church, it’s wrapped up with me too, you know. I mean that uh the Lord can see me through … the hardships and you know…many time I will be right down here (living room) praying.
CHAPTER 5
DISCUSSION AND IMPLICATIONS

Although several studies have extensively documented that self-neglect is the leading cause of abuse and neglect among older adults, when compared with abuse and neglect, it remains highly understudied and underfunded. The changing demographic patterns projecting an increase in the number of the elderly population bring us to the urgency of the situation and the need to gain new knowledge that will ultimately provide a guide in our prevention and intervention strategies in the area of self-neglect. The purpose of this study was to document how older persons identified as self-neglectful viewed their circumstances. The Adult Protective Services’ 1991/2004 definition of self-neglect was used in designing the interview guide, with the study’s focus on how participants who were accessed through Adult Protective Services and a home health care agency viewed their situations.

In this last section, I briefly discuss the three theoretical perspectives that guided this dissertation and discuss a summary of the findings, followed by methodological limitations and recommendations for future research, and concluding with implications for policy and social work.
Theoretical perspectives that guided this study were: compliance, ecological, and symbolic interactionism. Because an overwhelming majority of elderly persons who are reported to be self-neglectful are also reported to be “noncompliant” and/or refuse needed social services, understanding this “noncompliant” behavior was critical to understanding self-neglect. Ecological theory with its focus on the life course perspective in understanding interactions between the elderly person and his/her environments also is relevant. Given the long-standing controversy surrounding the language and the definition of self-neglect, the questions related to the inclusion or exclusion of self-neglect in the elder abuse literature, and the provision of services to those older adults who are identified, I incorporated concepts used in symbolic interaction. Previous experts, for example, Bozinovski (1995), have used symbolic interaction to study self-neglect. Theorists who advocate symbolic interaction perspectives underscore the need for understanding people’s subjective interpretations of their surroundings and to identify the meanings they attribute to their experiences. In this study, by using these perspectives and a qualitative methodology, I uncovered salient themes that participants whom APS and health practitioners deemed as self-neglectful constructed to make sense of their world.
5.1 Discussion of the findings

5.1.1 Theme One

The first common theme that emerged in this study was chronic medical/health condition, incidents of falls, and complaints of physical weakness. Others, e.g., Pickens et al., (2006), Bozinovski (1995), Longres (1994), NAAPSA (1991), and Vinton (1991) also found multiple medical and disabling conditions among older adults who had been identified as self-neglectful. Several participants shared that they had chronic medical/health problems, including but not limited to, arthritis, lower back pain, foot problems, diabetes, chronic headaches, and vision and hearing problems. For example, in this study, Ms. Gardner shared her experience of a 30-year problem she had with her feet. She said she had these “operated on,” but added she was told that “bones shift” and having additional surgery would not benefit her. Similarly, Ms. Peoples referred to her lower back problem and her pain, which made it difficult for her to stay up when she sat down. From a compliance theoretical perspective, the older adults in this study as shown by the examples above, were noncompliant. Compliance theorists maintain older adults do not seek medical help when they need to. Older adults who may appear sick and unhealthy may not necessarily feel sick and thus may not seek appropriate medical attention or follow up on recommended medical regimens. The experience of living with these chronic medical/health and disabling conditions is perhaps captured best by Charmaz (1991), who has researched and documented the experience of individuals living with chronic illness. Charmaz (1991) explains:
From getting through the day to dealing with the inequities of medical care, living with chronic illness can result in unending knotty problems and unforeseen hardships....many people live with a serious chronic illness and move between being immersed in it and keeping it contained. As they do so, their priorities change, and often along with them, their perspectives....Though living with chronic illness may mean entering and being swept away by a separate reality, more adults enter it as they age and as the incidence of chronic conditions increases (pp. 4-5).

Also discussed as a subtheme were falls, which commonly occur in late life (Chou & Chi, 2007; Tideiksaar, 2002; Yardley, Bishop, Beyer, Haur, Kempen, Piot-Ziegler, Todd, Cuttelod, Horne, Lanta & Holt, 2006). It has been recognized that more than one third of adults over the age of 65 fall each year, with the very old and frail most at risk (Yardley et al., 2006). Falls are implicated in and are believed to be the most common cause of injury among older adults and have been observed to lead to permanent loss of ability to take care of one self and even result in death (Yardley et al., 2006). Most falls occur at home and are usually caused by tripping, slipping, or a change in posture (Sweeney & Chiroboga, 2003).

Seven participants in this study mentioned a fall that took place either at home or elsewhere. For example, Ms. Lamb talked about the fall she had in her home early one morning while on her way to the bathroom. Ms. Clay similarly explained how she rolled out of bed and fell on the floor. While Ms. Lamb and Ms. Clay both fell at home, Ms. Knight fell outside her home. She was on her way home from the doctor’s office when she fell and was carrying packages when she lost her balance. Ms. Knight said she broke her hand, which had to be put in a splint, as a result of falling. Ms. Summer, Ms. Peoples and Mr. Movva had similar experiences. About 50% (“conservative estimates”) of
individuals who fall often avoid participating in activities of daily living because they fear falling again (Tideiksaar, 2002). Ms. Clay admitted that she was “afraid of falling.” Because restrictions in activities of daily living strike at the core of self-neglect, future investigators need to examine how self-neglect and fear of falling are related.

Another subtheme referred to as “weakness” corroborates Dyer’s (2005) previous study on self-neglect. Dyer noted that some older adults become so weak they are unable to get up and their homes become dirty and unsanitary. Ms. Summer similarly explained that her feelings of weakness had prevented her from taking the walks that were recommended she do, and Mr. Movva mentioned that sometimes his hands became so tired and weak that things would drop from his hands. He struggled to hold a glass of water. Given the fact that the overwhelming majority of older adults identified as self-neglectful have limited mobility and are restricted in their activities of daily living, more social work researchers should follow-up on the adverse consequences when older adults complain that they feel weak. We need more community-based services and programs that focus on strengthening these frail older persons and keep them from falling and becoming weak.

