

Immigrant Elder Women and Their Long-term Care Planning

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Dedicated

In Loving Memory

To

Dad and Nanny,

And

Sheldon, too

Acknowledgements

While a social worker in aging and health care services, I came across older adults from many different walks of life. While there were many different kinds of diversity represented, I noticed that policies and programs were geared toward a generic older adult, but also stressed the need for culturally competent or bilingual-bicultural staff. This created a tension of conflicting mandates that left some without the services they needed.

To address the needs of all older adults, several components need to be in place. First, there needs to be acknowledgement of the biases engrained in the current policies and programs. Second, information needs to be gathered across the diverse population of older adults. This research provides new insights into some of these information gaps. It was only made possible by the generosity of the immigrant elder women who shared their stories and information through this research.

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Abstract

The older adult population continues to grow in numbers and in diversity. In preparing for this increasingly larger and more diverse older adult population, it is important to understand what their long-term care needs, wants and expectation are. This research focuses on immigrant elder women and their long-term care plans. This is a descriptive study which utilized qualitative and quantitative research methods by interviewing 13 immigrant elder women. They were recruited primarily through the International Women's Club in Monroeville, Pennsylvania.

This research has four major findings regarding immigrant elder women's long-term care plans. These immigrant elder women plan to remain living in the United States instead of returning to their county of nativity during older adulthood. These immigrant elder women plan to remain living in their own home for as long as possible, financially and medically. Immigrant elders do not wish to be dependent on their families to meet their long-term care needs. When the time arises that they may need paid care, these immigrant elder women are more concerned with having competent caregivers than with cultural issues. These findings parallel trends regarding long-term care plans and concerns of the general older adult population. This may be due to a combination of factors, such as: country of nativity, socio-economic status, availability of children as social supports, a multicultural identity, and level of acculturation and cultural allegiance.

Recent policy developments support increasing home and community based long-term care services. These changes in policies and programs should continue to be expanded to better meet the needs current and future older adults, including immigrant elder women.

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1. Introduction

The older adult population in the United States is growing in size and in its proportion to the rest of the American population. Since 1994, the older adult population (65+ years) has increased from 3.1 million to 36.1 million; this is 12.4% of the American population (Greenberg, 2005). By 2010, the older adult population is projected to increase to 40 million, a 15% increase for the decade (Greenberg, 2005); this is approximately 20% of the American population (Angel & Angel, 1999). By 2020, the older adult population will increase an additional 36% to reach 55 million (Greenberg, 2005). In a similar fashion, the older adult population that is 85+ years will increase 40% by 2010 and an additional 44% by 2020 (Greenberg, 2005). The upcoming cohort of older adults requires special consideration regarding its long-term care needs due to its numbers and rate of growth.

Living arrangements and level of care are critical factors in projecting older adults' long-term care needs. Long-term care includes a wide variety of care and support services at home and within facilities. In 1999, approximately 11 % of older Medicare enrollees receive assistance with their personal care from paid or unpaid caregivers (Greenberg, 2005). Approximately 5% of older adults reside in long-term care facilities (Hooyman & Kiyak, 2008). Of the non-institutionalized older adults, 31% live alone (Greenberg, 2005). This implies that a fair portion of older adults is receiving care in the community from staff, family and friends.

Nearly 90% of older adults indicate that they would like to live "in my home" while they age and not live in their relatives' homes or in a long-term care facility (Novelli, 2006). While "my home" may be the option of choice, older adults may not have the required resources to meet changes in their care needs. One study showed that 30% of older adults would prefer to die than to be placed into a nursing facility (Mattimore, et al., 1997). For 70% of older adults where they

are living on their 65th birthday will be where they will live the rest of their life (Seniorsource.com, n.d.).

In their later years, older adults have a 40% of risk of needing to be placed into a nursing facility (American Association of Homes and Services for the Aging [AAHSA], 2006a). In any given year, about 10% of older adults spend some time in a nursing facility for a short-term respite or rehabilitation stay or permanent stay (Mattimore, et al., 1997). It is projected that 43% of older adults will be admitted to nursing facilities for needed care some time prior to their death (Mattimore, et al., 1997). By 2020, the number of older adults requiring long-term care will reach 12 million (AAHSA, 2006a).

Long-term care services will need to prepare for the complexities of larger numbers of older adults. Grounded on the assumption of a homogeneous older adult population, long-term care policies tend to take a generic approach and fail to take into account ethnic and cultural diversity of the older adult population (Angel & Angel, 1999). The older adult population has diversity of income, education levels, family and primary caregiver networks, race and ethnicity, and language (Angel & Angel, 1999; Standford, & Yee, 1992; Taeuber, 1990). In 2004, 18.1% of older adults claimed a minority ethnic status (Greenberg, 2005). In 2010, older adults from minority groups are projected to be 8.1 million that will be 20.1% of older adults (Greenberg, 2005). By 2020, older adults from minority groups are expected to be 23.6% of older adults (Greenberg, 2005). This means that in the next several decades one in five of the older adults will have the face of a minority group. As a multicultural society, the United States must consider diversity a key factor to understand projected long-term care needs (Angel & Angel, 1999).

The results of this generic approach toward long-term care can be implied from utilization rates of formal long-term care services for older adults of minority groups. Historically, older adults of minority groups have substantially lower utilization rates of formal long-term care services than non-Hispanic Whites (Dilworth-Anderson, Williams & Gibson, 2002; Wallace, Levy-Storms, Kingston & Anderson, 1998). Utilization rates of formal long-term care services continue to show a much lower rate for Asians, Hispanics and Native Americans than for Blacks, and all were lower than for Whites (Himes, Hogan & Eggebeen, 1996). Asian, Black and Hispanic older adults are more likely to live in extended family households than Whites (AARP, 2001). This would imply that older adults from minority groups are more likely to receive care in the community and would benefit from additional community supports for themselves and their caregivers. While social, cultural and financial factors can influence the utilization of formal long-term care services; the rationale for under utilization of formal long-term care services remains unknown. To date there have been few studies focusing on how to measure culturally competent care and its consequences (Geron, 2003). The assumption that culturally competent care is good has not been based upon research (Geron, 2003). There is a need to explore the long-term care needs and expectations of older adults across ethnic and racial groups—including immigrant elders from various groups.

1.1. Immigrant Elders

Immigrant elders are older adults who have immigrated to the United States. Their immigration experiences can be very different. Some may have come to United States as a child when their parents immigrated. Some may have come to America as young adults or adults for education or to launch a career. Through family reunification programs, others have come to the United States in later life to reunite with their adult children and live out the older years.

Furthermore, they may have entered the United States with a legal status of immigrant, refugee, or illegal immigrant and may have changed their citizenship status over time. Throughout this text, the term immigrant elder will refer to foreign-born older adults age 65 years and older.

The immigrant elder population provides a wealth of diversity. Immigrant elders speak a multitude of languages and come from around the globe (He, 2002). The majority of immigrant elders have lived in the United States for more than 30 years, and they are naturalized citizens (He, 2002). Immigrant elders continue to lag behind older adult native citizens in college attainment and in completing high school (He, 2002). This could contribute to immigrant elders having higher rates of living with family, rates of poverty and rates of participation in mean-tested programs than older adult native citizens (He, 2002). Due to the limits of the census questions and data, it remains unclear if economics or culture contributes to immigrant elders living with family (He, 2002). Furthermore, 45% of immigrant elders lack health insurance (He, 2002). Immigrant elders may live with their families for a combination of reasons, including: culture, economics, lack of health insurance, and their need for care.

While there has always been an immigrant presence in the United States, the composition of the immigrant population has changed over time and has become increasingly diverse. Over 53,000,000 immigrants came to America between 1820 and 1986 (Barressi & Stull, 1993). Colonists and early immigrants were primarily of European descent (Stacy & Lutton, 1985). Immigration policy continued to favor immigrants of European descent through the 1950's (He, 2002; Potocky-Tripodi, 2002; Stacy & Lutton, 1985). Likewise, Europeans constitute 38.6% of the foreign born elders (He, 2002). With the Immigration and Nationality Act Amendments of 1965, the quota system ended and opened immigration worldwide (Congress, 2009; He, 2002). Beginning in the 1960's & 1970's, there was a growing influx of immigrants arriving from Asia

and Latin America (Congress, 2009; He, 2002; Stacy & Lutton, 1985). As a result of this trend continuing, He (2002) suggests that there will be a significant increase in foreign-born elders from Asia and Latin America. Over the last fifteen years, the United States has had the largest immigration wave in history (Casanova, 2001). The immigration trend has created unprecedented religious diversity including large Muslim, Buddhist and Hindu populations (Casanova, 2001). These population changes are projected to increase the demand for formal long-term care services by the older adults from minority groups (Morrison, 1986). This demand is coupled with issues of funding and qualifying for public welfare benefits.

Historically, immigrant elders regardless of their citizenship status were considered “deserving” to receive public welfare benefits and services like all United States residents (Fix & Tumlin, 1997). This has changed in the last twenty-five years based upon a combination of immigration reforms and public welfare reforms. The Immigration Reform and Control Act of 1986 required the States to verify the legal status of immigrants applying for public welfare benefits (DeLaet, 2000). This marks the initial change in that only legal immigrants could receive public welfare benefits.

The next revolution regarding public welfare benefits to immigrants was the Personal Responsibility and Work Opportunity Act of 1996 (PRWORA) (Fix & Tumlin, 1997). PRWORA marks for the first time that legal immigrants are categorized as qualified and unqualified for public welfare benefits (Congress, 2009; Fix & Tumlin, 1997). This categorized legal immigrants into “deserving” and “undeserving”. Title IV of the PRWOA denied access to many services for foreign-born elders by tying many of these benefits to their citizenship status and year of entry (Binstock & Jean-Baptiste, 1999; Fix & Tumlin, 1997; Yoo, 2001). The

PRWORA mandated sponsor-deeming for all means-tested benefits for qualifying immigrants (DeLaet, 2000). This greatly increased the financial burden on immigrant families.

Due to immigrant advocacy groups, some retrenchment of PRWORA's restrictions occurred through the 1997 Balanced Budget Act (Fix, & Passel, 2002). Derivative Medicaid and Supplemental Social Security Income benefits were restored to all elderly and disabled immigrants who were receiving these benefits before the 1996 act (Binstock & Jean-Baptiste, 1999; Fix, & Passel, 2002; Yoo, 2001). In 1998, about thirty percent of immigrant elders made ineligible by PRWORA for federal food stamps had their eligibility restored to by the Agricultural Research Extension and Education Reform Act (National Immigration Law Center, 1998). These repeals and provisions have improved the situation for some of the immigrant elder poor population. While some immigrant elders fair well under these policies, many are left vulnerable by living in poverty and without access to health insurance or health care.

1.2. Gaps in Research of Immigrant Elders

Researchers in gerontology and immigration studies have underserved immigrant elders. Research of older adults has focused on racial differences and has created a gap in research by not focusing on ethnic, cultural, immigrant differences (Gaines, McDonald, & Wykle, 1999). The few studies regarding immigrant elders were specific to a single country of origin (Gupta, 2002; Shibusawa & Chen, 2002; McConatha, Stoller & Oboudait, 2001; Stokes, Thompson, Murphy, & Gallagher-Thompson, 2001, Ward, 2000). This has recently begun to change with the 2004 Annual Meeting of the Gerontological Society of Aging. At that conference, there were multiple presentations on immigrant elders (Choi, 2004; Falcon & Tucker, 2004; Gordon, 2004; Mui, Kang, Akashi, & Wang, 2004; Park-Lee, 2004; Sellers, & Ward, 2004; Smith, 2004; Wu & Tran, 2004). Furthermore, policy analysts have provided insight as to the ramifications of public

policy based upon nativity versus citizenship across the life span (Binstock & Jean-Baptiste, 1999; Fix & Tumlin, 1997; Yoo, 2001). Studying older adults based upon their citizenship status remains a fairly new arena in gerontology and immigration studies, which have not produced much research focused on foreign-born older adults.

For millions of adults aging in alien cultures, the host society often may be perceived as intolerant of foreigner's needs and practices (Kalache, 1995). Since foreign-born elders are presumed to have assimilated to American culture, there are few studies regarding immigrants that include elders (Gaines, McDonald & Wykle, 1999). More than four percent of legal immigrants are over 65 years old or older (Winokur, 1998). Not including these foreign-born elders creates a gap in research regarding immigrants.

This research expands upon on a mini qualitative project, which found immigrant women had multiple concerns about their long-term care (Hackman, 2003). These concerns included declining health, social support, and their need for future placement. Immigrant women's primary concern was that the facility provided quality care. A secondary concern was meeting their ethnic needs. For immigrant women considering their long-term care needs quality care was more important than having their ethnic needs met. With a larger study focusing on immigrant elder women, could similar results be found?

1.3. Purpose of the Study

The federal and state governments spend significant amount of funds to provide long-term care services to older adults (AASHA, 2006a). There is a multiplicity of long-term care services provided at home and in facilities (AASHA, 2005). With the general increase in the older adult population, the Administration on Aging predicts a significant increase in demand for all types of older adult service sectors and their staff, such as: retirement, healthcare, long-term care

(Carbonell, 2003). Currently, the government wants the long-term care delivery system to be more responsive to older adults' needs and preferences (CAS, 2003; Carbonell, 2003).

In 2005, a White House Conference on Aging convened focusing on issues in aging and the impact of the Baby Boomers (2005 White House Conference on Aging, 2005). The top ten resolutions of the 2005 White House Conference on Aging primarily supported continuing and strengthening pre-existing programs (Thompson & Wesolowski, 2005). These programs have not served all older adults equally well as demonstrated by under utilization rates for formal long-term care services by older adults of minority groups (Angel & Angel, 1999).

The increasingly ethnic and cultural diversity of the older adult population cannot be denied (Standford, & Torres-Gil, 1992; Capitman, Hernandez-Gallegos, & Yee, 1991; Hikoyeda & Gordon, 2005; Greenberg, 2005; He, 2002). The preparation, provision and financing of long-term care services needs to address the diversity of cultures, histories, circumstances, and needs of ethnic minorities (Barressi & Stull, 1993). Since the older adult population has significant diversity, research is required to identify the common needs of all and distinguish particular needs that are derived from that diversity (Standford, & Torres-Gil, 1992). In gathering information to guide their decision-making, policy makers have not given all groups equal access to voice their specific needs and preferences, such as immigrant elders.

As a response to the generic approach being taken, the Make Room for All summit held hearings and gathered testimony from panelists, experts, and consumers (Hollibaugh, 2006). This summit was held prior to the 2005 White House Conference on Aging to raise these issues and to give voice to the heterogeneity of the older adult population (Hollibaugh, 2006). While one of the top ten resolutions from the 2005 White House Conference on Aging refers to

attaining culturally competent staff (Thompson & Wesolowski, 2005), it fell short of many of the recommendations of the summit to meet the needs of a heterogeneous older adult population.

This research will provide information to policy makers as they begin to implement various resolutions to the 2005 White House Conference on Aging and the Money Follows the Person Rebalancing Initiative (2006). This purpose of this descriptive study is to learn what are immigrant elders' expectations, wants, and long-term care needs. Specifically, this research seeks to answer the following questions:

1. What long-term care needs do immigrant elders identify?
2. What long-term care concerns do immigrant elders identify?
3. What long-term planning have immigrant elders completed to date?
4. What cultural considerations do immigrant elders identify as part of their thoughts regarding their long-term care?

1.4. Relevance of this Research to Social Work Practice

The relevance of this research to social work practice can be evaluated by how it intersects with the *Code of Ethics* (National Association of Social Workers [NASW], 1996). The *Code of Ethics* (NASW, 1996) describes social workers' ethical responsibilities to the profession and others. This research is relevant to the following responsibilities outlined in the *Code of Ethics* (NASW, 1996): competence (standard 1.04 & standard 4.01), cultural competence and social diversity (standard 1.05), integrity of the profession (standard 5.01), evaluation and research (standard 5.02), social welfare (standard 6.01), social and political action (standard 6.04).

How these ethical standards of behavior intersect with this research will be explored throughout this section. The intersections are grouped into these broader topics: competence in aging, cultural competence, and immigrant elders as a vulnerable population.

Competence in aging (related standards 1.04 & 4.01). Social workers are mandated to only practice social work in arenas in which they have been trained (NASW, 1996). Due to the rising number of older adults, social workers need to be prepared to work with seniors (Yagoda, 2004). Regardless of the service setting social workers are more and more likely to interact with older adults (Council on Social Work Education, 2002) or their families (O’Neill, 2001). The social work profession is in a crisis due to a dearth in specialized social workers in aging and an increasing need for their services (O’Neill, 2001). In response, Lenard Kaye, Chair of NASW’s Section on Aging, indicates that there is a growing sentiment for the social work “profession to mobilize its resources and further develop its expertise on behalf of older citizens” (O’Neill, 2001). This research will increase the social work knowledge regarding older adults—specifically, immigrant elders. Likewise, the increase in knowledge can then be applied to increase the competence of social workers regarding this population.