5.1.2 Theme two

A second theme that emerged from this research revolved around health and medical care. The ecological theory is useful in gaining an understanding of the deeper meanings in the lives of the participants with regard to their health and medical care as explained below. Because most older adults who are identified as self-neglectful have multiple medical conditions, social workers must better learn how these older persons
perceive their health and how they feel about seeking medical care. The participants’
views about this varied. For example, some participants, such as Ms. Gardner, believed
that it was unnecessary “to see a doctor every year” because Medicare would not pay for
these visits. She only saw doctors when she was pregnant. Ms. Waters also said she had
not “been sick,” and explained, “What if you’re not sick and don’t need to go to the
doctor and you don’t even have the money even if you were sick? Then what? What
would you do? What would you do? ...” Some reasons stated by Ms. Gardner and Ms.
Waters for their reluctance to seek medical care have been previously documented. In a
study of older adults suffering from arthritis, Barney and Neukom (1979) found that
patients were reluctant to participate in an arthritis outreach program. It is believed that
these elderly patients’ reluctance were due to the following reasons:

skepticism about benefits to be derived from professional help, reluctance to pay rising costs related to difficulty,
pain and money, ...a tendency to associate use of health care with decline, dependency, and the dreaded ultimate solution, institutionalization (p. 554).

Ms. Lane only saw her doctor at the “last minute,” that is, when her symptoms
“come down hard,” and Ms. Lane often used “left over medications.” Some participants
relied on their own medical treatments. For example, Ms. Summer said that when she
was growing up in the South she “didn’t go to the doctor.” She stated that “when you fall
down and hurt your leg and your knee be bleeding, they put red mud on it till it feel better
with that... We didn’t do nothing and got along fine and didn’t go to the doctor.”

Although Ms. Lane and Ms. Summer were African-American, their views differed. Ms.
Lane would use left over medications if she had any and only went to the doctor when the symptoms persisted and “come down hard.” Ms. Summer referred to her Southern health practices that emphasized traditional, non-medical treatments. Others, including Edmonds (1990) and Satcher, (1973), emphasized the importance of culture on people’s views about medical care. In studying the health of older African-American women, Edmonds (1990) identified twelve significant factors that explain health seeking behavior among these older persons. He referred to:

1) Segregation experiences in the formative years, especially in the rural South, where many blacks were reared, that led to minimal or less-than-adequate health care use and where there was an absence of preventive measures
2) Suspicion of the dominant culture and its institutions
3) Reliance on kinship and friendship networks in order to cope with health concerns
4) Preference, in some areas, for traditional medicines and for faith healing
5) Religious beliefs, some of which direct an individual to look to heaven for relief from all pain and anguish rather than to the health care system
6) Lack of understanding about the consequences of the denial of signs and symptoms of illness
7) Unwillingness to adopt the sick role, whenever possible, because of more pressing obligations
8) Lack of adequate health care information, leading to inappropriate health care practices and behaviors
9) Unrealistic perception of good health, indicated by Black women as they get older, a self-appraisal that may give a false sense of wellness, leading to inappropriate utilization of health services
10) Poverty and, therefore, lack of adequate health insurance
11) Lack of an adequate number of Black health care planners, who may more adequately plan the service needs for Black aged

12) Lack of an adequate number of Black health care practitioners whom aged Black females might better accept and trust (p. 216).

Health practitioners, including social workers, will better serve older persons who need help if they consider cultural and other traditions that influence help-seeking behavior, which is more complex than professionals have assumed. We need more studies to focus on older persons’ subjective views about medical care and use of services. The prevalence of chronic medical/health conditions among self-neglectful elderly persons is most likely underestimated. Older adults refuse and avoid health care for various reasons, and social workers need to understand these perceptions and behaviors among older adults from different ethnic groups. Such information would help social workers deliver more effective services to self-neglectful older adults. Because we look at people within the context of their social situations, we must consider these social factors more seriously and how they impact the health behaviors of older persons.

5.1.3 Theme three

Compliance theory is applicable in discussing the third theme, which focused on participants’ sense of mistrust. The mistrust was directed to health care professionals, prescribed medications, recommended medical regimens, and relationships with friends and family, which Bozinovski (1995), Dubin and colleagues (1988), Griffin (1994), Longres (1994), Mixson (1991), and Vinton (1992) already have documented. In this study, Ms. Summer stated she did not know whether to believe it when the doctor said
she had pneumonia. She was mistrustful of this doctor’s diagnosis.

Mr. Movva lacked faith in the efficacy of the treatment and questioned whether it was effective. Mr. Movva had stopped therapy and perceived the side effects of the treatment that he previously received did more harm than good. The adverse side effects of taking multiple medications simultaneously was described by Mr. Wells, who maintained that while some medications are good for some illnesses, these same medications also may adversely affect other parts of the body and cause additional health problems. Previous studies have suggested that patients who are in treatment are:

primarily in a struggle to regulate their lives, to keep in control...taking the medicines may often be seen as making them feel more stigmatized or dependent (Zola, 1986, p. 75).

Ms. Lamb shared that the doctor withheld medical information from her, specifically, information about her eye, and, as a result, she had “lost a sight in her eye.” Zola (1986) corroborated these findings and stated that:

“take one’s medicine” is in no sense the “natural thing” for patients to do. If anything, a safer working assumption is that most patients regard much of their medical treatment as unwanted, intrusive, disruptive, and the manner in which it is given presumptuous. Sometimes medical providers recognize this. But more often than not they do so after the fact, after noncompliance becomes an issue. Then it is too late. The patient has already been disappointed and is distrustful. The time to start is before. But it is hard to change, particularly since health professionals have strong opinions about letting the patient know too much. In perhaps no other area of human contact has it been so strongly and wrongly assumed that a little knowledge is a dangerous thing (p. 76).

Participants’ mistrust of friends and family members, found in this study,
resembles results that Bozinovski (1995, 2000) discovered:

for older people, distrust stemmed from repeated and life-long experiences in which other persons betrayed confidences, abandoned them during time of need, and covertly and overtly deceived them... Common attitudes toward specific and general others included beliefs that people are “just out to get you,” “want to steal from you,” “want to use you,” “are selfish,” “deceive you,” “will take advantage of you if they can,” and “are trouble.” (2000, p. 45).

The next aspect of mistrust was participants’ sense of vulnerability. Both Ms. Knight and Waters expressed their sense of vulnerability. While the sense of vulnerability may be connected to the participants’ past experiences, the incidence of the victimization of older adults has been recognized and is often reported in the media. As documented by the National Institute on Aging (May, 2006) older adults are:

often targets for robbery, purse snatching, pick-pocketing, car theft, or home repair scams. They are more likely than younger people to face attackers who are strangers. During a crime, an older person is more likely to be seriously hurt than someone who is younger (National Institute on Aging, May, 2006, p. 1).

We need to advocate for safer neighborhoods and strengthen “Neighborhood Watch” programs.

5.1.4 Theme four

The fourth theme was difficulty with activities of daily living/instrumental activities of daily living. Desai, Lentzner and Weeks (2001) found unmet needs were common with age and disability. Several of the participants were confined to their homes except for doctor visits. Also, it seemed housekeeping standards had gradually eroded for several of the study participants, specifically for example, Ms. Flowers, Ms. Knight, and
Ms. Roebuck. When participants realized they could no longer safely perform daily living chores, they either avoided completing them or claimed the chores were no longer a priority as they once were. Ecological theory was relevant in understanding older adults’ difficulty with daily living tasks and chores. As noted by Charmaz (1991):

> When those who are ill try to organize their lives, they weigh and measure what they can do and the importance of doing it; “they make trade offs”... These people simplify their lives, reorder their time, and juggle and pace their activities to fit their lives.” (p. 143).

Two participants, Ms. Clay and Ms. Waters, appeared physically unkempt. Ms. Waters’ living environment was also in deplorable and filthy condition. There were cockroaches in three apartments, and some homes were in need of cleaning. Ms. Clay had on layers of dirty clothes and a pajama bottom. Wiener (1975) observed that:

> As simplified routine grows familiar, it seems normal to the ill person but perhaps bizarre to others. Thus, isolated and depressed ill people “normalize” wearing dirty clothes, living in pajamas, and bathing infrequently (in Charmaz, 1991, pp.146-150).

In situations where seniors would otherwise be evicted because of their failure to maintain minimum housekeeping standards, a case manager suggested property managers and staff appropriately and promptly address any problems identified during annual inspections and avoid waiting only for the problem to magnify, and, thus, require major legal intervention. The case manager maintained that the eviction of an elderly person from his or her apartment is a problem because there would now be a “senior who is homeless.”

The ability to manage one’s finances is an important factor for independent living.
However, two of Adult Protective Services’ participants had difficulty managing their finances. It is estimated that 5% to 10% of older adults living in the community could benefit from daily money management. Daily money management programs provide assistance with routine tasks such as paying bills, preparing checks for signature, making bank deposits, and dispensing cash (National Center on Elder Abuse, June, 2003). The National Center on Elder Abuse (June, 2003), outlined older adults who would benefit from daily money management service. They included those with:

cognitive impairment, arthritis or other conditions that limit the person’s ability to write, visual impairment, vulnerability to pressure or undue influence, the loss of a spouse, family member or friend who previously handled the person’s finances, limited literacy in English and/or in the elder’s primary language, lack of familiarity with standard banking, credit, and tax practices (e.g. recent immigrants) (pp. 7-8).

The areas of financial management in addition to the growing incidence of financial exploitation of older adults were of concern to the Adult Protective Services’ supervisor and the case managers. Some suggested programs to help seniors with check writing and bill paying. One case manager suggested a bill box and described it this way:

To help seniors pay their bills, have the senior put the bills in a box. An agency to come out once each month to organize it, making sure the bills are paid. The senior writes the amount, signs the check and have them paid. The senior must have money in the account. This prevents utilities shut off, disconnection. Ensures continuity in services. Some seniors might get paranoid the person is taking their money, but these should be reputable individuals, agencies (N. Cole, personal communication, October, 2006).

About financial exploitation, a case manager recommended:
Stiffer penalties for those who scam the elderly. A lot of the time it’s too late. The monies are not discovered, leaving the senior vulnerable. The scammer goes on to another vulnerable senior. It needs to stop. Can be reason for self-neglect. Can be reason for already self-neglectful situation getting worse (A. Johns, personal communication, October, 2006).

5.1.5 Theme five

The fifth theme was participants’ inadequate resources and lack of services to help them maintain their support systems and to pay for necessities such as heat to keep the home warm, their prescription medication, and home repairs. Previous studies (Bozinovski, 1995; Lauder et al., August-2005; Vinton, 1991) had found inadequate resources and lack of needed services among older adults identified as self-neglectful. This finding had relevance to ecological theory and is a significant aspect in the study of self-neglect because studies show that lack of services contributes to self-neglect.

The literature supports the findings in this study, specifically, the problems that confronted widowed participants. For women, living longer translates to “higher health costs, and a lack of adequate personal assets or governmental assistance,” and, thus, they are at greater risk for living in poverty during old age (Bolig, Borkowski & Brandenberger, 1999, pp. 67-69). A recent study estimated that in 2005, older women were estimated to have a poverty rate of 12.3% (Administration on Aging, 2006).