Cultural competence (related standard 1.05, 5.01 & 5.02). Social workers are mandated to obtain education about cultural differences (1.05c), obtain a knowledge base of their client’s culture (1.05b), and provide culturally sensitive services (1.05b)(NASW, 1996). The first social workers to recognize a commitment to cultural sensitivity were from the settlement house tradition (Trattner, 1999). The settlement house social workers encouraged immigrants and taught the immigrants’ children to maintain and have pride in their parents’ culture of origin (Trattner, 1999). Jane Addams, founder of the settlement house Hull House, recognized that immigrants bring “gifts” of cultural diversity, which enrich American society (Trattner, 1999).

Immigrant elders bring a multiplicity of cultural diversity to the older adult population. The John A. Hartford Foundation recognizing the heterogeneity of the older adult population has funded projects in New York, Texas and Michigan with the focus to “exposed [students] to a diverse elderly population...” (Onaitis, 2004). Social work educators are urged to provide students with field experiences with diverse older adults.

The United States Commission on Civil Rights identified cultural barriers to formal long-term care services (Beserra, et al, 1982). The State units on aging and the Area Agencies on Aging identified the following barriers to minority utilization of services: a) not feeling welcomed, b) inadequate transportation, c) services outside of the minority community, d) staff not fluent in minority language, e) staff’s lack of knowledge of cultural differences (Beserra et al, 1982). According to SAGE-SW, the lack of research regarding a diverse older adult population has created a dearth of easily accessible models and best practices (O’Neill, 2001). Social worker researchers are called to conduct research focused cultural diversity in the older adult population. Through immigrant elders identifying cultural considerations regarding their long-term care, this research will build on the knowledge of immigrant elders. As part of a growing knowledge base on older adult diversity, this information can be used by social workers as they work toward cultural competence. Furthermore, this study may lead to additional research to develop models and best practices for social work practice with immigrant elders.

Immigrant elders as a vulnerable population (related standard 6.01 & 6.04). Social workers are mandated to advocate for social justice for vulnerable populations (NASW, 1996). In this research, the immigrant elder population is a vulnerable population for potentially many reasons, such as: limited English proficiency (Hikoyeda & Gordon, 2005; Reiss-Koncar, 2000), limited

health care insurance (He, 2002), poverty (He, 2002; Kalache, 1995), and cultural barriers to service (Beserra et al, 1982). This research will provide evidence as to what the immigrant elder population is seeking in long-term care. This evidence can provide the foundation to changing policy, programming and funding better meet immigrant elder' long-term care needs.

2. Literature Review: Developments in Long-term Care

There are many elements that have created the current long-term care system. They range from who is providing care, what services are being provided, where those services are being provided and how those services are being funded. This section describes how this multi-faceted long-term care system developed and has been funded over time.

The long-term care system is a continuum of care to assist individuals with activities of daily living (Tucker, Kassner, Mullen, & Coleman, 2000). This care can be provided in facilities or at home by family and friends or paid agency staff (Tucker, Kassner, Mullen, & Coleman, 2000). Services may be paid for privately or publicly through Medicare, Medicaid, Office of the Aging Services funding, private insurance, often in combination with private dollars (AAHSA, 2006a; National Association for Home Care & Hospice [NAHCH], 2006c; Tucker, Kassner, Mullen, & Coleman, 2000). With technical legal assistance and consultation from the Office of Civil Rights, the Centers for Medicare and Medicaid Services (CMS) and the Administration on Aging (AoA) including all of its services and service providers are required to provide “equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination”(AoA, 2004). Nevertheless, immigrant elders and minority elders have lower utilization rates for formal long-term care services (Doorenbos, 2003; Gupta, 2002; He, 2002; Lillie-Blanton & Hudman, 2001; Winokur, 1998; Barresi & Stull, 1993).

The long-term care system developed as a two-pronged system of care: home care and facility-based care. This two-pronged long-term care system is reflective of beliefs in how social welfare should be provided. Outdoor relief included cash or in kind goods and services (Katz, 1996), which is the conceptual foundation of home care. When social welfare was provided as outdoor relief, it was provided with the belief that individuals would use what was given them as needed to provide adequate care (Katz, 1996). Indoor relief consisted of goods and services provided within the care of an institution (Katz, 1996), which is the conceptual foundation of facility-based care, such as: nursing facilities and personal care facilities. In contrast, indoor relief was provided with the belief that facilities could more efficiently and effectively utilize monies than individuals who could be fraudulent with handouts (Katz, 1996). A review of social welfare history focusing on the precursors of long-term care will demonstrate how this was implemented.

Since colonial times, social welfare was provided as outdoor relief to support families in caring for older adults in private family homes in the community (Trattner, 1999; Katz, 1996). Family-care giving, as a precursor to healthcare at home, was the first building block of the long-term care system. Once the only option, aging at home continues to be the preferred option (Novelli, 2006; Mattimore, et al., 1997). As Baby Boomers age, 89% of them indicated that they wish to age in their own homes (Partners for Livable Communities, 2004).

Aging at home has evolved into the modern concept of aging in place. Aging in place uses a broader definition of “home”, but continues to mean that people can grow older without being required to relocate (Seniorsource.com, n.d.). For people to age in place, communities must have services and physical environments to meet the aging adults’ needs and to support their independence (McNulty, 2005). For people to age in place, there needs to be radical

redesign of towns and suburbs including zoning changes, and improved public transportation access to services (Peirce, 2001). These are not small changes, but some cities have taken on the challenge. The AoA sought communities that were actively working on making their communities more supportive of older adults and all populations (Dalrymple, 2005). Based upon this search, it named the seven most “Livable Communities for All Ages”: Atlanta, Georgia; Broome County, New York; Central, Virginia; Dunedin, Florida; Milwaukee, Wisconsin; New York City, New York; and Tamarac, Florida (Administration on Aging, 2005; Dalrymple, 2005). The increasing demands that people put on their communities as they age can exceed their communities’ current resources, thus forcing older adults to seek care in facilities (McNulty, 2005). This was also true in earlier eras. The local community would become overburdened and would seek assistance from higher authorities like state and local authorities (Katz, 1996).

With the rise of the Industrial Revolution in the United States came the rise of poorhouses increasingly replacing indoor relief with outdoor relief (Katz, 1996). Likewise, poor older adults were sent to the poorhouses to live and to receive food, clothing, and shelter (Katz, 1996). Poorhouses varied greatly across the nation, but in general, they were overcrowded, dirty, and unpleasant places to live (Katz, 1996). Furthermore, poorhouses did not provide any specialized care (Katz, 1996). When society believed that children required special care, orphanages were created; children moved out of the poorhouses and were placed into orphanages (Katz, 1996). Mental asylums were created in response to society’s belief that the mentally ill required special care (Katz, 1996). Since many of the adult women in poorhouses were believed to be mentally ill, they were moved from the poorhouses and placed into institutions (Katz, 1996). The exodus of children and women from the poorhouses dramatically transformed the poorhouse demographics—leaving primarily older adults (Katz, 1996). These demographic

changes converted poorhouses into the initial old age homes, but continued to provide poor living conditions (Katz, 1996). Over time, these older adult poorhouses added specialized care (Katz, 1996), which made them the precursor to the nursing facility and the assisted living facility.

Born out of that tradition, facility-based care continued to develop into impersonal, controlling and sterile institutions. For years facility-based care was institutionalized care focusing on tasks to care for older adults (Evans, & Scalzi, 2004). Facility-based care devalued older adults and their caregivers (Pioneer Network, n.d.b). Currently, there is a movement of culture change to deinstitutionalize facility-based care, empower residents and staff, and create a more hospitable environment (The Eden Alternative, n.d.; Pioneer Network, n.d.a; Evans, & Scalzi, 2004; Sherman, 2000). The familiar model is called *The Eden Alternative™* that works to create better social and physical environments by focusing on what is best for the resident, by giving staff greater power in decision-making and by incorporating pets, plants and children into facilities (The Eden Alternative, n.d.; Evans, & Scalzi, 2004). Like all institutional change, culture change in nursing facilities and assisted living facilities is a slow and on-going process (The Eden Alternative, n.d.; Pioneer Network, n.d.; Evans, & Scalzi, 2004; Sherman, 2000). There are only 250 facilities nation-wide that have adopted the *The Eden Alternative™* (Moody, Jr., n.d.). Since not all nursing facilities and assisted living facilities have begun this transformation, facility-based long-term care remains fairly institutionalized.

A growing concern throughout long-term care system is the health care staffing shortage and its impact on the quality of care. The health care staffing shortage is pervasive throughout the healthcare system effecting hospitals, nursing facilities, and community-based-care settings (Heinrich, 2001). While the health care staffing shortage covers a wide range of occupations,

most notable is the emerging shortage trend in nursing (Heinrich, 2001). In 2003, the national nurse vacancy rate was 13.9% and was projected to increase due to nurses retiring from the field (Moon, 2004). The nursing shortage is accompanied by shortages of nurse aides, nursing attendants, orderlies, personal aides and home health aides (Health & Medicine Week, 2006; Heinrich, 2001). Demographic changes are expected to create more serious shortages due to the Baby Boomers' increasing demand for services and due to the supply of traditional nursing workforce of women ages 25-54 years remaining unchanged (Heinrich, 2001). This chronic and increasing nursing and nursing assistant shortage undermines quality care in nursing facilities (Smoker, 2003).

To improve the quality of care, long-term care providers must be aggressive in recruiting and retaining staff. To ease the nursing aide and nursing assistant shortage, the Centers for Medicare and Medicaid Services issued a new federal rule to permit long-term care facilities to use trained paid feeding and hydration assistants which will allow certified nursing assistants to care for more complex patient needs (Smoker, 2003). To decrease the nursing assistant shortage, the Better Jobs Better Care reports various creative long-term care provider and workforce development initiatives, such as: pre-employment coupled with post-employment training, "earn while you learn" program, and training and career model programming (Nursing Home & Elder Business Week, 2006). To recruit nurses, scholarships and repayment programs are used as incentives (Heinrich, 2001). To reduce the shortage of nurses, long-term care has aggressively recruited foreign nurses, primarily from developing countries, including: Mexico, Philippines, India, South Korea, and Nigeria (Moon, 2004; Medical Letter on the CDC & FDA, 2004). Recruiting foreign nurses is complicated by limited visas for each country being issued each year (Fong, 2005). In May 2005, President Bush signed legislation to designate up to 50,000 visas for

foreign nurses (Fong, 2005). As the immigration debate continues in 2006, the American Health Care Association and the National Center for Assisted Living advocated for Congress to boost legal immigration to address the health care staffing shortage (Elder Law Weekly, 2006). Nevertheless, the availability and use of foreign nurses will not resolve the nursing shortage (Fong, 2005). To improve the quality of care, the long-term care industry, older adult and disability advocates, policy analysts and policy makers must continue to raise and to struggle with the issue of the nurse and nurse aide staffing shortage, in order to create initiatives and incentives to reduce this shortage.

Long-term care encompasses a broad range of services in the home and in facilities that provide multiple levels of care. Home care includes family care giving and home care organizations. When family caregivers require significant hours per week of respite, the older adult can receive adult day services at a facility for the day (National Adult Day Services Association [NADSA], 2006b). Facility-based care includes assisted living facilities, also referred to as personal care homes, and nursing facilities. In addition, hospice services provide supportive services and palliative care for dying individuals at home or in facilities (National Hospice and Palliative Care Organization [NHPCO], n.d.a). Each of these types of care will be discussed along with recent policy developments. Unfortunately, there is a dearth of statistics describing their use by immigrant elders.

2.1. Family Caregivers

Outdoor relief has been the foundation of home care. Multiple levels of care can be provided through home care. An older adult may only require minimal assistance, such as: supervision or medication management. Others may require more assistance, such as hands on help with the following activities: bathing, dressing, grooming. Still other older adults require extensive care,

such as: complex medical care, or hospice care. This care may be provided through informal, unpaid care by family and friends and through formal services with paid trained and professional staff.

Family care giving for older adults appears throughout history (Trattner, 1999; Amramovitz, 1996). This informal support has always been a significant component in keeping older adults in the community. In the United States, approximately 19% of adults provide care to a family member or friend who is over 50 years old (Barrett, 2009). While family care giving to older adults continues to be a traditional responsibility of women: daughter (44%), or granddaughter (11%) (National Alliance for Caregiving [NAC], & AARP, 2005), men's participation in care giving has continued to increase to 44% (National Family Caregiver Association [NFCA], 2000). Historically, family caregiving has been raised as an issue for ethnic and minority families, which has been based upon cultural differences and/or economic necessity (Gelfand, 2003; Dilworth-Anderson, Williams & Gibson, 2002; Scharlach, Fuller-Thomson & Kramer, 1995). Nevertheless, current research regarding caregiving to older adults reports that 76% of care givers are non-Hispanic Whites, 10% are Hispanic, 11% African-American and 2% Asian-American. These are important trends in understanding family caregiving.

Care giving tends to be an intergenerationally transmitted value and family legacy (Piercy, & Chapman, 2001). Younger generations adopt caregiver roles for older family members and pass those values and behaviors to the next generation (Piercy, & Chapman, 2001). Some caregivers (37%) indicated, "no one else provided unpaid care to the person they care for during the past year" (NAC & AARP, 2005, p. vii). While it may be a family legacy, not all members of the family assist in caregiving.

Family care giving encompasses a complex set of activities. On average a caregiver provides 21 hours of care per week on these varied tasks (NAC & AARP, 2005). Most caregivers (80%) provide assistance with three or more instrumental activity of daily living; the top three were transportation, grocery shopping and housework (NAC & AARP, 2005). Half of all caregivers assist with activities of daily living, but only 18% indicate that they received any formal training (NAC & AARP, 2005). In addition to these basic caregiving tasks, family caregivers also may provide emotional support (Bakas, Lewis, & Parsons, 2001), behavior supervision (Jansson, Nordberg, & Grafstrom, 2001), pain management (Ferrell, 2001), high-tech home care and healthcare advocacy (Levine, Reinhard, Feinberg, Albert, & Hart, 2003/2004).

Caregivers have multiple unmet needs including formal training in caregiving tasks and high-tech care and issues regarding healthcare advocacy. Approximately 30% of caregivers need assistance in providing activities for the person whom they care for and in keeping that person safe (NAC, & AARP, 2005). Furthermore, 22% caregivers need help talking to doctors and healthcare professionals (NAC, & AARP, 2005). The first source of information that caregivers turn to is the internet (NAC, & AARP, 2005; Silver, & Wellman, 2002). While caregivers could get lost in cyberspace, healthcare professionals are called to recognize this trend, to direct caregivers to helpful sites, and to provide them with more information and training (Silver, & Wellman, 2002; Alexy, 2000).

For the most part, family caregiving has not been reimbursed and has been minimally supported by the government (Arno, Levine & Memmott, 1999), exceptions include when the family member is paid as a self-employed contractor, and similar contractual arrangements. This task has been primarily provided by women and considered part of their assumed roles (Amramovitz, 1996). Since colonial times, there has been a debate and a changing policy about

paying family members to provide care for an older adult (Katz, 1996; Trattner, 1999). Initially, it was solely the family's responsibility, but this was problematic due to some older adults overburdening their family's resources or not having any family. This gave rise to greater community support.

Currently, qualified older adults and their family members can participate in the National Family Caregiver Support Program (Social Security Administration, 2003). This program provides family caregivers with some finances for home adaptations, support groups, respite care, and case management and care services for the older adult. While this program was reauthorized in 2000, additional funding is required to provide additional support to family caregivers (Older Women's League, 2001). Furthermore, family members can take advantages of the Family Medical Leave Act to care for an older adult and to have job security (The U.S. Equal Employment Opportunity Commission, 1995). These social policies and programs provide assistance and support to family caregivers including home and community base services provided by home health organizations.

2.2. Home Health Organizations

Another component of outdoor relief is the formal home health care agency. In the 1880's, the first home health care agencies were formed (NAHCH, 2004). From the beginning, visiting nurses cared for immigrant and ethnic patients of numerous nationalities (Buhler-Wilkerson, 2001). Armed with germ theory and medical knowledge, visiting nurses were charged to educate immigrants of the benefits of maintaining good personal hygiene and to transform them into orderly, healthy Americans (Buhler-Wilkerson, 2001). Due to difficulty communicating with immigrants, visiting nurses began to carry foreign language phrase books and to become familiar with foreign languages (Buhler-Wilkerson, 2001). Visiting nurses formed clubs to study

immigrants' ethnic culture and needs (Buhler-Wilkerson, 2001). Not until the early 1900's did home health care agencies begin to hire ethnically diverse staff (Buhler-Wilkerson, 2001).

The transition from this kind of visiting nursing to the modern home health care organizations was spurred on by funding and regulation through Medicare, Medicaid, Title XX of the Social Security Act, and the Older Americans Act (AAHSA, 2006a; NAHCH, 2006c; Buhler-Wilkerson, 2001). In the 1990's, home health care organizations were the fastest growing health service modality (Mullner, Jewell, & Mease, 1999). While home health care services are available, they remain under-utilized by minority elders (Barresi & Stull, 1993). A hindrance to utilization of home health care services is a lack of information or misinformation regarding what the services are, how to access services and how services will be paid (Neal, 2001).