In addition to the lack of adequate financial resources to pay heating bills and buy medication, some homeowners are unable to afford to repair their homes. Previous studies, which cite the lack of adequate social support services as a contributing factor to
self-neglect, have been reinforced in a recent study (Lauder, Anderson, and Barclay, Aug., 2005). Lauder and his colleagues maintained that:

More fundamentally, circumstances of self-neglect need to be firmly embraced as a legitimate indicator of need for support services, along with the other, better established, community care groups (p. 324).

Future studies of self-neglect should include these segments of self-neglectful elderly: widows, widowers, caregivers, and homeowners.

5.1.6 Theme six

The theme of pride in self-sufficiency is consistent with previous studies (Byers and Lamanna, 1993; Dubin et al., 1988; Longres, 1994; Vinton, 1991) that found that due to sense of pride, some older adults are often reluctant to ask for or accept help. A symbolic interactionism perspective in this study helps us to gain a deeper understanding of why a behavior that may be interpreted as refusal of services can also be perceived by the older adult as an assault on their sense of pride. This sense of pride could translate into service refusal among older adults identified as self-neglectful. As observed by Rathbone-McCuan and Bricker-Jenkins (1992),

Professional intervention might be unnecessary if all aged people were capable of self-care tasks sufficient to assure their well-being and if, when assistance was needed, they could receive help without fear, loss of dignity, and loss of personal control. Unfortunately, these are not the real conditions that face many elderly persons...(pp. 20-21).
5.1.7 Theme seven

The manner in which older adults view themselves should be taken into account when working with them. In this study, participants recalled their memories of who they were when younger and things they felt they had done well, and how they had “extended” themselves to other people who they thought were in need of their help. By sharing resources with and giving to others, some participants like Ms. Summer believed things would work out for them. The importance of incorporating the older adult’s “sense of history-who they are, who they were when younger” in the therapeutic process has been identified in the self-neglect literature (Longres, 1994). The findings in this study illustrate the importance of life review with older adults. We must provide the opportunity to those older adults who are still capable of communicating their “sense of history” and telling their stories. Perhaps understanding their “sense of who they were and are in the process of becoming,” we could ease some of the resistance and find a common ground in providing those services that would best meet their needs as they define them. Coleman (1999) found that:

Personal identity rests on one’s whole life story. Yet service providers often do not sufficiently acknowledge a person’s strengths as being relevant to their current condition….Assessment schedules should help place “deficiencies” in their proper context, starting from people’s own view of themselves and their lives (pp. 66-67).
5.1.8 Theme eight

The eighth theme that emerged was participants’ experience of unfulfilled dreams. Some participants talked about childhood aspirations, such as the dream to become nurses, dreams for a well-paying employment, and having and raising children that were left unfulfilled. The ecological framework was also relevant to this theme due to the fact that some of the participants attributed their lack of inadequate resources in late life to perhaps earlier dreams that were left unfulfilled. This theme shares similarity to the previous theme and both demonstrate the essence of life review among older adults. Although these participants were unable to attain some of the personal goals that they had set for themselves, they sounded content with their lives. As documented by Coleman (1999):

> Older adults seem to suppress former dreams and desires, and many are aware of the necessity to find new goals. They refer more to wanting peace and quiet. Fulfillment is spoken of in terms of satisfaction or contentment, implying acceptance of life conditions, rather than of happiness as a state of feeling consequent upon achievement (p. 58).

5.1.9 Theme nine

The connectedness to places and things or “attachment” to familiar environments has been extensively researched (Cookman, 1994; Proshanky, Fabian, & Kaminoff, 1983; Rowles, 1979), and has also been documented in a study of self-neglect among the elderly (Bozinovski, 1995). Relph (1976) believed that “through a personal attachment to geographically locatable places, a person acquires a sense of belonging and purpose which give meaning to his or her life” (Proshansky, Fabian, and Kaminoff, 1983, p. 60),
and for these participants, “the past is retained through the place” (Rowles, 1979, p. 166). For example, in this study Ms. Waters said she had lived in her house for “fifty years” and had her animals there, and then she asked, “Why should somebody take me out of my house?...” Similarly, Ms. Roebuck said she had lived in her house “since 1952” and for her that was the “perfect place” to retire. This theme was important in understanding the use of ecological theory in the study of self-neglect among older adults. As people age, their physical ability diminishes and, thus, the environment becomes challenging. However, most older adults prefer to remain in familiar environments due to physical as well as psychological reasons. Relph (1976) recognized that “Without exception, the home is considered to be the ‘place’ of greatest personal significance on one’s life—‘the central reference point of human existence” (Proshansky, Fabian, and Kaminoff, 1983, p. 60). The importance of and the interconnectedness between “place identity” and the process of life review for the aging person as he or she experiences physical and psychological decline has been most poignantly stated by Rowles (1979), who put it this way:

As people grow older, and physiological and psychological capabilities become progressively impaired, physical participation in environment becomes increasingly supplanted, and gradually supplanted, by emotional and vicarious participation in place. As this occurs, and as reminiscence and processes of life review become more significant (Butler, 1963; Lewis, 1971; McMahon & Rhudick, 1967), place past and hence autobiographical insideness assumes increasing importance. Place becomes a scrapbook, a repository for the drama of one’s life as selectively construed with the vision of hindsight—it conveys ongoing identity (p. 165).
Like several participants in this study, most older adults want to remain in their homes even if their safety and autonomy are compromised by a decrease in their functional abilities to provide self-care and by homes that are old, in need of repair, and no longer able to meet the physical demands posed by changing needs (Sanford & Butterfield, 2005, p. 389). A case in point, Ms. Summer did not want nursing home placement; she would do everything possible to remain in her home.