The term home care organization refers to various types of agencies that provided medical and non-medical care services at home care, such as: home healthcare agencies, home care aide organizations, and hospices (NAHCH, 2006a). These provide a range of services: high-tech and complex medical care, skilled nursing care, rehabilitation services, social services and aide service for assistance with activities of daily living (NAHCH, 2006b). Services may be paid for privately or publicly through Medicare, the Medicare hospice benefit, Medicaid, veterans benefits; the Office of the Aging Services, private insurance, and/or private dollars (AAHSA, 2006a; HAHCH 2006c; Department of Veterans Affairs [VA], 2005; Tucker, Kassner, Mullen, & Coleman, 2000). Currently, the United States has 7,530 home health care agencies (AAHSA, 2006a). In 2002, there were 657,000 formal caregivers employed in home care organizations (NAHCH, 2004). In 2000, home care organizations served 7.2 million people (AAHSA, 2006a). Nationwide, based on the first six months of 2001, there were 38,000 Medicare beneficiaries

who utilized and average of 25 visits (United States General Accounting Office, 2002). On average, 8,732 veterans utilized home care services daily in 2003, which is projected to continue to increase (VA, 2005).

Formal care giving through home care organizations does not replace informal and family care giving (Li, 2005; Levine, Reinhard, Feinberg, Albert, & Hart, 2003/2004). Managing the home care organization and its staff becomes an additional task of the family caregiver (Levine, Reinhard, Feinberg, Albert, & Hart, 2003/2004). Family caregiving tends to stabilize after an initial adjustment phase (Li, 2005). Home care organizations are a complement to informal and family caregiving. Receiving services from home care organizations is just another option in the realm of services that assist individuals to age in place, which can be additionally supported with adult day services.

2.3. Adult Day Centers

There are more than 3,500 adult day centers (NADSA, 2006a). Adult Day Centers provide care to older adults in a protected setting for less than 24 hours in a day (NADSA, 2006b). There are two types of Adult Day Centers: Adult Day Services and Adult Day Health Care (NADSA, 2006b). Adult Day Services uses a social model of care that provides social and other related supportive services to older adults (NASDA, 2006b). Adult Day Health Centers uses a medical model of care that provide all the adult day services plus additional health related services (NADSA, 2006b). Services at Adult Day Centers are funded through participant fees, third party payers, public programs and philanthropic sources (NADSA, 2006a). Some public financial assistance is available through the Veterans Administration, Older Americans Act, or Medicaid (AoA, n.d.b; VA, 2005). In 2006, the Centers for Medicare & Medicaid Services (2006) continue to evaluate expanding the home health benefit to include medical adult day

services. This would shift payment from participant fees and third party payers to Medicare (CMS, 2006). This demonstration of Medicare funding medical adult day services will continue for three years and provide recommendations to Congress based upon its findings (CMS, 2006).

Daily, 150,000 older adults receive care at an adult day center (NADSA, 2006a). The average age of these older adults is 72 years (NADSA, 2006a). Most of the older adults using adult day centers are women (66%) (NADSA, 2006a). Half of the older adults using adult day centers have cognitive impairments (NADSA, 2006a). Three quarters of the older adults using adult day centers live with informal caregivers: spouse, adult children, other family and friend (NADSA, 2006a). On average, VA Adult Day Health Care Centers served 320 veterans daily in 2003, which is projected to increase (VA, 2005).

Older adults using adult day centers receive significant amounts of care. For activities of daily living, 59% of them require assistance with two or more tasks while 41% of them require assistance with 3 or more tasks (NADSA, 2006a). Nursing services are required by one third of the older adults who attend adult day centers (NADSA, 2006a). Due to this high demand for care, adult day centers provide family caregivers with respite and the opportunity to work: home chores or a paid job (NADSA, 2006b).

Nevertheless, family caregivers of older adults in adult day centers continue to report caregiver burden and caregiver stress (Reever, Mathieu, Dennis, & Gitlin, 2004). Adult Day Service Plus is an adult day center program that is augmented with case management services to family caregivers (Reever, Mathieu, Dennis, & Gitlin, 2004). “Case management services have been shown to be highly effective in decreasing depression and burden in families” (Reever, Mathieu, Dennis, & Gitlin, 2004, p. 338). The Adult Day Service Plus is a program that has demonstrated “clinically significant benefits for participating families” (Reever, Mathieu,

Dennis, & Gitlin, 2004, p. 338). Reeve, Mathieu, Dennis, & Gitlin (2004) recommend extending the role of social workers in the facilities related to the adult care center to implement this program and argue that the cost is reasonable. It remains unclear if this program that recognizes the family caregiver as part of the client system will become a model for adult day services. Overall, adult day services provide additional support to family caregivers.

2.4. Domiciliary Care Homes

When someone does not have family but still wishes to have a homelike environment, domiciliary care can provide that option. Domiciliary care has been applied differently in different states and different agencies. This section provides a general definition and compares it to the Pennsylvania State's Office of Aging program. This section will end with federal definition provided by the Veterans Affairs and describe differences in programming.

In general, domiciliary care homes are small residential facilities, usually with less than 10 residents (Family Caregiver Alliance [FCA], 2001). Residents live in traditional homes in residential neighborhoods (FCA, 2001). Normally, residents share bathrooms, bedrooms and living spaces (FCA, 2001). These are supportive residences that aim to maximize the residents' independence (FCA, 2001). Adults of all ages who have some disability qualify to live in domiciliary care homes.

In Pennsylvania, Domiciliary Care Homes are similar to adult foster care homes in that the resident lives with a family (Allegheny County Area Agency on Aging [AAAA], n.d.; Philadelphia Corporation for Aging [PCA], n.d.). In a home-like setting, domiciliary care residents share living arrangements (Jefferson County Area Agency on Aging [JCAAA], n.d.; York County Area Agency on Aging [YCAAA], n.d.; AAAA, n.d.). Within this supportive environment, residents receive assistance with activities of daily living and instrumental

activities of daily living (YCAAA, n.d.). Priority is given to low-income applicants (JCAAA, n.d.; PCA, n.d.). The cost of domiciliary care is paid for through a special Social Security Supplemental Income payment or private pay (PCA, n.d.).

Through the Department of Veterans Affairs, ambulatory disabled veterans can receive domiciliary care that includes health and social services (VA, 2005; Delaware Healthcare Association, n.d.). According to the VA (2005), domiciliary care is provided in residential facilities for two purposes: short-term rehabilitation or long-term health maintenance for veterans who require minimal medical care. With most veterans returning to the community, veterans tend to use domiciliary care to recover from medical, psychiatric and psychosocial problems (VA, 2005). The VA provides additional programming to meet veterans' special needs, such as: post-traumatic stress disorder, substance abuse, homelessness due to being chronically mentally ill (VA, 2005). In 2003, this benefit provided domiciliary care to 5,425 veterans at 43 VA national facilities and 3,758 veterans at 49 state homes in 33 states (VA, 2005). The VA projects that there will be an increase in domiciliary care use and more veterans will be served through state homes (VA, 2005).

For domiciliary care to be available there has to be families willing to open their homes to provide this service. Furthermore, people need to be comfortable in joining with a strangers' family. More often than not, this is not a realistic option and folks turn to assisted living facilities to meet their living and care needs.

2.5. Assisted Living Facilities

Assisted living facilities may also be referred to as personal care homes, but some states differential them as two levels of care. While called assisted living facilities, most states still recognized these facilities as residential care or board and care home (Hawes, Rose, & Phillips,

1999). They are regulated at the state level with each state defining the scope of services (Hawes, Rose, & Phillips, 1999). Assisted living facilities can be freestanding facilities, with or without being affiliated with a nursing facility or on a campus as part of a larger continuing care retirement community (AoA, n.d.a; Hawes, Rose, & Phillips, 1999).

Assisted living facilities are residential facilities that provide personal care and health related services (Assisted Living Federation of American, [ALFA], n.d.). These services cover a broad range of activities of daily living and instrumental activities of daily living (Hawes, Rose, & Phillips, 1999). As a residential facility, meals, laundry, housekeeping and transportation are provided (AoA, n.d.a; ALFA, n.d.). In regards to personal care services, assisted living facilities provide bathing, dressing and may also provide assistance with toileting and walking (AoA, n.d.a; ALFA, n.d.). In regards to related health services provided, services vary, but may include 24-hour security and staff, health promotion and exercise programs, medication management, and access to health and medical services (AoA, n.d.a; ALFA, n.d.).

Since assisted living facilities offer health related services, the issue of aging in place arises. The assisted living philosophy is in accordance with aging in place in that it promotes resident control (Chapin, & Dobbs-Kepper, 2001). To make aging in place a reality, the assisted living facility must be flexible in service provision (Chapin, & Dobbs-Kepper, 2001). In 1998, aging in place in an assisted living facility was highly unlikely (Hawes, Rose, & Phillips, 1999). Residents were discharged who needed increased care, even for as little as two weeks (Hawes, Rose, & Phillips, 1999). In 2001, 44% of assisted living residents were discharged to a hospital or nursing facility (National Center for Assisted Living, 2001). In 2005, the trend is for more medical care to be brought into assisted living facilities where staff members are embracing it

(ALFA, 2005). The potential to age in place in an assisted living facility is becoming a real option for more and more assisted living residents.

Over one million adults reside in assisted living facilities (AAHSA, 2006a). They range from young adults to older adults (ALFA, n.d.). As with traditional board and care homes, assisted living facilities serve a mixed population of residents, such as: people with mental illness, people with mental retardation or developmental disabilities, frail older adults and older adults with cognitive deficits (Clark, Turek-Brezina, Hawes, & Chu, 1994). The majority of assisted living facilities serve older adults (Hawes, Rose, & Phillips, 1999). Half of the older adults in assisted living facilities are aged 85+ (United States Department of Health & Human Services [HHS], 2001). Older adults residing in assisted living are more likely to be white (96%), female (77%), and single (83%): widowed, divorced, separated, never married (Spillman, Liu, & McGilliard, 2002). Older adults reside in assisted living facilities for many reasons, such as: cognitive impairment (25%), and assistance with activities of daily living (20%) (HHS, 2001).

Both the affluent and poor reside in assisted living facilities (ALFA, n.d.). Older adults residing in assisted living facilities tend to be relatively affluent (HHS, 2001). This is reflective of how the cost of assisted living is paid. The cost of assisted living facilities is primarily billed to the resident or their family (AoA, n.d.a; ALFA, n.d.). For moderate and low-income older adults (75+ years), assisted living is not affordable unless they convert all assets to cash to supplement their income (Hawes, Rose, & Phillips, 1999). Additional sources of payment are some long-term care insurance and financial assistance from the assisted living facility (AoA, n.d.a, ALFA, n.d.). Initially, public funding for assisted living was limited (Hawes, Rose, & Phillips, 1999). One example is that Veteran Affairs has a Community Residential Care benefit

that covers assisted living facilities (VA, 2005). States and local governments have created multiple programs to support residents in assisted living facilities, such as: subsidies to low-income elders, additional payments through Supplemental Security Income or Medicaid, or Medicaid waiver programs (AoA, n.d.a; ALFA, n.d.). As of 1998, there were at least 35 states in the process of establishing Medicaid benefits to cover care in assisted living facilities (Mollica, 1998). By 2015, more options for moderate and low-income older adults are predicted (ALFA, 2005).

Currently, Pennsylvania is in the transition into a two-tier system. Assisted living regulation—Act 56 will have separate licensing for personal care home and assisted living facilities (Pennsylvania Health Law Project, 2007). Assisted living facilities will be held to higher standards, such as: private rooms, the option to age in place with waiver services, staffing and their training (Pennsylvania Health Law Project, 2007). The Office of Long Term Living continues to develop the proposed regulations; the latest draft was released in June 2009 (AAHSA, 2009). It remains unknown when these regulations will be finalized for implementation. Overall, this regulation supports older adults aging in place once they have relocated into an assisted living facility. Nevertheless, some folks require extensive or high tech care, which may best be provided through nursing facilities.

2.6. Nursing Facilities

Gradually, the poorhouses were transformed into homes for the aged with increasingly diverse types of services and levels of care (Katz, 1996). In the 1900's, many older adults were still cared for in psychiatric hospitals and county homes (Brody, 1977). By the 1920's, a prominent change in facility-based care was the appearance of non-profit homes for the aged that increasingly began to provide various types of medical care (Brody, 1977). In the 1960's, a

proliferation of nursing facilities began (Brody, 1977; Dunlop, 1979). This proliferation was spurred on by the financial assistance for building facilities provided through the Hill-Burton Act (1954), the Small Business Act (1958), and Small Business Investment Act (1958), the National Housing Act Amendment (1959) and the Kerr-Mills Act (1960) (Dunlop, 1979). Furthermore, older adults were better able to pay for their care in these facilities due to Medicare (1965) and Medicaid (1965). Likewise, this government funding gave preference to facility-based care, which has continued until recently (FCA, 2005).

In the United States, 15,989 skilled nursing homes are licensed (AAHSA, 2006a). Nursing homes provide 24-hour care that includes medical care, nursing care and personal care (AAHSA, 2005). Nursing facilities provide two levels of care: skilled nursing facility services and nursing facility care (Moody, Jr., n.d.). Skilled nursing facility services are recuperative in nature, such as: post-operative follow-up care, post-hospitalization follow-up care, and rehabilitative therapies (Moody, Jr., n.d.). Skilled nursing facilities provide rehabilitative services, such as: physical therapy, occupational therapy, and speech therapy (AAHSA, 2005). Nursing facility care refers to a variety of services that are considered intermediate care, sometimes referred to as custodial care, and the criteria for these differ based upon each state's definition. Nursing facilities provide assistance with activities of daily living, meals, laundry services, housekeeping, activities, social services and religious services (AAHSA, 2005). Nursing facility care is provided to residents at both levels of care.

In 1997, there were 105,066 special care beds in nursing facilities (Moody, Jr., n.d.). Of these, 65,304 residents (62%) were receiving care for Alzheimer's Disease (Moody, Jr., n.d.). There were 3,013 residents receiving care for AIDS and an additional 4,303 were receiving hospice care (Moody, Jr., n.d.). In these special care beds, 5,699 residents were living due to a

ventilator (Moody, Jr., n.d.). The remaining 26,746 special care beds served residents requiring special medical care, which may include high-tech care (Moody, Jr., n.d.).

In 2003, there were 1,351,159 residents in nursing facilities (statehealthfacts.org, n.d.). In 2000, approximately 66% of nursing facility residents did not have other relatives (Moody, Jr., n.d.). Women are the majority of nursing facility residents; women have consistently been 65-70% of nursing facility residents since the 1980's (Moody, Jr., n.d.). According to the Agency for Healthcare Research (2000), from 1987 through 1996, the population of nursing facility residents remained predominantly white (approximately 90%). In 1999, over 75% of nursing facility residents required assistance with four to six activities of daily living (FCA, 2005). Cognitive impairment is prevalent in about 65% of nursing facility residents (Moody, Jr., n.d.). At any given time, up to 20% of nursing facility residents are restrained to not harm themselves or others (Moody, Jr., n.d.). Of the nursing facility residents, older adults require greater levels of care and assistance than other residents (FCA, 2005).

Veterans can receive nursing facility care at a VA-operated unit, community nursing facilities and state nursing facilities (VA, 2005). In 2003, there were 33,408 veterans in nursing facilities (VA, 2005). In 2005, the projected number of veterans in nursing facilities is expected to fall while non-institutional care to veterans is expected to increase by 65% (VA, 2005).

Aside from veterans' benefits, there are more sources of payment for nursing facility care. The older adult is still responsible for paying what other third parties do not cover. Long-term care insurance will cover nursing facility care, but individual contracts vary greatly in coverage (AAHSA, 2006b). Based upon the residents' level of care, the residents will qualify for different benefits to pay for their care. Medicare pays for skilled nursing facility care

(Moody, Jr., n.d.) Medicare pays for limited short-term rehabilitative service and recuperative care (AASHA, 2006b). On-going care qualifies for different benefits.

Medicaid pays for nursing facility care that is intermediate care (AASHA, 2006b; Moody, Jr., n.d.). People with chronic care needs may qualify for Medicaid (AASHA, 2006b). Since Medicaid was designed as health care coverage for low-income people, nursing facility residents must “spend down” their assets for Medicaid to pay for their care (AASHA, 2006b). Since most of the older adults “spend down” their assets within a year of entry into a nursing home (AASHA, 2006b), even middle-class older adults become qualified for Medicaid (Moody, Jr., n.d.). Medicaid pays for approximately 65%-70% of all nursing home residents (AASHA, 2006b; Moody, Jr., n.d.).

These differences in payment schedules impact care or at least the options that older adults may have. In 2002, one administrator said, “If you got money, you can find a (nice) place. If you don’t, it’s very hard” (Moody, Jr., n.d.). Residents who live in private pay nursing facilities receive a higher quality of care than Medicaid nursing facility residents (Moody, Jr., n.d.). The National Senior Citizens Law Center argues that Medicaid residents are discriminated against by nursing facilities in receiving inferior food or services, in being relocated to a different wing, or in being evicted (Moody, Jr., n.d.). Some of the information on the internet becomes inflammatory to encourage purchasing long-term care insurance or elder law services, but caution is in order. There are plenty of variables to impact the care received at a nursing facility. In a 2002 the News Hour with Jim Lehrer, the Kaiser Family Foundation, and the Harvard School of Public Health joined in a national survey that found that most people reported that the nursing facility residents that they knew received quality care and few reported receiving poor care (Moody, Jr., n.d.).

2.7. Continuing Care Retirement Communities

While a nursing home can stand alone, it may be part of a bigger campus known as a continuing care retirement communities (CCRC) (Sanders, 1997). Since individual's level of care can change over time, it was useful for assisted living facilities and nursing homes to have cooperative agreements to accept each others' patients through these transitions. This led to the development of campuses with multiple levels of care. Many of these campuses have converted to CCRC's. These CCRC's campuses have many different features, services and payment options (Sanders, 1997). Currently, CCRC's are adapting facilities and services for the baby boomer cohort by creating community centers on campus, designing CCRC's that are better connected to the larger community, and providing multiple levels of care within the "household" (Anderzhon, 2006). While CCRC's can be expensive (Sanders 1997), some CCRC's have added low-income housing onto their campus and are using Housing and Urban Development monies to convert apartments into personal care home and assisted living facilities for those residents (Hayunga, 2005).

In addition, the CCRC has not only developed as a campus but also into insurance products (PA Department of Insurance, 2006; Sanders, 1997). A licensed CCRC requires an admission or enrollment fee plus on-going monthly fees in exchange for a comprehensive care package that provides services across multiple levels of care (PA Department of Insurance, 2006). In Pennsylvania from 2003 to 2008, licensed CCRC's increased over 50%, totaling 237 CCRC's throughout the state (PA Department of Insurance, 2006). As an insurance product, licensed CCRC's have continued to expand with the latest developments being the CCRC's "without walls". CCRC's "without walls", or "Continuing Care at Home (CCAH) program, provides the same range of services that are provided on campus, but at the residents' home in the community (Dube, 2008) Pennsylvania has two CCAH programs; one in the greater

Philadelphia area and the other in the greater Pittsburgh area (Dube, 2008). In developing their long-term care plans, older adults can use CCRC's and CCAH for financial peace of mind, but they differ from long term care insurance.

2.8. Long Term Care Insurance

Long-term care insurance is an insurance product and its coverage is determined by the individual's policies. In 2005, almost all (90%) long-term care insurance policies provided coverage for institutional care and home care services (Life Plans, Inc., 2007). To provide additional financial security, over 75% of long-term care insurance policyholders opted for some form of inflation protection in 2005 (Life Plans, Inc., 2007). Since long-term care insurance coverage increased while premiums stayed stable from 1995-2005, consumers receive a greater value in their long-term care policies (Life Plans, Inc. 2007). Nevertheless, consumers remain fairly confused about long-term care policies in regards to benefit coverage and taxes, etc. (Life Plans, Inc. 2007).

In Pennsylvania, these long-term care insurance trends have been further supported by Pennsylvania Act 40, which established the Long Term Care Partnership (Mulvaney & Hackman, 2008). PA Act 40 requires that all long term care insurance policies for Pennsylvania have comprehensive coverage, which provides benefits for skilled nursing facilities, intermediate care facilities, custodial care and home health services (PA Dept. of Insurance, 2008). In addition, these policies are tax qualified and provide inflation protection and Medical Assistance Asset protection (PA Dept. of Insurance, 2008). Current long term care policyholders are able to exchange their previous policies for one of these comprehensive partnership plans (PA Dept. Insurance, 2008). Unfortunately, consumer choice is limited to the eight private insurance companies offering comprehensive partnership plans (Mulvaney & Hackman, 2008).

Nevertheless, this legislation promotes financial security for older Pennsylvanians while safeguarding them from purchasing long term care policies that may not meet their future care needs (Mulvaney & Hackman, 2008).

Pennsylvania is one of eighteen states participating in the “Own Your Own Future Initiative” (U.S. Dept. HHS, 2008; Mulvaney & Hackman, 2008). The “Own Your Future” initiative is an educational campaign designed to help Americans take an active role in planning ahead for their future long-term care needs through encouraging the purchase of long term care insurance (U.S. Dept. HHS, 2008; Mulvaney & Hackman, 2008). It is administered by HHS’ Centers for Medicare & Medicaid Services (CMS), Administration on Aging (AoA), and Office of the Assistant Secretary for Planning and Evaluation (ASPE) (U.S. Dept. HHS, 2008; Mulvaney & Hackman, 2008). With escalating health care costs and concerns about the solvency of Medicare and Medicaid, the “Own Your Own Future” initiative is a governmental push for individual responsibility in planning so that older adults will have greater choices in their long term care services.

2.9. Hospice

Another support in long term care is hospice. Unlike the other long-term services that focus on services that support living through older adulthood, hospice focuses on services during the dying process. “Hospice is primarily a concept of care, not a specific place of care” (AoA, 2003, p.1). Hospice services can be provided in the home, freestanding hospice facilities, hospitals, nursing facilities and other long-term care facilities (AoA, 2003; NHPCO, n.d.a). A key to qualifying for hospice services is that the individual must have a life-threatening or terminal illness (NHPCO, n.d.b). Hospice provides dying individuals support to live their remaining days with dignity and control and to die with dignity and with comfort measures

(AoA, 2003; NHPCO, n.d.a). This switches the focus of treatment from curing the illness or injury to caring for the individual (Hospice Foundation of America [HFA], 2006; NHPCO, n.d.a). During this time, hospice care provides significant support to families to assist them in coping and respecting the individual's wishes for care (NHPCO, n.d.a).

Hospice care is coordinated care provided by many different kinds of caregivers. The staff of the hospice team is interdisciplinary and comprised of the following members: doctors, nurses, home health aides, social workers, counselors, clergy and trained volunteers (HFA, 2006; AoA, 2003; NHPCO, n.d.b). The patient, a primary caregiver, and family are significant members of the hospice team (HFA, 2006; AoA, 2003; NHPCO, n.d.b). To coordinate care, an individualized care plan is created. This planning process employs a family-centered approach to decision-making (HFA, 2006; NHPCO, n.d.b).

Hospice care provides a broad array of medical services and emotional and spiritual support to patients with life-limiting illness or injury (HFA, 2006; AoA, 2003; NHPCO, n.d.a). In regards to medical services, hospice care provides pain management, symptom management, medication, medical supplies, medical equipment; and home health aide services, including assistance with activities of daily living (NHPCO, n.d.b). Some patients require special services, like speech therapy or physical therapy to provide comfort and quality of life (NHPCO, n.d.b). In regards to emotional and spiritual support, patients receive counseling services by social workers, counselors, and clergy regarding loneliness, fears, issues and other aspects of dying (HFA, 2006; NHPCO, n.d.b). This holistic approach is to assist patients in their dying process.

Hospice care, also, provides the primary caregiver and family with a broad range of services. Hospice staff members encourage and foster communication among family members (HFA, 2006). Family members receive coaching and training in caring for the patient (NHPCO,

n.d.b). Special training is given to the primary caregiver, who is often a life partner, relative, or friend (HFA, 2006.). The primary caregivers are trained specifically to assist patients with “feeding, bathing, turning (and repositioning), administering medications, and monitoring changes in the patient’s condition (HFA, 2006). To assist the family and caregivers, the hospice staff is always available to them, 24 hours per day, every day (AoA. 2003; HFA, 2006). To relieve family members of their caregiver duties, hospice care provides respite care and short-stay inpatient care (NHPCO, n.d.b). Families and caregivers receive counseling regarding fears, loneliness and other issues during the dying process (HFA, 2006; NHPCO, n.d.b). Upon the death of a patient and for at least one year after, the family and caregivers are offered bereavement services, such as: phone calls, visits, receiving written material about grieving, support groups, individual counseling and referrals for counseling (HFA, 2006; NHPCO, n.d.b). These family services provide support to family members and caregivers not only during the dying process, but also through the death and grieving process.

In 2004, there were 3,650 hospice programs that served 1,060,000 patients and their families (NHPCO, 2005). Regardless of race, age, religion or illness, hospice services are available to anyone with a terminal diagnosis (NHPCO, n.d.a). Nevertheless, in 2004, the majority of hospice patients were Caucasian (77%) (NHPCO, 2005). Hospice patients tend to be older adults. In 2004, older adults, age 75+ years, comprised 65% of hospice patients; the majority were older adult women (NHPCO, 2005). In 2006, older adults, age 65+ years, comprised 80% of hospice patients (NHPCO, n.d.c). While cancer remains the admitting diagnosis for most hospice patients, other admitting diagnoses include end-stage heart disease, dementia, debility, lung disease, end stage kidney disease, and AIDS (HFA, 2006; NHPCO, 2005). In 2004, hospice patients primarily used routine home care (95.7%), which was

supported with continuous home care (1%) and respite care (.2%) (NHPCO, 2005). In 2004, only 3% of hospice patients received general inpatient care (NHPCO, 2005). Since 70% of Americans would prefer to die at home surrounded by family and friends (Moody, Jr., n.d.), the demand for hospice services will continue.

By definition hospice patients need to be terminally ill. Most hospice patients are living out their last six months of life (HFA, 2006). In 2004 on average, hospice services were delivered 57 days (NHPCO, 2005). Utilizing the median length of hospice service delivery, the typical patient received 22 days of hospice care (NHPCO, 2005). Furthermore, within seven days of hospice admission, 35.1% of hospice patients died (NHPCO, 2005). This apparent under utilization of hospice services by patients who have accepted hospice services has no clear explanation, but these are three potential reasons:

1. Patients may have a relatively short dying process,
2. Doctors may not be making the diagnosis of terminal until late in the patient's dying process
3. Patients may be reluctant to accept their dying process and opt for hospice services late in their dying process.

In any case, individuals interested in hospice services need to be forthcoming with their physicians and their family so that they can receive the many benefits of the hospice program instead of struggling through the dying process without this support.

Paying for hospice care is less difficult than other long-term care services. Hospice services are covered through private health insurance, veterans' benefits and Medicare; Medicaid, also provides coverage in over 40 states (VA, 2005; AoA, 2003; NHPCO, n.d.c). Since 90% of hospices are Medicare certified, and 80% of hospice users are 65+ years, most

hospice patients qualify for the Medicare Hospice benefit (NHPCO, n.d.c). Since the Medicare Hospice benefit covers almost all costs associated with care of the terminal patient, the family incurs minimal out-of-pocket costs (NHPCO, n.d.c). Choosing hospice services to support an individual and their family through the dying process has many benefits with few financial costs to the individual or their family.

2.10. Recent Policy Developments Regarding Long-term Care

Historically, the structural design of Medicaid favored institutionalization (Crisp, Eiken, Gerst & Justice, 2003). Starting as early as the 1970's, the federal government provided some flexibility to states in the provision of personal care as an optional service (Crisp, Eiken, Gerst & Justice, 2003). In 1981, Medicaid was expanded to include Home and Community-Based Services Waivers that allowed states to provide various community-based services to individuals who met the criteria for nursing-facility level of care (Crisp, Eiken, Gerst & Justice, 2003). The Centers for Medicare and Medicaid Services continued to work with states to create greater flexibility.

In 1999, there was a resurgence of urgency regarding the need to provide more community-based care. The delegates to the Personal Assistance Services in the New Millennium conference stated "Government policies and funding should not perpetuate the forced segregation, isolation or institutionalization of people with disabilities of any age" (The Center for an Accessible Society [CAS], n.d.). In the same year, two branches of government spoke to this issue. Donna Shalala, as Secretary of Health and Human Services, stated, "No one should have to live in a nursing home" (CAS, n.d.). The Supreme Court through the Olmstead Decision upheld that whenever possible the individual has the right to receive care in the community instead of being institutionalized (FCA, 2005). While this decision focused on

people with disabilities, the Olmstead Decision initiated dramatic changes throughout the long-term care system in regards to the following issues: who was receiving care, where they are receiving care, and with what kind of government funding and benefits are being used to pay for care.

In supporting this trend, the Centers of Medicare and Medicaid Services worked with individual states to support them in better coping with this trend. To better serve residents in the community, states needed to rebalance their long-term care delivery system (Crisp, Eiken, Gerst & Justice, 2003). There are three general strategies to facilitate rebalancing: 1) legislative actions, 2) market-based approaches, 3) programmatic linkages (Crisp, Eiken, Gerst & Justice, 2003). Legislation, creating new social policy regarding long-term care, has been passed in the following states: Texas, Utah, Vermont, Missouri, Maryland, Nevada and North Dakota (Crisp, Eiken, Gerst & Justice, 2003). Market-based approaches, focusing on consumer needs and service providers, have been taken by the following states: Arizona, New Jersey, Michigan, Arkansas, Florida, New Hampshire, South Carolina, and Louisiana (Crisp, Eiken, Gerst & Justice, 2003). Programmatic linkages, aiming at streamlining referrals and better coordination of services, have been the primary strategy for Maine and Indiana (Crisp, Eiken, Gerst & Justice, 2003). Oregon, Washington, and Wisconsin have taken a systematic approach utilizing all three strategies (Crisp, Eiken, Gerst & Justice, 2003). As states have attempted to rebalance their long-term care budget, success has occurred based upon these common elements: improved access to the system, revising financing of programs and services, improving service sufficiency and provider capacity, and continued quality assurance and improvement initiatives (Crisp, Eiken, Gerst & Justice, 2003).

Since some states have provided successful long-term care budget rebalancing demonstrations, the next step was to expand these options by increasing federal funding for community-based services at home. This has been a bipartisan effort (CAS, 2003). Under President George W. Bush, the government continued to expand its support for home and community-based services (Carbonell, 2003). The “Money Follows the Person” Rebalancing Initiative was part of President Bush’s 2004 budget and was supported with bipartisan legislation in Congress, which became P.L. #:109-171. The conceptualization of “Money Follows the Person” is that money will follow the person as the individual transitions from a nursing facility or other institution to home and community-based services (CAS, 2003). While people prefer to age in place at home, the decision to utilize a nursing facility or other institution has historically been based upon what Medicaid will reimburse instead of what the individual needs (CAS, 2003). Reflecting the Olmstead Decision, the “Money Follows the Person” Act supports that individuals should not be institutionalized solely for reimbursement purposes if they can receive appropriate services at home in the community (CAS, 2003; Carbonell, 2003).

While “Money Follows the Person” Rebalancing Initiative benefits individuals, the initiative is aimed at states rebalancing their long-term care delivery system. This five-year program is to encourage states to transition appropriate residents into the community, and to better balance in the provision of community-based services with institutionalization (Carbonell, 2003). At the time of enactment, it was uncertain how many individuals would meet the criteria for nursing-facility level of care. In any case, under this act, states are provided greater flexibility in utilization of federal funds to readjust their long-term care system based upon consumer needs and preferences (Carbonell, 2003). This is a fairly new development. Statistics

regarding its progress were limited at this time. Nevertheless, allowing states more flexibility only further supports aging in place.

Over the last decade, there have been dramatic changes in long-term care in Pennsylvania. In 2007, Governor Ed Rendell created the Office of Long-Term Living within the Department of Welfare (Hall, 2007). Bringing staff from Department of Public Welfare, Department of Aging and the Governor's Office on Health Care Reform, the Office of Long-Term Living was created with a new philosophy not solely focused on older adults, but any adult with long-term care needs (Hall, 2007). The Office of Long-Term Living has responsibility for the state nursing home budget and eight of the home and community based waivers (Hall, 2007). Intrinsic in this philosophical change is a shift toward more person-directed models of care (Mulvaney & Hackman, 2008). There are three basic types of person-directed models of care: personal assistance, brokered support, as well as cash and counseling (Powers, Sowers, & Singer, 2006). The personal assistance model provides home and community based services typically provided for through Medicaid waivers (Powers, Sowers, & Singer, 2006); this continues to be prevalent in Pennsylvania (Mulvaney & Hackman, 2008). New to Pennsylvania are brokered support models that typically involve providing the care recipient an agent to advocate and coordinate care that would support achieving their life goals (Mulvaney & Hackman, 2008; Powers, Sowers, & Singer, 2006). The cash and counseling model provides the most flexibility by providing care recipients with an individual budget to purchase care and supplies (Powers, Sowers, & Singer, 2006). In Pennsylvania, this model is being piloted in thirteen Area Agencies on Aging as the Services My Way program, which is funding through the PA Department of Aging (PDA) waiver and Department of Public Welfare Attendant Care waiver (Mulvaney &

Hackman, 2008). These changes in home and community based services provide more choices to Pennsylvanians who need these supportive services.

Another significant development in Pennsylvania has been the creation of the Nursing Home Transition program that provides long-term living counseling to everyone entering a nursing home to generate community-based care plans (Office of Long Term Living, 2007). The program has grown and developed significantly over the last 10 years from pilot projects to state-wide implementation (Office of Long Term Living, 2007). Currently, the program uses a mix of waiver and funding streams (Office of Long Term Living, 2007). For 2005-June 2006, 474 people transitioned from nursing homes back to the community with services (Office of Long Term Living, 2007). While the Office of Long Term Living (2007) recognizes affordable and adequate housing as a barrier, case workers across the state report issues of waiting lists, delays in processing authorizations, and lack of service providers (Mulvaney & Hackman, 2008). Pennsylvania continues to enhance and expand these programs and encourage economic development to further support home and community based services.

Overall these new developments sound promising for older adults to be able to age in place. Unfortunately, the latest developments regarding long-term care continue to take a generalist approach ignoring the heterogeneity of the older adult population. It remains unclear if policy makers specifically sought input from all older adults, including immigrant elders. This research will gather data on immigrant elders and their long-term care needs, wants and expectations, which policy makers may utilize in policy decisions.