In a survey of nursing home residents, 95% of those interviewed reported that they had either been a victim of neglect or witnessed the neglect of another resident (Gibbs and Mosqueda, 2004). Although some nursing home facilities do provide good care and are well managed, and many adults of all ages do go to these facilities for short-term rehabilitation and return home safely, we must never ignore the fact that some residents do suffer abuse and neglect and that most elderly persons consider placement in these facilities as “warehousing” of the aged and as the last stop before death. Older adults must be provided with other options such as remaining at home and hence services to support aging in place, which are needed more now than ever.

Although there is need for home modifications, it is believed that these services are currently inadequate (Sanford & Butterfield, 2005) and that the majority of older adults who need home modification services to help them remain in their homes lack the resources necessary to do so. It is estimated that while 2.1 million households with older
adults would benefit from these home modifications, only 1.14 million have them
(Sanford & Butterfield, 2005). Pynoos, Liebig, Overton, and Calvet (1996) have cited
factors that are believed to contribute to the lack of home modifications. These factors
are:

1) Limited awareness of home modifications among older adults,
2) Institutional appearance associated with many modifications,
3) A lack of affordability, limited funding for home modification
   programs, and a fragmented, difficult-to-access service delivery
   system that includes few providers with expertise in both the needs
   of older adults and environmental modifications to meet those

Advocating for funding and programs should be made available in order to
provide seniors with these options, such as needed home repairs and modifications.
Reputable agencies should be identified, licensed, and regulated for home modifications
for older adults. Most importantly, we must advocate for better quality of care in our
acute and long-term care institutions and help provide public education that will
ultimately change the negative perceptions about institutional care. The significance of
personal objects to older adults is discussed next.

Ms. Waters was a hoarder and had a strong connection to the things and objects in
her home and surrounding environment. Her house had been “cleaned out” about one
year and a half previously. However, she had reverted to the same behavior, and at the
time of the study she herself stated that she had “stuff and mess” in her house. When Ms.
Waters described the things and objects that were taken from her house at the time of the
clean out and those that she still had in her home, she attached a personal significance
and meaning to them. I reviewed the literature on the significance of personal objects and
the meanings attached to those objects by the participants and found documentation to validate the findings in this study. The significance of personal objects to older adults has been documented among the general elderly population (Cookman, 1994; Rubinstein, 1992) and specifically among Adult Protective Services’ clients identified as self-neglectful (Bozintoshki, 1995). In a study that asked older adults to personally name objects and discuss their meanings, Rubinstein (1992) noted a number of themes from the analysis of responses that were provided by informants in his study. These were:

1) objects’ roles as connection to other people,
2) in representing the self,
3) in enhancing defense against deleterious change,
4) as objects of care,
5) as foci of sensuousness,
6) and as representation of the past (p. 58).

Almost all the themes cited above in Rubinstein (1992) study were common to the meanings that Ms. Waters attached to the things and objects that she had in her house.

Ms. Waters talked about her “pictures and things from special friends.” She said she “have a lot of good friends that gave [her] things...a lot of good friends...real nice people who had given [her] things over the years...” Similarly, a woman in Rubinstein’s (1992) study was quoted as saying, “everything you see here is a gift” (p. 64). These findings, according to Rubinstein, illustrate the significance of “other peoples’ high regard for her” and her view that “people love to give her things” (p. 64). Thus, these items that Ms. Waters talked about showed other peoples’ “high regard” for her and connected her to them. According to Rubinstein, Ms. Waters’ “little heater” was the object that served as a “defense against negative change and events” (p. 65).
Three participants in this study had pets, and these are referred to as objects of care (Rubinstein, 1992). Objects of care are believed to “generate a feeling that one is needed, a feeling that is often highly valued by older people” (Rubinstein, 1992, p. 66). Cookman (1994) also believed that animal companions are a “great source of emotional comfort and support for some older people” (p. 104). In a study of self-neglect, Lauder, Anderson and Barclay (2005) suggested the significance of pets as they may be the “most important form of friendship and comfort to the self-neglecters” (p. 321). In this study Ms. Waters, Ms. Lane, and Ms. Knight had pets. However, for Ms. Waters these pets had a special meaning. Although at the time I met her, the pets were not receiving the care that they needed, Ms. Waters described her pets as family and objects of care.

The decision making process involved in what to discard and what to keep may not come easy, as demonstrated by Ms. Waters and Ms. Lamb. Ms. Lamb had bought a shredder and had piles of papers in her house, but she had yet to sort them out. In contrast, Ms. Roebuck said she was getting rid of the paperwork because she did not want to get overloaded with too much paperwork. While others may want to let go, others may want to hold on to “stuff” because these objects may have deeper meaning. Clearly, the objects, things, and items that older adults may have in their home and surrounding environments might have more significance to them than to other people.
5.1.10 Theme ten

In this section, I discuss the tenth and last theme and cite some of the examples from the data analysis. The tenth theme was God, prayer, and coping mechanisms. One participant, Mr. Wells, was engaged in “self-enhancement” whereby he described that other people, specifically those who ambulated with the aid of assistive devices such as wheelchairs, were worse off than himself. He added that he was satisfied with his life. Mr. Wells felt better about himself when he would compare himself to others. According to Taylor, Jones and Burns (1998), “self-enhancement” occurs “when persons can increase their subjective well-being through comparison with a less fortunate other” (219).

Nine participants overwhelmingly shared their beliefs and strong sense of spirituality and faith. Spirituality is defined as the “life principle that pervades a person’s entire being and that integrates and transcends one’s biologic and psychosocial nature” (Taylor, Jones & Burns, 1998, p. 215). The use of spirituality as a coping mechanism among chronically ill persons has been documented and is perceived as a “will to wellness” (Taylor, Jones, & Burns, p. 215). Two male participants, though not very vocal about their beliefs like the female participants, had religious symbols mounted in their apartments. Older adults who engage in the use of spiritual and religious resources may find meaning even when faced with multiple challenges (McFadden, 1996). For example, several participants shared they read the Bible, prayed, and believed in God. Understanding the subjective meaning of God, spirituality and prayer as a coping mechanism among older adults identified as self-neglectful will be critical in addressing some of the barriers to effective intervention. Some
older adults may refuse needed services while relying on prayer alone and the belief that God will “provide.” Hopefully, counseling these older adults will provide the insight that God has the ability to help them through these community agencies and the service delivery personnel. Further studies focusing on spirituality and older adults who are identified as self-neglectful are needed.

5.2 Implications

The data obtained from 12 older adults, who were identified as having met criteria based on Adult Protective Services’ definition of self-neglect and willingly participated in this study, provided thick descriptions of their subjective experiences of self-neglect and the meaning of those experiences. Giving these findings, the major question to now ask is, “What does it all mean?” A critical aspect of the remaining pages in this dissertation is to illustrate how these findings will impact social work practice and service delivery for older adults who are identified as self-neglectful.

As previously stated, the rationale for this study focused on the applicability of the current definition of self-neglect to the general elderly population identified as self-neglectful. The Adult Protective Services’ and others’ definitions of self-neglect are a problem because they focus on the individuals and blame the individuals instead of looking at the social, structural system that contributes to self-neglect. This “blaming the victim” definition of self-neglect leads to interventions that focus on the individual level rather than the societal structural level. Thus, many individual interventions will fail to get at the root causes of the problem.
The United States elderly population is very diverse for generalization on a subject matter as sensitive as self-neglect. It has been documented that the broad application of this definition is problematic (Griffin, 1994) and that it would negatively impact intervention and service provision in situations where the elderly perception differs from the professional conducting the investigation (Moon, & Williams, 1993). Factors such as age, marital status, educational attainment, income, living arrangement, level of social support, degree of impairment, etc., varied. While it may be impossible to have different definitions of self-neglect for every ethnic group or community, there is a need to develop an understanding of the uniqueness of every older adult, to understand the complexities of their presenting concerns, and to find a common ground in addressing those concerns. While the findings of this study highlight the commonalities of those older adults who are identified as self-neglectful, they also point to the heterogeneity among self-neglectful older adults. As in Bozinovski’s study (1995), the 12 participants in this study did not “interpret” their situation as self-neglect although participants talked about chronic health issues, pain, weakness, inadequate resources, and lack of supportive network.

Although some may not assign blame to older adults for their self-neglecting behaviors, the name is “problematic” and professionals should reconsider a change. There is abundant evidence (Bozinovski, 1995; Griffin, 1994; Longres, 1994; Rathbone-McCuan and Bricker-Jenkins, 1992; Lauder et al. 2005; Vinton, 1991; Woolf, 1998) that the majority of older adults who are identified as self-neglectful have multiple service needs. Factors such as inadequate income and services for financial management,
crime prevention and drug and substance abuse programs for potential care givers to their elderly parents, lack of resources/services to assist elderly homeowners to make needed repairs on their homes, transportation, lack of adequate coverage for dental care, the poor care and high incidence of abuse and neglect in nursing homes and other health care facilities, economic injustices and gaps in service utilization (Richardson, 1992; Spence & Atherton, 1991), all come to bear on self-neglect. Advocating for funding geared toward senior preservation services/programs would sound more acceptable than funding for prevention of self-neglect. The provision of effective intervention and prevention of self-neglect among older adults goes above and beyond most agencies’ resources. Addressing the major issues of self-neglect amid a diverse growing elderly population requires both individual and societal interventions if we are to eliminate the factors that lead to self-neglect. In addition, social workers must strengthen individual older adults and their families, build supportive communities, and advocate for stronger governmental action to prevent and address self-neglect. It takes a family, a community, a responsive government, and a society to adequately address the multi-layered and complex problem we refer to as “self-neglect” if we are to protect and preserve our seniors.

Before the study was undertaken I talked with friends, colleagues, and professionals in different communities regarding self-neglect among older adults. One question that emerged from those conversations was, “How do you define ‘self-neglect,’ and are you going to ask these seniors if they had been self-neglectful?” A friend stated, “These seniors are not self-neglectful, they need help with meals, transportation, and they need our support” (A. Washington, personal communication, Apr., 2006). In another
communication, an APS administrator stated that “…most older adults do not identify as self-neglecting…” (C. Smith, personal communication, Apr., 2006). The themes that emerged from these conversations were consistent with the findings from the data gathered from the 12 participants who were interviewed for this study. These older adults did not interpret their behaviors as self-neglectful. When asked what they would say to someone who might see their unmet needs like not making necessary repairs on the house, not having enough money to buy food, etc., the study participants responded that they “take care” of themselves, do their “best to make ends meet,” they prioritize and “let other things go.” The 12 older adults who were interviewed for this study did not interpret their behavior/actions as self-neglectful.

5.2.1 Summary

The goal of this dissertation was to contribute to knowledge in self-neglect. In this study, self-neglect was examined within the context of three theoretical frameworks: compliance, ecological with a focus on the life course perspective, and symbolic interactionism. The older persons who were deemed self-neglectful in this study were less likely to comply with medications and treatment regimens and they mistrusted healthcare professionals. Some themes that emerged from this study resembled those from previous studies of self-neglect such as Bozinovski (1995) and Longres (1994), but some also differed in that they were new and not previously reported. Themes such as participants’ perceptions of health/medical care seeking behavior, difficulty with ADLs and IADLs, God, prayer, and coping mechanisms were themes that had not been previously identified.
5.2.2 Recommendations for future research

The establishment of a strong knowledge base is critical to understanding the complexities involved in elder self-neglect. Furthermore, research is needed to determine the incidence and prevalence of self-neglect among different segments of the elderly, and we need more qualitative and quantitative studies. Future research on self-neglect must investigate the following areas:

1. Comparative studies of self-neglect among Caucasian and other ethnic minorities.
2. Self-neglect among seniors providing care to frail spouses and other family members.
3. Quantitative studies of self-neglect among older adults involved with APS and those in other settings.
4. Self-neglect among elderly men as a group.
5. Self-neglect and the nature of neglect (i.e., diet and nutrition, housing repairs, hoarding) among elderly persons, home owners.
7. More qualitative studies focusing on the views of older adults identified as self-neglectful.
8. Surveys of different communities and residents, including older adults who have not been identified as self-neglectful, to determine what people associate with the word “self-neglect.”
5.2.3 Implications for social policy and social work practice

The findings from this study have policy and practice implications. Thanks to the efforts of senior advocates, elder abuse and neglect has received some attention, but the majority of the referrals that are received by agencies designated to receive reports of abuse and neglect are those who might be self-neglectful. As the American elderly population changes and the need for social services increases, social policy must change to adequately address these changing needs.