3. Methodology

This descriptive study is designed to provide insight into immigrant elders' expectations, wants, and long-term care needs. As stated previously, there is a dearth of knowledge in this field. Qualitative methods are suitable for research seeking insight into the participants'

understanding and for topics with little previous research (Ruben & Babbie, 2001). While this research meets these criteria, the research design will use a multiple method approach including both qualitative and quantitative methods.

Qualitative methods and quantitative methods have many parallels. In lieu of a traditional theory section, the chapter begins with “The Etic Perspective” that provides the researcher’s worldview and conceptual assumptions. This is followed by the research design with special attention given to combining qualitative and quantitative methods, participants, recruitment and issues of human subjects, instrumentation and data analysis. Since some critics consider qualitative methods “less scientific” (Ruben & Babbie, 2001), the chapter ends with a section addressing issues of rigor.

3.1. The Etic Perspective

When qualitative researchers begin fieldwork, they bring an inductive nature to inquiry and their previous knowledge and understandings (Patton, 2002). This previous knowledge and understandings form the foundation of a social scientific perspective. The qualitative researcher’s preconceived ideas and social scientific perspective is called the etic perspective (Fetterman, 1998). Since it is an inescapable lens, the etic perspective inherently influences the research question and all aspects of the research design. While the etic perspective acts as the conceptual starting point, it does not negate inductive processes of qualitative research. The qualitative researcher must be attentive to biases of the etic perspective to be more receptive to inductive processes and their findings.

The researcher is a social worker, licensed in Pennsylvania, with over 20 years of experience in aging and medical services. The researcher repeatedly had cases involving immigrant elders and their long-term care needs. In working with immigrant elders and their

families, the social worker became aware of cultural concerns and issues of competence in care giving that immigrant elders and their families had. The immigrant elders in this study are not and have not been clients, but are predominantly women from the International Women's Club in Monroeville. Because of cultural interests and research interests, the social work researcher became a member of this club, but attend irregularly due to scheduling conflicts.

Part of the etic perspective arises from the researcher's professional discipline and training. As this researcher is a social worker, the *NASW Code of Ethics* (1996) and social work knowledge and theory guides her work. Key social work knowledge and theoretical underpinnings related to this research are presented below.

In social work, the concept of the person-in-environment is foundational (Kirst-Ashman, & Hull, 2006; Hepworth, Rooney & Larsen, 2002). This concept is derived from the work of Kurt Lewin (1935) who describes this relationship as an interaction of the person and the environment that generate human behavior, and Urie Bronfenbrenner (1988) who indicated that human development is a function of this relationship. These concepts are closely related to the ecological perspective utilized in qualitative research.

Ecological psychology was developed by Robert Barker (1968) and Hebert Wright (1967) (Patton, 2002). Ecological psychology proposed interdependence between individuals and the environment (Patton, 2002). The ecological psychology perspective focuses on the relationship of the individual in their environment.

As a perspective in qualitative research, the ecological psychology perspective provides a framework for organizing the data analysis. Attention is given to report a pure and detailed description of the person in an environment (Patton, 2002). From these data, observed "streams of behavior" are analyzed in relation to perceived goals (Patton, 2002). In utilizing this

perspective, the research focuses upon the individual's specific actions and behaviors within a specific environment to achieve certain goals (Patton, 2002). In this research, the focus is upon immigrant elder's behaviors related to long-term care goals within the physical and social environment. Areas of their physical environment that are of interest include her home in the community and care facilities, such as a continuing care community, personal care home, or nursing facility. Elements of the social environment that are of interest include culture, financial/economic, and social support.

The person-in-environment concept and ecological psychology perspective provide the theoretical foundation that shapes this research. Additional assumptions are integral to this research's overall conceptual framework. Derived from theory and knowledge, these additional assumptions can be grouped into several topics: the individual as a system, culture, immigrant and multicultural society, and healthcare utilization.

In describing the individual as a system, there are these key related concepts:

1. A person is a system of systems, such as: biological, psychological, social, cultural, and spiritual (Kirst-Ashman, & Hull, 2006; Hepworth, Larsen, & Larsen, 2002; Longres, 2000).
2. A person functions as a complex and dynamic set of systems, such as: biological, psychological, spiritual, etc. (Tillich, 1963, Ellor, 2000).

It is important to understand that not only the person as a whole, but also as a set of interrelated systems. A person functions based upon the interplay of these systems. These concepts give importance to understanding an individual's age, gender, race/ethnicity, social status, religious affiliation, physical and psychological health and cognition.

Social workers place a high value on being culturally competent (NASW, 1996). In describing the significance of culture, there are these key related concepts:

1. Culture is the “entirety of psychological, social, material, and symbolic (knowledge and) resources that humans have developed over millennia and that are transmitted across generations (Staudinger & Bluck 2001, p. 25).
2. Culture provides a context for understanding human behavior and interpreting human psychological functioning (Berry, 1994).
3. Culture provides a group identity through multiple mediums, such as: norms, values, traditions, language, music, food, clothing, etc.
4. Culture is part of all social environments: family, friendship circles, groups, organizations, institutions, communities and society.

Culture is everywhere and exhibited in many different aspects of life. Culture is different from group to group and provides its members with a group identity. It is important for social workers to understand individual’s cultural and various group cultures.

In this research, culture is a key concept. Since the population being studied is immigrant elders, it is important to recognize how immigrant elders retain their own culture. How immigrant elders’ perceive the culture of organizations like Office of Aging and institutions like nursing homes is also significant. In addition, understanding each immigrant elder’s culture will be informative in clarifying statements made during data collection and interpreting their behaviors as part of the data analysis.

Since this research is about immigrant elders, it is important to understand the interplay of immigrant cultures with the multicultural host society. In describing this interplay, there are these key related concepts:

1. Immigrants adapt to a host multicultural society through interplay of ethnic distinctiveness and of desirability of ethnic contact (Berry, 1984, 1997,1999; Berry, Kim, Power, Young, & Bujaki, 1989).
2. The way a host society receives immigrants influences how immigrant adapt to that host society (Bourhis, Moise, Perreault & Senecal, 1997).
3. Some immigrants will adopt a multicultural identity in which they maintain their distinct cultural heritage, affiliate with many groups, and become part of the pluralist society (Kim, 2001).

Immigrants adapt to their host society based upon their need to preserve their ethnic identity and how the host society receives their culture. While some immigrants will become assimilated and “Americanized”, others may adopt a multicultural identity. Although the host society is multicultural, the policy makers have taken a generic approach in addressing issues of long-term care. For this research, it is critical to understand what emphasis immigrant elders’ place on their own culture versus American culture regarding ideas about long-term care.

The long-term care system includes multiple types of healthcare services provided by various agencies and facilities. While healthcare is broader than long-term care, the two are related. There are many aspects of healthcare utilization behavior, such as:

1. Healthcare utilization is based upon three factors: predisposition to use health services, access to service (enabling factors or barriers), and the perceived need for formal healthcare services (Andersen, 1968, 1995).
2. Immigrant elders’ understanding of health is influenced by social and cultural factors (Emami, Benner, & Ekman, 2001).

Social and cultural factors shape immigrant elders' understanding of health and likewise, perceived need for formal healthcare services. Since many immigrant elders lack health insurance, their access to healthcare services and their predisposition to use healthcare appear curbed. This research will describe immigrant elders' long-term care planning in relation to cultural factors and financial and economic concerns.

Understanding the etic perspective is important to understanding potential biases in the research. The researcher's worldview and preconceived ideas inherently create a lens by which the research questions, overall design, and data analysis are influenced. With a clear understanding of the etic perspective, the researcher can proceed with inductive inquiry and focus attention to the immigrant elders' voice, the emic perspective.

3.2. Research Design

The purpose of this study is to describe immigrant elders' expectations, wants, and long-term care needs. By utilizing a multiple method approach, qualitative and quantitative data will be gathered and analyzed. The rationale and utility will be discussed under "Combining Qualitative and Quantitative Methods". Some of the processes regarding combining qualitative and quantitative methods will be discussed in this section while issues of "Data Analysis" will be discussed in that section.

In accordance with the ecological psychology perspective, the unit of analysis is the individual (Patton, 2002). This research utilizes purposeful sampling. To gain insight into their situation, the investigator will interview immigrant elders in Pennsylvania. Recruitment of participants continued until no new themes arose, which occurred with 13 participants. Recruitment and data collection lasted 6 months.

Data was gathered through in-person structured interviews that included qualitative questions and quantitative questions. Most of these interviews were conducted in the immigrant elder's home. Upon request, one interview was conducted at a local public library. All interviews were digitally recorded. The recordings were important in capturing direct quotes describing the individual's experiences. The researcher transcribed the interviews. During transcription, the researcher removed any names used and replaced them with pseudonyms to preserve confidentiality. Once these recordings were transcribed, they were audited for corrections. The recordings were erased at the end of the study when data analysis is completed. The written transcript was used for data analysis. To maintain confidentiality, the immigrant elder's confidential contact information was kept separate from the transcript of the structured interview and the interview reporting sheet.

A research journal was maintained. Field notes were taken to capture immediate perceptions and thoughts as well as later reflections related to the participants and the structured interviews. The journal maintained an audit trail that describes research activities, such as: date of interview, length of interview, date of transcription, date of transcription audit, date of coding. A thematic log will also be maintained in the research journal to capture new and emerging themes and to solidify recurrent themes. Decisions related to this research that are made during the research process have been documented in the research journal including this information: date, decision, and rationale. The research journal included a self-reflective analysis of potential biases. The research journal compiles the research documents that form the audit trail.

Qualitative data analysis was iterative. Based upon data analysis, no modifications were needed to the probes for qualitative questions. In regards to the qualitative data, inductive analysis and creative synthesis were used as a data analysis strategy. This study used the

following qualitative analysis techniques: content analysis and sensitizing concepts for coding. Quantitative data was analyzed to provide descriptive univariate statistics to describe the sample and to support or otherwise to give insight to qualitative findings.

Reasonable accommodations were provided to immigrant elders to facilitate their participation in this study. To address potential vision problems, the interviews were conducted in person. To assist participants regarding the use of different scales, a response card in large print was designed and available for each of the scales utilized. For immigrant elders with a hearing deficit or with limited English fluency, the interviewer repeated questions or provided limited clarification for questions. Each in-person interview lasted approximately two hours with a short break at the transition from the qualitative to quantitative questions. Several participants took a break from the interview for several reasons: consulting or acknowledging their spouse, low stamina, answering the phone or doorbell. Providing reasonable accommodations to immigrant elders supports the data collection of this study.

This research received financial support from two sources. The School of Social Work at the University of Pittsburgh gave the investigator pre-doctoral fellowships that provided stipends for participants, summer funding for her dissertation work, funding for training in ATLAS.ti software, and funding for equipment and supplies, such as: laptop computer, digital recorders, software, photocopying, and inter-library loans. The Kutztown University gave the investigator a research grant that was used to purchase ATLAS.ti software for data organization and ease in data analysis.

3.3. Combining Qualitative and Quantitative Methods

In designing a research project, the research methods need to fit the research question. To address the research question multiple research methods may be employed. While derived

from different paradigms, qualitative and quantitative methods may be combined throughout the research design (Flick, 2002). Qualitative and quantitative research can utilize approach recognizes each method as autonomous, operating concurrently, and converges at the research topic (Flick, 2002). This complementary approach compensates for the weaknesses of utilizing a single method with neither method being considered as superior (Flick, 2002).

All participants in this study answered qualitative and quantitative questions in the interview. This parallel process of collecting qualitative data and quantitative data at each in-person interview is one of the four ways to integrate qualitative and quantitative methods (Miles & Huberman, 1994), By this approach, participants provide qualitative and quantitative data that are “compared with each other and referred to each other in the analysis” (Flick, 2002, p. 266). For this research, the data analysis will compare the qualitative and quantitative data and report combined results.

Combining qualitative and quantitative results may be done for two goals: attain a broader knowledge than a single approach would provide, and mutually validate findings (Flick, 2002). According to Kelle and Erzberger (2002), this multiple method approach creates three outcomes:

1. Mutual confirmation of qualitative and quantitative results supports the same conclusions.
2. Complementary and different aspects of the issue are highlighted providing a fuller picture.
3. Contradictory and divergent results are found between the qualitative and quantitative data. (Flick, 2002).

The rationale to combining results in this research is to provide a deeper insight into the findings through confirmatory and contradictory or divergent results. Furthermore the nature of the qualitative and quantitative questions of the interview lend themselves to highlighting different aspects of the immigrant elder's thoughts regarding their long-term care wants, needs and expectations.

While from opposing paradigms, qualitative and quantitative methods can be considered incompatible for combining (Flick, 2002). Nevertheless, there are multiple reasons that support combining these two approaches. This research design combines qualitative and quantitative methods through its integrative data collection approach and combining results for validating findings and creating a fuller picture.

3.4. Recruitment and Participants

This study recruited immigrant elder women from Pennsylvania. The immigrant elder is someone who is 65 or more years of age and foreign-born. Individuals were recruited based upon meeting the following criteria: a woman, age of 65 years or older, being foreign-born, having a legal immigration/citizenship status, having at least conversational spoken fluency in English. These criteria create a sampling bias due to gender, functional cognitive status, level of acculturation and possibly socio-economic status.

Recruiting of participants continued until the qualitative themes were saturated. The initial plan for identifying and recruiting participants was to recruit up to 30 participants with the following distribution: 10 participants of Asian descent including India and the Middle East, 10 participants of European descent including Scandinavia, and 10 participants of Central and Latin American descent including the Caribbean. Since most long-term care facilities and community agencies have no tracking system of foreign-born elders, my primary recruitment site was the

International Women's Club and its affiliated groups: Mah-Jong special interest group, informal foreign language conversation groups, L'Alliance Francaise, etc. This investigator worked with Elizabeth Dorkhom, the Email Coordinator, who is one of the primary gatekeepers for the group. The Email Coordinator sent out a general email to all members of the club notifying them of this research project, requesting assistance in recruitment via referral of others or self-volunteer, and notifying them of additional contacts until all participants are recruited. In addition, the investigator recruited at several meetings of the International Women's Club. Since the members could refer others, recruitment through snowballing occurred within this design. Since the themes were saturated by the thirteenth participant through this recruitment method, the researcher did not need to implement any additional recruitment strategies.

The qualitative themes were saturated with a total sample size of 13 participants. All participants were immigrant elders who were women. Their ages ranged from 66 – 92 years old, with the mean age of 76 years old. They were primarily Caucasian, non-Hispanic (69%) with Asians (15%), Hispanic (7%) and Other (7%). Most of the women were married (62%) or widowed (23%), with the remainder divorced or separated. Most of the women (69%) immigrated with family. Their average age at immigration was 34 years old. All of them have lived in the United States for at least 25 years with an average of 44 years. While all of the participants were foreign-born, all were naturalized citizens at the time of the interview. Each participant was given a \$10 Giant Eagle gift card as a token of appreciation for participating in the study.

3.5. Issues Related to Human Subjects

This research was approved by the Institutional Review Board and data collection did not begin until after its approval was received. When recruiting participants, the investigator clearly

stated that participation was voluntary, that information regarding immigration would be asked, and that all data would be kept confidential and secured. Generally, the investigator contacted the participants three times: one recruitment contact from a representative from their organization, one telephone call to screen the participant and schedule the interview, and one face-to-face interview. Some had additional contact through recruitment at the International Women's Club meetings, snowballing or their changing and full schedules. All confidential contact information was kept separately from the interview data. According to the Institutional Review Board, there was no a need for a signed consent form since the contact information is separate from the data. All participants had the right to decline answering individual questions or further questions at any time during the interview.

While there were multiple potential and perceived risks to participants of this research, but the overall risk to participants is minimal. Potential risks included retrieval of negative memories and generalized anxiety. Participants might have feared that participation could cause religious or ethnic persecution and discrimination, loss of public welfare benefits and social service benefits and/or the potential for deportation. In a post-9/11 United States with the issue of immigration being contested, immigrants could have been reluctant to participate. If this occurred, most likely, the immigrant elder self-selected not to participate in the study. Furthermore, discussing long-term care plans could have increased the participant's concerns regarding their health conditions and their future planning. The researcher had contact information for the Office of Aging to available to participants who wanted more information regarding long-term care services. Having a home visit for the research interview, they risked having a stranger enter their home. To identify the researcher, the interviewer will carried at least two forms of photo identification. In addition, to accommodate the immigrant elder woman

willing to participate, but not willing to have the interview in her home, the researcher conducted this interview at a local public library.

There were multiple potential benefits to participating in this research. One benefit was a \$10 gift card from Giant Eagle, which was a token of thanks for their participation and should not influence their responses. Potential benefits included an opportunity for someone to visit, an opportunity for someone new to talk to about their life, and an opportunity for reminiscing on good memories. Another potential benefit was the sense of giving back in that their information would increase the knowledge about immigrant elders and could be used toward influencing policy for all immigrant elders.

3.6. Instrument

This research utilizes a three-part interview schedule designed specifically for this study. The interview schedule begins with an introduction to the research study including a confidentiality statement. Qualitative questions are followed by demographic questions and ends with quantitative questions. The interview schedule has been designed for in-person interviews in which the interviewer can repeat or clarify questions or answer choices for the participant. The interview typically requires two hours to administer.