The subject matter of self-neglect is complex, the factors that contribute to it are multiple, and the task at hand is as challenging as both this subject matter and multiple factors would indicate, but I believe this combination also provides an opportunity for social work to live up to its historical commitment to helping those in need of their expertise. Social work should assume greater educational and advocacy roles in serving the elderly. Social work education must pay close attention to the inclusion of gerontology programs and encourage students from diverse backgrounds to commit to these programs if we are to adequately address the diverse needs of our aging population. This will increase the probability that even those who are old and may be vulnerable, when provided with the resources and services they need, will continue to contribute and feel useful to our society.
5.3 Limitations of the Study

As with every qualitative research study, the results from the findings of this dissertation have several limitations. Lincoln and Guba (1985) discussed several methodological issues that pose limitations on the findings of qualitative research. In this study, the sampling technique, issues pertinent to trustworthiness, interviewing only study participants, and conducting one interview per participant posed limitations.

The use of purposive sampling, which is intended to afford “maximum variation,” may also pose limitations for generalizability of the study’s findings (Lincoln and Guba, 1985). Given the qualitative nature of the research design in this study, random sampling would have not have been appropriate and therefore was not used. Rather, purposive sampling techniques were utilized. This study’s sample consisted of 12 participants, which was considered small and posed another limitation of the findings.

Another limitation pertains to trustworthiness. Three participants were not available at the time of member checks, which posed another limitation. Had I conducted more than one interview per participant and, perhaps, interviewed family, service delivery personnel, or health care providers, these methodological issues would have been addressed, which would have increased the trustworthiness of the study. However, I have provided thick descriptions from the data gathered from the 12 participants, and I triangulated these findings with other studies of self-neglect in the literature. The findings of this study are not intended for generalizations to the self-neglectful among the general elderly population. Rather, these findings are limited to those older persons from whom the data were collected.
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APPENDIX A

LETTER TO AGENCY ADMINISTRATOR – AGENCY 1
Dear ________________

My name is Mamie Mariama Gombeh-Kutame and I am a doctoral candidate in the College of Social Work at the Ohio State University working under the direction of Virginia Richardson, Ph. D., Professor in the College of Social Work. I am in the process of conducting a research study, “Understanding Self-Neglect from the Older Person’s Perspective,” as partial fulfillment for my doctoral degree. I am writing to ask for your support in identifying staff members who will introduce my study to clients served by your agency; adults 60 years or older who may have experienced self-neglect and are willing to share their stories.

I have been a social worker for the last eighteen years and have, for the most part, worked with older adults. During these years, I have grappled with the various definitions of self-neglect. Self-neglect is a complex and poorly understood phenomenon. However, most of the experiences of self-neglect in the literature have been inferred from those who have not directly experienced self-neglect. We need to understand the perspectives of elderly persons who have been identified as self-neglectful because self-neglect is the most common and accounts for the majority of Adult Protective Service referrals. Furthermore, self-neglect is the most problematic in the elder abuse and neglect literature and has been linked with diminished quality of life and is associated with high mortality.
rates. Therefore, we need to understand the “perspectives and experiences” of elderly persons who have been identified self-neglectful if we hope to serve them more effectively and help address the social, structural system that contribute to self-neglect among older adults.

The methodology for the study will be qualitative in nature. The aim of the study is to gain a deeper understanding of self-neglect from the perspective of older persons. The overarching research questions for this study are: “What is the lived-experience of the elderly persons who has been identified self-neglectful? And what are the meanings of those experiences?”

A total of fifteen elderly participants will be needed in order to complete the proposed study. The data collection procedure will consist of one face-to-face interview. The interview will be audio taped, transcribed verbatim and analyzed. The findings from the study will become my dissertation. I pledge to uphold confidentiality of each participant; no names will be used in the final report and no information will be reported in such a way that others can identify the client.

Please let me know in writing if you will be able to assist me. If you have any questions or suggestions, I can be reached at (773) 782-0398 or by email at kutame58@comcast.net.
Thanking you in advance for your support and in helping me complete the final phase of my doctoral study.

Sincerely,

Mamie-Mariama Gombeh-Kutame
Doctoral Candidate
APPENDIX B

LETTER TO AGENCY ADMINISTRATORS-AGENCY 2
Dear __________

My name is Mamie Mariama Gombeh-Kutame and I am a doctoral candidate in the College of Social Work at the Ohio State University working under the direction of Virginia Richardson, Ph.D., Professor in the College of Social Work. I am in the process of conducting a research study, “Understanding Self-Neglect from the Older Person’s Perspective,” as partial fulfillment for my doctoral degree. I am writing to ask for your support in identifying staff members who will introduce my study to clients served by your agency; adults 60 years or older who may have experienced self-neglect and are willing to share their stories.

I have been a social worker for the last eighteen years and have, for the most part, worked with older adults. During those years, I have grappled with the various definitions of self-neglect. Self-neglect is a complex and poorly understood phenomenon. However, most of the experiences of self-neglect in the literature have been inferred from those who have not directly experienced self-neglect. We need to understand the perspectives of elderly persons who have been identified as self-neglectful because self-neglect is the most common and accounts for the majority of Adult Protective Service referrals. Furthermore, self-neglect is the most problematic in the elder abuse and neglect literature and has been linked with diminished quality of life and is associated with high mortality rates. Therefore, we need to understand the “perspectives
and experiences” of older persons who have been identified self-neglectful if we hope to serve them more effectively and help address the social, structural system that contributes to self-neglect among older adults.

The methodology for the study will be qualitative in nature. The aim of the study is to gain a deeper understanding of self-neglect from the perspective of older persons. The overarching research questions for this study are: “What is the lived experience of the elderly persons who has been identified self-neglectful? And what are the meanings of those experiences?”

A total of fifteen elderly participants will be needed in order to complete the proposed study. The data collection procedure will consist of one face-to-face interview. The interview will be audio-taped, transcribed verbatim and analyzed. The findings from the study will become my dissertation. I pledge to uphold confidentiality of each participant; no names will be used in the final report and no information will be reported in such a way that others can identify the client.

Please let me know in writing if you will be able to assist me. If you have any questions or suggestions, I can be reached at (773) 782-0398 or by email at

kutame58@comcast.net.
Thanking you in advance for your support and in helping me complete the final phase of my doctoral study.

Sincerely,

Mamie-Mariama Gombeh-Kutame
Doctoral Candidate
APPENDIX C

LETTER TO STUDY PARTICIPANTS
Dear ____________________________

Thank you for your interest in participating in my research study that seeks to understand your experiences as they relate to unmet needs like food, clothing, housing, medical care etc., which are necessary for your physical, mental health and well-being. Your participation in this study will help me write my dissertation to complete the final phase of my Doctor of Philosophy education at the Ohio State University.

Your sharing personal information about your life experiences and the meanings you assign to those experiences during my interview with you will not only help me understand how you define areas of your unmet needs but assist me in designing programs and services that might be helpful to you and other seniors who may be in a similar situation.

During our meeting, I will use a tape recorder to record our conversation. We will meet once for about two or three hours. Personal information such as your name, address and family situation that you may share with me will be kept private and not be given to anyone. The tape recorder that will record your voice will not have your name written on it. Instead, a number will be written to disguise your name. On the day of our meeting, you will have the right to refuse the interview and if you change your mind and decide to not participate in my study you can ask me to turn off the tape recorder to end the
interview.

Again I thank you for your willingness to share your thoughts with me on issues that are very personal to you, and I look forward to meeting and talking with you.

Sincerely,

Mamie-Mariama Gomboh-Kutame
APPENDIX D

BIOGRAPHIC SHEET
Name:__________________________________________________________________

Address:________________________________________________________________

Phone Number:______________________________________

Age:_______________________________

Marital Status: Married____ Separated_____ Divorced_____ Single _____ Widowed____

Gender: ______________________________

Race/ethnicity: ___________________________

Educational Level:_______________________________________________________

Income: ________________________________
APPENDIX E

OSU CONSENT FORM
The Ohio State University Consent to Participate in Research

Study Title: Understanding Self-Neglect From the Older Person’s Perspective
Principal Investigator: Virginia E. Richardson, Ph.D.
Co-Investigator: Mamie Mariama Gombeh-Kutame

Sponsor: None

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose: The purpose of this study is to understand what it feels like to experience unmet needs in areas such as food, clothing, shelter, and medical care, providing goods and services that you need to maintain physical, mental health, emotional well-being, general safety, and/or managing financial affairs. Also, another purpose of this study is for you to help me understand how you perceive your situation and the meanings that you assign to your experiences.

Procedures/Tasks: Interview-You will be asked series of questions and the conversation will be audio-taped.

Duration: The interview will take between two to three hours.

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.
Risks and Benefits: There are no known risks to this interview. The benefits of this study and the information you provide will contribute to our knowledge and understanding of how you experience those unmet needs related to goods and services that are necessary to maintain good health, general well-being and safety and to help develop and make available services that will address and possibly meet those.

Confidentiality: I pledge to uphold confidentiality. Your name, address and/or any personal information that will identify you will not be made public and will be destroyed as soon as I write my dissertation.

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives: A small token of appreciation in the sum of $10.00 will be given to you at the end of the interview. You will still receive the $10.00 incentive even if you withdraw from the study.

Participant Rights: You have the right to refuse to be interviewed, to end the interview at anytime or request the audio-tape be given to you if you decide that the information you provide during the interview not be used in the study.

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.
An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions: Dr. Virginia Richardson (614-292-1507) and/or Mamie Gombeh-Kutame (773-782-0398).
For questions, concerns, or complaints about the study you may contact Dr. Virginia E. Richardson (614-292-1507) and/or Mamie Gombeh-Kutame (773-782-0398).

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact Dr. Virginia E. Richardson at 614-292-1507 and/or Mamie Gombeh-Kutame at 773-782-0398.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

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| Relationship to the subject | Date and time |
**Investigator/Research Staff**

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

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APPENDIX F

INTERVIEW GUIDE
Interview Guide

1. As you go through the day in providing for yourself necessities like food, clothing, housing, medical care, general safety etc., which of these areas do you feel you need help with?

2. Given the areas you have described as needing help with, have you always had problems in these areas? What do you think has changed to make the problem more difficult for you to manage now than before?

3. Some people might see your having unmet needs in these areas like not making necessary repairs on the house, not having enough food in the house, not having a well maintained house, etc., in a sense as not taking care of yourself the way you should. What would you say to some one who might say something like that to you?

4. What does it feel like to experience unmet needs in areas like food, clothing, housing, and medical care, physical health, mental health, emotional well-being and general safety, and/or managing financial affairs?

5. What are some of the things that keep you going from day to day? How would you describe those things?

6. What does it feel like to have the kinds of experiences you have shared with me? And what meaning would you assign to those experiences?