Pre-testing of the various parts of the interview schedule was completed at different times. The demographic and qualitative questions of the structured interview schedule were pre-tested with immigrant elders, ages 55-65 years, during the spring 2003. The demographic and quantitative questions of the interview were pre-tested with immigrant elders, ages 60-64 years, during the spring and summer of 2005. Based upon the feedback from pre-testing, improvements were made to the interview schedule prior to the data collection of this research project.

The sequencing of the interview is purposeful. The interview begins with qualitative questions so that the participant can feel more at ease. Further, asking the qualitative questions first reduces the potential of the quantitative questions influencing the qualitative responses. The qualitative questions cover four topics: immigration, perceived social support, long-term care knowledge, the individual's long-term care concerns and planning. The demographic questions are in the middle to provide a transition from one method of inquiry to the next. The quantitative questions are last due to their degree of specificity. The quantitative questions regarding receptivity to long-term care placement are more emotionally demanding and placed near the end of the interview schedule. To close the interview with less emotionally demanding questions, the interview ends with several quantitative questions regarding cultural concerns and long-term care placement.

The interview begins with the participant being asked to tell the person's immigration story. Additional probes about the participant's immigration story include questions, such as: How old were you when you immigrated? Why did you choose to immigrate to the United States? Do you have family living in the United States? These questions are asked to elicit information about immigration, culture of origin, host culture, and acculturation. Culture is recognized as an important aspect of the social environment that influences behavior.

The social support section asks the participant to describe who helps the individual in the person's daily life. The additional probes about perceived practical social support are questions, such as: Who provides you help or assistance? What kinds of tasks do these people do to help you? How often do these people help you? These questions are asked to elicit information about practical social support. Practical social support is recognized as an important aspect of the social environment that influences behavior.

The long-term care section asks the participant to describe the person's knowledge and understanding of long-term care services based upon personal experience or experience through being a family member or friend of a person receiving care. The additional probes regarding long-term care services and facilities are questions, such as: What are your thoughts about services that help older adults stay at home? What are your thoughts about facilities, like: personal care homes, nursing homes, and continuing care retirement communities?

The last qualitative question focuses on the immigrant elder regarding their long-term care needs, wants, expectation, and preferences. In addition, the participant is asked to share what, if any, long-term care planning they have done to date. The additional probes regarding the immigrant elders' long-term care needs, wants, expectations, preferences, and planning are questions, such as: What type of long-term care planning, if any, have you done for yourself? What activities, if any, of the participant's homeland's culture are important to you in your long-term care planning? These questions are integral to gaining understanding of the central research questions regarding immigrant elders' long-term care expectations, wants and needs.

There are a total of 23 demographic questions. General demographic information gathered includes, age, gender, country of origin, race, marital status, education, religious affiliation, employment status, individual and household annual income. Additional information related to being foreign-born is asked with questions, such as: How many years have you lived in the United States? From what country did you emigrate? Did you already have family in the United States? What is your current immigration status? These questions are asked to be able to standardize the demographic information gathered and have been used to describe the sample.

The quantitative questions are designed to collect data to compare, to contrast, and to complement the qualitative questions. The purposes of the quantitative questions are linked to

the qualitative questions. The 83 quantitative questions cover eight topics: English fluency and use, individual American acculturation, perceived practical social support, the context of care giving, personal experiences with long-term care facilities, long-term care planning to date, receptivity to long-term care placement, and cultural concerns and long-term care. The quantitative questions topics are asked in the order that they have been presented.

The sections of English fluency and use and individual American acculturation are designed to capture immigrant elder's acculturation and level of "Americanization". In this section, participants are asked questions, such as: How well do you read English? Do you speak English at home? Further, they are asked the degree of agreement with statements, such as: When I was growing up I was exposed to American culture. At home, I eat American food. Overall, I regard myself as an American. Since culture is an important aspect of the social environment, the participant's culture is expected to arise throughout the qualitative questions.

The perceived practical social support scale asks the participant to indicate how much "help" is available to you by thirteen different categories of people. "Help" is defined as financial assistance, housing, transportation, reminders, and linking to resources. For each person or group of people, the participant is asked to indicate how often this category of persons assists them. Participants may respond with answers, such as: spouse daily; children monthly; neighbors weekly. These questions provide a concrete understanding of practical social support that has been used in conjunction with the qualitative data regarding social support.

The next section regarding the context of care giving is five items. This section seeks to identify what institutional messages the immigrant elder has received regarding families' responsibilities for care giving of their older adults. In this section, participants are asked questions, such as: Through government policies and programs does your homeland promote the

idea of family care giving for their older adult family members? and Does your faith promote that family should care for their older adult family members? This quantitative data is complementary to the qualitative data collected regarding social support and long-term care planning and provided additional information about aspects of the social environment.

Since most people have had some exposure to long-term care facilities, that is the focus of the next section. There are ten items regarding familiarity with long-term care facilities, such as: personal care homes and nursing homes. First, the immigrant elder is asked if they are familiar with long-term care facilities. The remaining items focus how that personal knowledge was attained. The participant would respond with answers, such as: Yes, I am familiar with what a nursing home is. I know about nursing homes from public advertisement, and volunteering there. This quantitative data supports the qualitative data regarding long-term care and may provide new information regarding their understanding of long-term care facilities.

The next section is regarding long-term care planning activities that the immigrant elder has completed to date. It is a 16-item checklist of activities that the immigrant elder indicates “Yes”, “No” or “Not Applicable” regarding the person’s completion of that activity. Participants are asked questions, such as: Have you ever attended a program on retirement planning? Have you spoken with family members about your long-term care concerns and plans? Have you discussed with a financial advisor or lawyer how to get the most financial benefit from your equity & assets? Have you appointed a Financial/Legal Power of Attorney? Have you created a Living Will or Advance Healthcare Directive? This quantitative data will be used in conjunction with the qualitative data regarding long-term care planning by providing concrete examples of long-term care planning activities.

The next section asks about the immigrant elder's receptivity of long-term care placement. There are a total of nineteen questions. They start with a screen of the immigrant elder's anticipated use of long-term care facilities and why. The next set of questions are designed to have the immigrant elder grapple with situations that require assistance. Immigrant elders are asked "Do you think you would be able to manage at home..." under certain conditions that require assistance, such as: "if you needed assistance remembering to take your medications"; "if you needed 24-hour supervision for your safety", "if you needed hands on help with bathing". These questions are designed to address concrete situations that the immigrant elder may not have considered in long-term care planning. Likewise, this data has been complementary to the qualitative data regarding long-term care planning and be use in conjunction with that data.

The interview ends with a section regarding cultural and care giving concerns in long-term care. These questions do not distinguish if the care is given at home or in a long-term care facility. These seven items are specifically designed for the participant to rate the importance of culture to care giving. An additional three items are about quality care giving. Participants are asked to rate how important it is for them to have certain care giving conditions, such as: being served food from your native country, having a caregiver that speaks your native language, having a caregiver that treats you with dignity and respect. This complements the qualitative data on long-term care planning. Overall, the qualitative and quantitative questions of the interview provide parallel or complementary data.

3.7. Data Analysis

This research design will generate qualitative and quantitative data and data from combining methods. Each form of data will require its own data analysis techniques. These data

analysis techniques will be implemented under one comprehensive data analysis strategy: inductive analysis and creative synthesis.

Prior to data analysis the data was prepared for analysis. The qualitative sections of the interview were digitally recorded then transcribed. The transcriptions were audited against the digital recording. The transcriptions are the data used for analysis. The transcription was forwarded to the second researcher, as described below. Utilizing ATLAS.ti, a qualitative research software, the transcripts were organized for coding. The demographic and quantitative portions of the interview were documented on the interview schedule. The descriptive and quantitative data were entered into a SPSS file and cleaned prior to data analysis.

Inductive analysis and creative synthesis are the foundation of the qualitative data analysis strategy. This data analysis process consists of five basic elements: immersion of data details and specifics, uncovering patterns and interrelationships, exploration and confirmation of findings, analytical principles as guides instead of strict rules, and creative synthesis (Patton, 2002). Codes arise from the data's details and lead to patterns and conceptual interrelationships. The exploration and confirmation processes establish and support what become the guiding analytical principles. The emerging outcome of the data analysis process is a creative synthesis of discovered information (Patton, 2002). This data analysis strategy drives the researcher to use multiple techniques to analyze data.

One technique in the confirmation process is to utilize a second qualitative researcher to compare coding schema. In this research, the second researcher was forwarded the transcripts. The second researcher independently analyzed the data using the same data analysis plan, described below. The primary and secondary researchers compared coding for inter-rater reliability. The inter-rater reliability was high from the start and remained high through

subsequent transcripts. This solidified the coding the scheme within six transcripts. Dr. Janice Gasker, Professor of Social Work at Kutztown University, volunteered to be the second qualitative researcher for inter-rater reliability. Dr. Gasker was chosen due to her recent training in ATLAS.ti and her accessibility, availability, and willingness to volunteer in this capacity.

Another technique was combining qualitative and quantitative data analysis to gather confirmatory data within the case and uniform specific data across cases. For a single case, the demographic and quantitative data acted as a checklist to audit the qualitative data. For example:

If the participant indicated in the demographic information that they were born & emigrated from Italy, the researcher would check the participant's immigration story for that information. No action would be needed if the data were confirmed. If there were a difference, the discrepancy is added to a list and becomes additional data.

The discrepancies were analyzed for emerging themes. This technique aimed at finding consistencies and inconsistencies within the single case.

The qualitative data analysis was analyzed primarily through content analysis utilizing the ecological perspective. In accordance with the ecological psychology perspective, the qualitative data provided narrative descriptions generated from the first three questions regarding the immigration story, perceived social support, and long-term care planning. From these narrative descriptions, behaviors are analyzed in relation to perceived goals and their attainment (Patton, 2002). Coding behaviors will be based upon central features of the environment. For this research, the behaviors are the immigrant elder's tasks and activities related to long-term care goals, such as: planning and anticipated use. These behaviors will be coded in relation to the physical environment (home vs. care facility) and elements of the social environment (culture, financial/economic considerations, social support).

Beyond the content analysis, patterns, themes and interrelationships were analyzed through sensitizing concepts. Sensitizing concepts identify central elements of the area of inquiry through a fundamental and insightful framework (Patton, 2002). The sensitizing concepts that provided a foundation for this research are embedded within the etic perspective, presented earlier. Based upon fieldwork and qualitative data, this conceptual framework could be confirmed or need to be reshaped or otherwise modified (Patton, 2002). Utilizing sensitizing concepts in this approach to data analysis recognized common and individual aspects of social behavior (Patton, 2002).

For the demographic and quantitative data statistical analysis will be run through SPSS. Univariate statistics regarding the demographics were used to describe the sample. Additional univariate statistics provided descriptive statistics. These statistics provided complementary and supportive findings to the qualitative findings.

The goal of this data analysis plan was to generate a deeper understanding of immigrant elders' long-term care needs, wants and expectations. The focus was to generate descriptive statistics across the sample. Since there was a small sample, quantitative analysis for comparisons groups and for hypothesis testing were not conducted. The descriptive analysis alone will be important for policy makers to make more informed decisions regarding long-term care policy.

4. Findings

The interviews collected data on a wide variety of topics. Due to high the congruence between the qualitative narratives and corresponding quantitative answers, the findings will be presented jointly. While there were a total of 54 codes generated from the qualitative data, not all were directly related to the research question regarding immigrant elder women's long-term care needs, wants and expectations. Findings relevant to the research question will be presented

first. This will be followed by additional themes that naturally arose from the data and other interesting findings.

4.1. Findings Related to Long-term Care Issues

When asked the qualitative question about their long-term care needs, wants and expectations, the participants often responded regarding their planning, lack of planning or not thinking about the issue. Typically, what followed was a response detailing conversations that they had with family and friends about their concerns about the future. Regardless of their initial responses, all provided detailed information regarding their long-term care ideas through the qualitative and quantitative responses. Throughout the interview, it was evident that all participants had thought about their long-term care needs, wants, and expectations. All of them had spoken to someone about their future long-term care needs. They primarily spoke with family members and professionals, as seen in Table 1. Their conversations with their husbands ranged from health, financing, housing and living arrangements, and surviving after the death of a spouse, as seen in Table 2. The theme of the conversations with their children tended to be related to how their children thought should be done to “take care” of their parents’ as they aged, as seen in Table 3. Conversations with professionals led to concrete long-term planning activities, such as: creating a will, power of attorney (financial or healthcare), or a living will.

Table 1 People with whom participants spoke about their long-term care needs

Family	77%
Friends	54%
Religious leaders	39%
Lawyers	15%
Other Professionals	77%

Table 2 Topics participants discussed with husbands

- P02: “Long-term care insurance, and that kinda thing, we don’t, we don’t have. We talked about it and decided that starting at age 60, or whatever, it was too late. Ooo, no, not too late--didn’t want to pay the premiums that we would have to pay out for long-term car insurance because we have a reasonable financial backing that hopefully we won’t need it. That’s what we are up to.
- P03: “Yes, well, um...no...I mean, we never thought of Longwood at Home at the beginning. We just thought about moving ourselves out to an apartment or a house. We were on a waiting list for a two-bedroom house. And, so we had a deposit and had our medical stuff there, and, ah, um...(sigh). We saw the nursing home and been in people’s...We’d have meals out there. And, a friend who loves being there in a house. But, then, I thought-I don’t really want to move there [on campus]...And, that’s how we changed from the thought of going to Longwood to Longwood at Home.”
- P05: “ No, we haven’t gotten any planning done. Except, that we have joined the, em, oh, I forget what their called now, the cheap burial people. Em, both of us want to be cremated. And, eh, eh, golly, I’ve forgotten what it’s called-this, some sort of burial thing that we belong to. So, that they dispose of you pretty cheaply. You don’t have to go through the whole kit and caboodle. That’s really quite disgusting when they look at people’s bodies in this country, ugh (a quiver goes through her body). Um, em, I hope we can go on living in this house for as long as possible. Um, it is a very big house. And, eh, it suits us well. And, eh, until we can’t manage the stairs, I imagine we’ll stay here. Um, if anything happens to my husband, I would have to move ’cause I certainly couldn’t cope with it on my own.”
- P10: “There’s a nursing home...trying to pursue us for home care-while they have invited us out to visit the facilities... And, we went out to look at it. And, we said, “We weren’t ready.” --to be on their campus.... So, they decided that if we weren’t ready that maybe we would like to have home care...And, they-somebody came and interviewed us, invited us to their luncheon. Went there. We spoke to a number of people.... And, we told them to give us some time to think about it. And, so we still have a few months more. And, what they would do-is pretty expensive...And, we thought it was a pretty good thing. So, we are still thinking about that. And, we tried to find out if any of our friends had gotten involved with that, and they, too, are thinking about that. And, so-we haven’t really decided on what to do.”
- P13: “We have, also, looked at some places... For us, right now, that’s a little too isolated from where all our friends are. So, we have, also, looked into home health care, which Longwood at Home had a seminar. We went to that and thought, well, when the time comes maybe that’s the way to go...as a start... So, that kind of thing we would consider. But, we have not done anything.... So, it’s not something that we have considered that seriously, yet. We do know of all the options that exist. And, now, we are just saying with our health, we think that we’re at least another ten years away from that kind of thing. And, we’re not going to address it immediately.”
-

Table 3 Topics participants discussed with children

- P01: “Well, my daughter insists that as long as possible, she will keep me here and get someone in--you know...just today she said that she’ll just keep me here...”
- P04: “because I don’t have any money to say that I want this or that. Whatever my son says, I have to do it. Because, when there is a monetary issue--beggars can’t be choosers. It’s the way of life. I don’t know, if I fall, you know, where I’ll be--in the nursing home or in the day care (chuckling) and, or, in the rehab care or at home. I don’t know. So, it’s not for me to say anything, you know--that I want to have this or that or whatever. It’s up to him to decide.” [pause, silence, nothing more].
- P05: “All of our children, in fact, have said, that they would like us to come to them, if, ah, ah, we didn’t think we could keep a house going.... our son is very keen on us going to him, so he might not want us to...well, he might prefer us to go to him rather than to give us money to go...”[into a facility/retirement community].
- P12: “I said to her, “I don’t know what to do if something happened to Dad, really. “And, she said to me...and, I said to her, “I don’t know--maybe I won’t have enough money to go to nursing home, or something...” And, she turned from her work and she said, “Mother, do you think that we will let you have troubles or we did take care of you?” You know, she was almost--you will see, I was almost crying and my husband, too, because we didn’t really expect such a reaction. You know. They [my daughters’ families] probably spoke with that other one about it because when we were there, now--about 3 weeks ago--I told her something, again. And, she look at me, and she said to me, “No, it’s not problem, Mommy.” And, I was surprised that she said it right away--didn’t stop...like thinking. And, and, she probably think about it before--if something happen to me or my husband, what to do?”
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Universally, the participants had completed many long-term care planning activities to date. While only 39% of participants attended a long-term care planning or retirement planning meeting, all had made some preparations for the future or the unexpected. Their long-term care planning to date covered a broad range of activities, such as: applying to a long-term care facility, creating power of attorneys, making a living will, or making final arrangements, as seen in Table 4. It was important to the participants to ensure that their health care wishes were known and that alternate decision-makers were identified. In addition, the participants wished to ensure their future financial stability as demonstrated by their financial planning activities, such

as: savings, buying long-term care insurance, consulting with a financial planner, as seen in Table 5. While the researcher categorized these activities as being related to long-term care planning, the participants viewed them as routine preparations made by people their age.

Table 4 Long-term care planning completed by participants to date

Applied to a facility	31%
Created financial power of attorney	62%
Created health care power of attorney	77%
Created a living will	85%
Made final arrangements (prepaid funeral or bought burial lot)	54%

Table 5 Financial planning completed by participants to date

Savings	92%
Bought long-term care insurance	23%
Created an annuity	15%
Consulted a financial planner	69%

Based upon the participants' description of their long-term care needs and concerns, the researcher identified four major findings:

1. Immigrant elders plan to remain living in the United States instead of returning to their county of nativity during older adulthood.
2. Immigrant elders plan to remain living in their own home for as long as possible, financially and medically.
3. Immigrant elders do not wish to be dependent on their families to meet their long-term care needs.
4. When the time arises that they may need paid care, immigrant elders are more concerned with having competent caregivers than with cultural issues.

Each of these themes will be explored in-depth.

What country immigrant elders chose to live in older adulthood is an essential to understanding their long-term care planning. All the immigrant elder women indicated that they plan to continue to live in the United States. This idea is intricately intertwined with their sense of identity, of citizenship and of home or homeland, as seen in Table 6. All of the participants are naturalized United States citizens with an average of 44 years of living in the United States. While many described having children, grandchildren, living in the United States, all indicated that they had life-time friends living in the United States. They talked about how they have adopted the United States as their “new” homeland and do not plan on leaving in older adulthood. This is consistent with He’s (2002) findings from the U.S. Census that foreign-born older adults are more likely to be naturalized citizens and have lived in the United States for 30 years or more.

Table 6 Participant responses related to citizenship and homeland

P07: “I am now a United States citizen. I became a citizen, a Naturalized Citizen in 1996... when you choose to take citizenship of another country, then, that’s your country.”

P08: “I just feel that this is my adopted country, but is my country. I go as a foreigner to my country. I feel a foreigner there. I don’t feel like a foreigner here. I never did.”

P13: “So, this is home. This has been home[land] for half a century already.”

P02: “So, I do so enjoy going back [to my homeland] a great deal, but I’m more of a tourist than wanting actually to go back to live there.”

When considering long-term care options, these immigrant elder women preferred to remain at home instead of moving onto a retirement campus or long-term care facility. All of the participants were familiar with various long-term care options that influenced their decision to remain at home. Their long-term care experiences covered a broad range of activities, such as: advertisements, attending events, volunteering or working as staff, visiting friends or family who

were patients to being a patient, as seen in Table 7. Most of them related some negative experiences with long-term care facilities, as seen in their comments in Table 8.

Table 7 Participants' experiences with long-term care facilities and services

Advertisements (tv, radio, billboard)	77%
Direct mailings	70%
Attend an event	39%
Tour a facility/Went to an Open House	62%
Visited friends	85%
Volunteer	54%
Worked as staff	8%
Had a family member receive services	31%
Received services, themselves	8%

Table 8 Participants' quotes about nursing homes

P02: "I don't see myself in a nursing home. I don't want to be under that kinda care. And, it's soul-destroying and mind-destroying. You go in there and you know you are never coming out and have that feeling. And, the people who are in there have no hope of getting any better. And, I just, just. You mind goes whether you want it to or not 'cause there is no, or not enough, stimulation."

P04: "The nursing home, you know, what I felt, is rather depressing because, you know, there was one patient opposite to my room, who used to cry, and "Hell", and he used to cry and scream at night. You know, because, you can begin to understand why because he is a Vietnam patient, you know. He must have gone through so much, you know. But, this experience really scares you-to go to a nursing home, to be very honest."

P11: "A nursing home. Yeah. And, I went to see him there. It's depressing. It's depressing. These older people sitting there with their wheel chairs around a table, and, oh-it's not very nice."

P12: "I understand that it is not easy. They don't have enough people, I don't know. We have warded those people, those old ones, but, I think, many of them are not so stupid, but because they gave them some medications. This is what I think. I'm not sure about it, but I think they gave them something to be quiet."

P09: "The ones with children and they know that they at anytime drop in, they got good, good care. And, if they knew that a patient don't have anybody, they were always waiting until last. And, that I did not like."

P08: "There are some that are cleaner than others. That there are others that are more pleasant than others. Uumm. That you see more care in some than others. That's about it."

As a group, these immigrant elder women were less knowledgeable regarding services that they could receive at home. There was a basic understanding that someone could be paid privately to come to the house to provide services, such as: housekeeping, lawn care or nursing services. They had difficulty articulating what specific services were available through which agencies. In addition, how the services would be paid through Medicare, Medicaid or Office of Aging funding was not clearly articulated or consistently understood. This is demonstrated through their comments found in Table 9.

Table 9 Participants' quotes regarding services available at home

P02: “You can get home services through your insurance company who will come and take blood, do tests, do vital signs, and that kind of thing...um...give medications, IV’s, and what have you, if you have to be at home because that is how my son was being looked after when he was ill. So, that’s a good thing to have. And, they are very good services, as far as, I could see.”

P03: “I realize, here, when my husband had to have surgery, that a nurse came here and did dressings and stuff. Um, so, I know they are available, at a cost.”

P04: “Well, I should go back over the fine print, again. (chuckle---Ha,ha,ah). I understand that “they will take care of us” (ha, ha)... But, they give you a feeling that-a-they’ll be there anytime of the night or day for your call, and they will send help.”

P08: “My first hand experience was way back when in the 1980’s was with my husband and hospice. They were wonderful. We kept him at home and he died at home...They were wonderful. They were not only, um, integral in his life, but in ours as well.”

P13: “We ended up getting somebody on our own, a paid person to help out. And, that was much better. That person would come. We had two shifts because towards the end my mother really could not walk anymore...She needed to be helped constantly. So, we had two shifts and I would take over in the evening, and get her to bed. The morning person would get her out of bed, and get, her dressed, and get her meals, and so on. So, that is the most ideal situation. Again, you have to be able to afford that sort of thing.”

As noted in some of these quotes, the financing of care was a concern to these immigrant elder women. While all but one participant described having adequate finances in the qualitative portion of the interview, they voiced concerns that they may or may not have done enough financial planning for their future. Not only were these immigrant elder women concerned with the cost of care, 92% had made some financial arrangements to pay for future care, such as: saved money, created an annuity, bought long-term care insurance. During the qualitative portion of the interview, several of the women indicated that they were being pursued by a continuing care retirement community without walls, and one immigrant elder couple had already signed with this kind of agency, as seen in Table 2. In addition, several noted the physical layout of their home was a considered and may have been modified to accommodate living on one floor, as noted in their comments in Table 10. So, for this group of immigrant elder women, they had a strong financial base and had done some form of financial planning and or home alteration in hopes to be able to stay at home and pay for long-term care services provided there.

Table 10 Participants' quotes regarding their home's physical layout

P6: “Well, I guess, eh, essentially, w,what we have come down to is that we have made adaptations to this house to continue living here. The down side of it is that we do not have a bedroom on this level.”

P8: “So, when my husband was here. I moved the bed downstairs, but there is no bathroom. So, yes, it would be hard here. You know...I don't know...you know. Sometimes, I wonder. This is a big house and sometimes I wonder if I wanted to stay here. Yeah. That is something in my mind. Yes, well, maybe I will move into a place that will be just one floor.”

P13: “It's a full bath-actually, it's a very large shower. It was supposed to be, like, wheelchair accessible. This whole area is wheelchair accessible, so, we planned it that way.”

Other than finances, medical needs were another concern about staying home with services. During the qualitative section of the interview, participants were able to articulate that there may be a medical necessity for people to go into a long-term care facility, as per their quotes in Table 11. Only one indicated that she had been in a long-term care facility to recuperate after a hospitalization. According to the quantitative data, these immigrant elders were fairly equally split in foreseeing a need for long-term care placement (56% =yes; 46%=no). The quantitative questions further pushed immigrant elder women to consider, if they would be able to remain at home under certain circumstances, such as: medication monitoring and administration, laundry and meal preparation, dressing and grooming, bathing and toileting, and being unsafe. Needing assistance for several of instrumental activities of daily living and all of the activities for daily living were identified by some participants as conditions that would require long-term care placement, as seen Table 12. Notably, being at risk of violence to others, requiring 24-hour supervision for safety, and having hallucinations were the most common reason for needing long-term care placement, as seen in Table 12. Most of the participants (85%) identified at least one circumstance in which they would foresee the need for placement. The two women who did not foresee the need for long-term care placement are married and indicated that their husband would assist them as long as he could. So, social support demonstrated to be a factor in their deciding if a condition warranted long-term care placement.

Table 11 Participants' quotes as to when long-term care placement would be necessary

P01: “Now, like there could be some things that would be so serious that you could not stay at home-you know...and, you would not necessarily die right away.”

P02: “Long-term care is for if you have Alzheimer’s or something like that and you have to go into long-term care.... Well, the last two years she had to live in a home...because, she could not look after herself properly. She had..aah...head problems and...ahh. She was falling and that kinda thing, so. Oh, it was...oh, I’m sorry, any ways she ended up staying in a home some.”

Table 12 Conditions in which participants did not believe they could stay at home

If you needed assistance remembering to take your medications	8%
If you needed assistance taking your medications	8%
If you needed assistance walking indoors	8%
If you required 24-hour supervision for your safety	31%
If you required 24-hour supervision due to hallucinations	39%
If you were at risk of violence to yourself or others	54%
If you needed hands on help with bathing	8%
If you needed hands on help with dressing and undressing	15%
If you needed hands on help with grooming	15%
If you needed hands on help with eating	15%
If you needed hands on help with getting in or out of a bed	15%
--OR-- if you needed hands on help with getting on or off a chair	
If you needed hands on help with toileting	23%
If you were incontinent of bladder and/or bowel	31%

While being dependent upon a spouse appeared acceptable to these immigrant elder women, depending upon other family members was not always expected. While participants described families that were “close” or “had good relations”, they did not look at them as potential family caregivers. Often the children and grandchildren were considered “unavailable” to provide assistance due to distance or “busy lives”, as seen in their quotes in Table 13. This is further supported by the quantitative data, in which 23% of participants indicated that their children were available for social support only several times per year. Also contributing to their decreased expectation of children providing family care giving was the immigrant elders’ strong sense of independence, as seen in their comments in Table 14. Aside from the spouse, family care giving was not an expectation of immigrant elders due to their independence, their desire not to be burdensome on their children and grandchildren, along with the reality that some of their family members were otherwise “unavailable”.

Table 13 Participant quotes on children as potential social support

- P08: “And, the childrens are extremely busy. Well, maybe by then, they will not be that busy. But, now I hardly even see them. They have their obligations. They are so, so busy.”
- P09: “Most, well, I would say, half of them have children around here. And, if they can’t do it the children help a lot... [but] we don’t have that.”
- P13: “All our relatives are not in Pittsburgh. So, it’s a little more difficult to call on relatives.”
- P05: “But, I wouldn’t do that, I think, because it is too much of a strain on them. When kids are working hard, and they got their young families, and everything, I think it’s a bit of a drag to have, eh, old people living there.”
- P02: “I wouldn’t want to...I couldn’t ask my children. I think that would be too much of a burden on them...I can’t expect the kids to wait on me hand and foot in their household. They got their own lives to live, so. I would like to be able to do that, but I’m not sure (ha) that they (ha) would (ha) want to do (chuckling). I would not want to put myself in that position-making them feel guilty, making them look after me (chuckling).”
- P10: “We have our children, and they are all comfortable. We are financially comfortable-so, we won’t be a hardship on any of them to do anything for us. They are far away. It would be an inconvenience to be involved.”
- P12: “I don’t want to go there.... I would like to live close, but I don’t want to live with them [my children’s family] because I don’t want to bother them. And, I think those families are supposed to be alone.”
-

Table 14 Participant quotes on being independent

- P04: I need to help myself, whatever, I am doing by myself, I am doing it, you know....
And, for that I am thankful...”
- P06: “Well, truthfully, we are pretty well self-sufficient.”
- P10: “...because they know that we are pretty independent. And, we do what we want.
And, so they can’t see us as they helping us.”
- P05: “We would prefer to be independent, I think, of our kids.”
-

While immigrant elder women do not anticipate family to become caregivers, they have considered that they may need some assistance at home in the future. When considering paid

care giving at home or in a facility, all of the participants indicated the importance of having competent care givers, and that treated them with dignity and respect. They were divided equally in regards to how important it was to have a caregiver that was culturally competent. Overall, the participants were less concerned with cultural issues and having cultural needs met. For many of these immigrant elder women, it appeared that cultural needs relating to long-term care services were not even on their mind, and required prompting to elicit a response. It was intriguing to hear them discuss at length all of their self-identified issues regarding their long-term care needs, services, finances and plans, and then, ask if there was something else they were supposed to consider, like their cultural concerns, as demonstrated in their quotes in Table 15. This was further supported in the quantitative data. When asked about specific cultural concerns related to long-term care options, 92.3% of immigrant elders indicated that it was not important to be able to eat their native food, or wear their native clothes, or celebrate their native holidays. In addition, 85% of immigrant elders indicated that it was not important to have a care giver from their homeland or of their ethnic background. While participants did not articulate a specific rationale for their lack of cultural concerns for long-term care services, it could be related to their acculturation and their sense of “Americanization”.

Table 15 Participant quotes regarding cultural needs in long-term care services

P02: Well, I don't think that there are any cultural concerns, or that kinda thing.

P03: I suppose cultural things don't come into it.

P10: Cultural needs? No, none of those.

P13: Um, cultural-I don't think there's a problem because I've lived here practically all my life, and this is as much home as anywhere else.

This sample of immigrant elder women were not only all naturalized citizens, but had a sense of “Americanization”. Their sense of “Americanization” was based upon their use of

English, knowledge and participation in American culture, and self-identification. To participate in this study, all of the immigrant elder women had to be minimally conversational in English. All of them reported to understand English very well, and, did not need further interpretations of questions. They indicated to be fairly fluent in speaking, reading and writing English, as seen in Table 16. Most participants (77%) indicated that they spoke English at home all of the time. In addition, even more participants (85%) indicated that they spoke English all the time with friends now even though they did not have American friends growing-up. While most participants (70%) indicated that they had no exposure to American culture growing up, all of them reported being familiar with American culture now. Overall, they were more likely to engage with American culture through music, holidays and food, as per results in Table 17. For the majority of participants (92%), they considered themselves to be American and that American culture had been a positive influence on their life. Likewise, this affinity for the American culture may contribute to their lack of cultural concerns in receiving long-term care services.

Table 16 Participants' self-rating of English fluency

	<u>Fairly Well</u>	<u>Quite well</u>	<u>Very Well</u>
Spoken		31%	69%
Reading		16%	84%
Writing	15%	8%	77%

Table 17 Participants' self-rating of engagement with American cultural activities

	No	Yes, a little	Yes, a lot
I listen to American music.		31%	69%
I celebrate American holidays.		8%	92%
At home, I eat American food.	8%	38%	54%
At restaurants, I eat American food.	15%	8%	77%

While this group of immigrant elder women may not have a detailed comprehensive plan for their long-term care, all of them were able to articulate their likes and dislikes as well as their

wants. The participants discussed their social supports and indicate how they anticipated what social support they could expect in regards to family care giving from their spouse and other family members. While reluctant to consider being placed into a long-term care facility, all of them acknowledged that a time may come when they required paid care giving. When considering paid care giving, they were more concerned about having a competent care giver than cultural concerns.

4.2. Other Interesting Qualitative Findings

Aside from content relevant to long-term care planning, the other group of themes that arose naturally from the data related to different aspects of identity. The theme of identity arose from the content and the manner in which they answered questions. Their identity was multifaceted, including the following aspects, such as: citizenship, multicultural identity, and roles. While these aspects of identity may serve as a foundation for understanding immigrant elders' ideas about long-term care planning, these themes tended to emerge from a different context in the data. Since the participants' did not link these ideas directly to their long-term care planning, they are presented as other relevant findings.

Their themes regarding citizenship were multi-layered. While there was diversity in their country of national origin, the majority were from England, as seen in Table 18. Nevertheless, all of the participants naturalized citizens who expressed some pride in being naturalized citizens and loyalty to the United States, as seen in Table 6. A newer aspect that arose toward the end of data collection was dual-citizenship, as seen in Exhibit 4.1. It is unknown how many participants have dual-citizenship and how having dual-citizenship may impact them financially.

Exhibit 4.1 Exemplar regarding dual citizenship

P12: “And, we, a group of people who escaped after 1968, we can have Czechoslovakian or Czech citizenships. We are American citizens from 1967. And, we asked for that Czech citizenships. Now, we have two of them-American and Czech.”

Table 18 Participants according to national origin

England	4
Canada	1
China	1
Columbia	1
Czechoslovakia	1
India	1
Jamaica	1
Romania	1
Scotland	1
Yugoslavia	1

While not all the participants were members of the International Women’s Club in Monroeville, PA, all of them described a multicultural identity that was rooted in international and global experiences and a sense of heritage, supported by being multi-lingual, as well as a connected to American culture. While most of the women emigrated directly from their country of nativity, 38% of participants emigrated from other countries, as seen in Table 19. These women provided rich histories of living internationally and emigrating due to the economy or poor conditions after the World War I & II, as seen in Table 20. In addition, participants described with pride and detail their heritage that went beyond their country of nativity, such as: Zoroastrian Indian, Spanish Colombian, German Yugoslavian, Chinese Jamaican, “Saxon” Hungarian, and Moravian Czech, as seen in Table 22. With such a blending of cultures and experiences, most of the participants (85%) were multi-lingual, and spoke fourteen different languages, as seen in Table 21. Even with all this rich cultural aspects of their identity, most (92%) indicated that, overall they felt that they were “American” and that American culture had a positive impact on their life.

Table 19 Participants' country of emigration

England	3
Austria	2
Argentina	1
Canada	2
China	1
Columbia	1
India	1
Jamaica	1

Table 20 Emigration stories

P01: “I was only a child, you know....We had been in Canada for a while before we came down here. But, I was only 11 years old.... I never could get a good question/answer on that [why we emigrated]... I mean. At that time, I don't think people do it now, come from Europe, but at that time it was a common thing I think....We were born in Scotland, and then, we came out to Canada.

P06: “OK. Well, I guess, to start off with, although I come from England, em, we, we, our original intention was to emigrate to Canada, not the United States. And, so we went there in, aah, eh, 1957, and, eh, and, eh, we were there for less than two years when there was an e,enormous lay off in the aircraft engine business. So, we had to relocate for my husband's work. And, so, we had the choice of either going back to England, in less than two years... or else, come onto the United States because the United States, em, companies, were, em, going up to Canada and getting the engineers from this big lay off and bringing them to American companies. So, then we came, ah, ah, actually from Toronto, Canada, eh, into Cincinnati, Ohio, in 1959. And, we've been in the United States ever since.”

P09: “... we married when I came from concentration camp and when he came from the prisoner of war camp-in Austria, as refugees....And, we were supposed to go to Germany. Germany was supposed to take us-because our grandparents come from Germany.... But, they were overfilled with East Germans coming from everywhere and they just couldn't. So, Austria took us in a refugee camp. And, they could not give us a proper anything either-because they didn't have. Then, we heard that America is taking refugees. And, then we put our name in their and got here in America, and that was in 1956.”

P11: “We immigrated to Argentina. And, then, my husband got a job, here....[before that] we had to flee when the communist came. And, we had to leave everything, everything, houses, and everything. So, we went. They took us to Austria, first.... I was living in the American zone. Austria was divided in four zones: Russian-ah-French, Russian, American, English. OK. I was in the American zone, know? We lived in the American zone.... But, then, officially, the Austrian government and the American helped...”

P12: “In 1968, in August, Russians of the Warsaw Pact came to occupy Czechoslovakia. It was August 21st 1968. And, when we saw them, at night, coming with the tanks, we decided to go, then. But, we had been listening to the radio. And, BBC said that the borders are already closed and nobody can go out. And, we cannot go. And, we talk about it-after the occupation--a long time. Go...not to go. I had small children, 9 & 10 years old, parents-old parents on both sides. And, I have work. And, I said to my husband, “Will not be easy. I don’t know any language.” But, ah, after 10 months, I saw the situation was much worst. And, I decided to go away. And, ah-we just wait. And, school year ended. It ended on June 28th, 1969. We pack-like go for vacation. Closed our house. We didn’t tell anybody anything. And, crossed the borders from the Czech Republic to Austria...We asked for visa to go to Yugoslavia. And, last year, from 1968-1969, it was more open. And, we have some kind of relatives-very far, not very close relatives, in Austria in Vienna. And, we crossed border. We stopped in Vienna and went right away to USA embassy and Canadian embassy to ask for asylum to go here.... My husband went again to Canada-‘cause, first we think that we are going to go to Canada, Canada embassy and sign for asylum....And, we were camping at that time. We could not go to hotel. We didn’t have money, but we were camping. And, ah, um---But, we did reach those people, who were a little bit our relatives-if we can stay with them. They have one room, which they can give us. We stay in that room for almost 6 months. And, we...my husband has in USA some colleague from his work, who escaped in 1968. And, we tried to find him. And, we did. And, he wrote us letter. And, he said, “You are not exactly, too young”-‘cause he was 43 and I was 38. “And, it will be much better to start your new life in USA than Canada.” And, we decided to ask to come to USA.”

Table 21 Languages spoken by the participants

English	13
French	7
Spanish	4
German	3
Russian	2
Czech	1
Guajarati	1
Hindi	1
Hungarian	1
Latin	1
Mandarin	1
Marathi	1
Serbian	1
Yugoslav	1

Table 22 Participants' stories about their heritage

P04: “You know in different religions there are different traditions. I, being a Zoroastrian, have different traditions all together. Like, when we celebrate... We believe in nature. Nature is. Even our prayers are for nature. We believe in nature so much that even our thirty days are named after nature. Even our months are nature. We even have a different calendar all together. Our calendar begins the end of August because that’s the time that we landed in India from Iran. We are originally, from Persia. We are not from India.”

P08: “Maybe because I am European that I blend with the American people, but unless they see, hear, me talking.... On both sides”... [my family is Columbian of Spanish decent].

P09: “Well, you have to come along because you are Germans.... And, we stayed in Yugoslavia, and, then, Hitler lost the war. So, after the war, um, the communism come. And they say, “Ah, we got the Germans.” Now, they took, when they came in at night but you had [only] what you had on, and what you had on your chair was an article about your parents, your grandparents and your great-grandparents had.... I went to Austria. And, Austria could not take us because Germany was over filled with the East Germans with refugees. We should go back to Germany because our parents came from Germany. So, Austria took us as refugees.”

P10: “We are both from Jamaica. Our parents went to Jamaica, I guess, early-around 1920 or 1925. They migrated there from southern China. And, um. I met him in Jamaica. And, 1% of the population there are actually from China. And, they are all from the same area.”

P11: “No, I am from Transylvania. I am European. I am not South American, but we immigrated to Argentina.... My ancestors came from Alsace Lorraine, 1200. Because in that time, in Hungary, it was Hungary, Transylvania. In that time, there was a king, a Caesar, a Kaiser,...And, he went to...look for people who can come and build, not a wall, but castles and this kind of stuff, against the Turks. Because, there was always an invasion from Constantinople, from Turkey, all the time. And, so, my ancestors, as I said, this was 800 years ago, know? They came from Luxembourg and Alsace Lorraine. And, we are called Saxons, but we are not Saxons. It’s a tribe, know? We are more from that other side. But, since they, that Hungary was in that time was at war with the Saxons-everybody who spoke German was Saxon, know? It was not so good, but everybody still is Saxon. OK. So, they build their forts against the Turks, at that time.

P12: “Czech....And, I am proud that I was born because those people are very good. And, we are, we are, we are, em, ah-you know, very old kingdom, supposed to 900’s, 900’s, and, even, even older. Czechoslovakia used to be Czech, Bohemia, and Moravia, center, and Slovakia. Now, Slovakia is gone. They want to come back. And, I am from Moravia.”

Their roles presented another interesting aspect of their identity. In particular, the role themes that emerged naturally were those related to family and to work. The family roles that emerged were spouse, parent and child. Even though the interview questions were directed to the individual, the women fairly consistently told their family stories. Some, even, tended to answer questions as what “we” would do, think or say instead of “I”. While all of the women were married at some time, currently some were widowed or separated. They discussed the shared household chores and joint decision-making that they had done with their husbands regarding immigration, housing, raising their children, health care and long-term care planning, as seen in Table 23 and Table 2. They described care giving which they gave during a health crisis to their spouse or how the roles were reversed during their own health crisis, as seen in Exhibit 4.2. The participants’ stories were intimately intertwined with their husband’s life forming a core of their identity.

Table 23 Participants' shared responsibilities with their husbands

P02: “I have a spouse who helps with all the normal everyday things-takes me shopping if I need to be take, but most of the time I take myself.”

P05: “Oh, yeah, yeah. He will cook a meal and look after me. And, he will go an get prescriptions. And, ah, no-we’re very close. We help one another.... He’ll help Hoover, if necessary. And, eh, we do things together. We’ve had, eh, some good years together.”

P06: “And, while we can, the two of us, the two of us...what I can do. There are some things that I can’t do so well. And, there are some things he can’t do so well. But, we complement one another.”

P09: “Oh, yes, he still helps. He washes the dishes. I do the cooking. I do all the dusting and the bathrooms, and he does the vacuum cleaner.”

Exhibit 4.2 Exemplar of family care giving roles with husband

P12: “My husband didn’t help me too much when he was working. And, but, he, always, cut the grass. He did many things, like, repairing things, you know. I don’t know, exactly, what to say, now. Like, if I cannot close the door or something is wrong with window, and those things, he, always did. And, now, he has to help more, you know. He was very sick with those kidneys, and I had to take care of him. And, after my heart, I, always, said, “God, I hope that I am never so sick that I need his help.” Because he is absolutely cannot do any cooking. Absolutely, nothing. He learned how to cook potatoes when he was 62.”

Another role that was important to their identity was the role of parent. They describe themselves as parents who had sacrificed for and otherwise supported their children to have a better life than theirs. As an outgrowth of that, they were proud parents of their children’s achievements. In addition, they seemed lost and had difficulty articulating their children providing them social support instead of receiving social support from them. The potential role reversal was something that the participants struggled with.

The role of child continued to be an important part of their identity. While several women’s parents lived nearby, most of the women described the burden of being an emigrant while their parent ages. They described variations of how they were not able to meet the role expectation a child providing care of an elderly parent, as seen in Table 24. Their inability to successfully fulfill this role expectation continued to weigh heavy on some of them, even at the time of the interview.

While all these findings provide insight into who these women were, the participants’ did not link these aspects of their identity with their long-term care planning. Immigrant elder women have a multi-faceted and complex identity. This work only touches the surface of these individuals’ identities.

Table 24 Emigrants' issues of family care giving

- P03: "I went home first because my father was ill. He had cancer of the stomach. And, so, then I came back."
- P05: "I had an elderly mother. And, we had always promised--she was a widow-I'd always promised her that she could come to us when she was too old to keep a house for herself. And, ah, of course, I reneged on that and I felt guilty ever since."
- P07: "My mother was of that mind, but she could not look after herself anymore. And, she would just lay there. It was very interesting--so many women, so many family members went all the way out of their way. She would have us running around like chickens with our head cut off. Go here. Do this. Da,da, du, da,da, da. You know, I lived over 3, 000 miles away. So, it's a long way. And, when I would go home, I would spend a lot of time just doing things for her. And, her great fear is that she would die alone. My sister lived 2 or 3 blocks away for the care home. And, she came up all the time. So, that was good. But, you know, I could not bring my mother here because she was from another country. I couldn't afford it. It would be expensive."
- P09: "In Germany, the children have to help to pay. As long as you have children that work, and, then the parents go to a nursing home, and they have to pay and don't have money. Every child had to send their income in. And, then, they have every child's income. And, then, they get according to the family how much they need, and they have to help to pay there. Now, some cannot afford it, then the government pays.... In Germany, I know when my father was sick, and, they wanted to put him in a nursing home, and, my brother was in charge of all and he wrote that they, that they would have to pay, have to pay, then, he gets a nursing home. He said, they cannot ask anything of you because you are out of state, and we all have to pay. So, I took here a job with a very rich old man. His wife died. And, I went Saturdays to work for that man in Lancaster. I said the money I made there that's what I am going to send you, then, for my father. He said, "You don't have to because" "No, I want to pay my share." I said, and then, that's how it was. Then, my father died before he goes--so, nobody had to pay."
-

5. Discussion

The findings of this research seem to indicate that the predominant issues of these immigrant elder women are fairly universal in nature. The concerns that these immigrant elders expressed are embedded in the some of the developmental issues of older adulthood. This does not negate that immigrant elders have unique issues to be considered as variables that impact them

throughout their life course and their development into older adulthood. Furthermore, these participants do not represent the heterogeneity of all immigrant elders.

This research indicates that these immigrant elder women have the same issues regarding long-term care as those noted in the literature review regarding the general older adult U.S. population. Immigrant elder women spoke with family, friends and professionals about their long-term care concerns. The participants were well versed in some of the jargon, such as: annuity, power of attorney, living will, will, and final arrangements. All of them had executed some of these documents. They were less versed in the differences between the various levels of care, the kinds of services available in facilities and at home. They were least knowledgeable about potential sources of payment for these services in facilities and at home. These activities are appropriate for their developmental stage and are fairly consistent with the general older adult American population. Anticipating changes in their physical and mental functioning, older adults tend start putting their affairs in order, such as: financial planning, creating powers of attorney and living wills, seeking information about aging and long-term services and facilities (Hooyman & Kiayak, 2008).

As naturalized citizens, immigrant elders have created a life here in the United States. They had minimal or broken ties to their former homelands. In addition, most of them had children and grandchildren living in the United States. Based upon these ties, these immigrant elder women plan on spending their older adulthood in the United States. This finding could have inherent bias based upon the fact that all the participants were over 65 years old and still living in the United States. There could be others who immigrate to the United States solely for education and work who do not become naturalized citizens and return home to retire. Likewise, the older adults who left the United States would not have met the recruitment qualifications of this study.

Like the general older adult population, immigrant elders prefer to spend older adulthood living at home instead of an institution. Many immigrant elders have negative past experiences and attitudes towards nursing homes. This may reflect similar findings that Holocaust survivors and other older adult's attitudes about nursing homes were predictive of their willingness or the lack thereof to be placed in a nursing home (Lester-Pouw & Werner, 2003). Regardless of being foreign-born, people who have negative experiences with facility care tend to not want to be placed in nursing homes.

In general, the participants indicated that they had medical and financial concerns about being able to remain at home. They described their fears of deteriorating health would lead to the need for expensive health care and additional expenses in regards to home making and home maintenance. With the exception of one woman who described herself as "poor", all described themselves as being financially secure, but still leery about being able to pay for additional expenses. This seems accurate when you consider that many of the participants worked part of their lives and all of them had husbands who worked, primarily at high income jobs, such as: professor, or engineer. All of these families had done some financial planning, if only savings, for their future. In addition, the family roles seemed fairly traditional in that the husbands handled the finances. So, part of the women's uncertainty appears to arise from not knowing their family's true financial status. Older adult women in the United States face health and financial issues (Hooyman & Kiayak, 2008; Hillier & Barrow, 2007) similar to those issues raised by these immigrant elder women.

Another financial aspect deals with a limited understanding of various insurances' coverage and program benefits. With the exception of two participants, the women qualified for Social Security and Medicare. All of the participants qualify for Office of Aging services and various

waiver programs through the Money Follows the Person Act. So, these participants would have the same eligibility requirements for services at home and at a facility as a native-born citizen. In addition, two women indicated that they received a government pension from their country of origin. It is unclear if the other participants would qualify for similar pensions and if the participants would qualify for other benefits from their country of nativity. Overall, due to the on-going legislative and programmatic changes to provide additional funding for long-term care services at home, all of these immigrant elder women would qualify for various long-term care services at home. The on-going changes to older adult program benefits hinder people from being knowledgeable about current benefits and eligibility requirements. Nevertheless, for immigrant elders, this becomes further complicated with immigration issues, such as: work history in the United States and their country of nativity and qualifying for benefits from their country of nativity.

Their concerns about formal services at home are off-set by their ideas of family care giving. For the married women, they anticipate that their husbands will assist them as long as they can. This is consistent with Cantor's (1979) hierarchal compensation of family caregiving patterns, in which the spouse is the initial person called upon (Gelfand, 2003). In addition, several have children who live nearby that provide some assistance. One participant actually lives with her son. While the remainder claimed "close" relationships with their children, they did not want to be a burden to them or their children were "unavailable" to them. This is consistent with differences in the amount of contact ethnic families may have even though many ethnic cultures have a strong family orientation (Gelfand, 2003). Their comments further dispel several myths identified by Treas (2009) about immigrant elders and their families, such as--being family

dependents in “traditional” families. This seems to arise, in part due to their sense of identity based upon their role as mother and continuing concept of an independent self.

One aspect related to these immigrant elder women’s family care giving expectations is their role as parent. These immigrant elder women were generally proud about successfully launching their children into their own education, jobs and family. As part of that process, they wished their children on-going success that may be thwarted if family care giving expectations were put upon their children. Women identifying as mothers benefit from their children’s success throughout their life course. According to McCall & Simmons’s identity theory (1960, as found in Turner, 2003), the children’s success is performance evidence for role support and role identity as a mother. Likewise, hindering their children’s success to meet their own care giving needs would alter the ability to fulfill the role of mother, create a role transition to care receiver, and change the locus of control of the relationship.

Another aspect of these immigrant elder women’s family care giving expectations is their on-going sense of independence. These women had overcome many difficulties throughout their life. They described themselves as fiercely independent. As these women progress into older adulthood, they will meet additional challenges, such as: changes in physical and/or cognitive functioning, changes of roles, etc. According to continuity theory, individuals develop coping mechanisms, stress and frustration tolerance levels and ego defenses in their younger years; this becomes the foundation of an on-going sense of self (Hillier & Barrow, 2007). Likewise, the skills and abilities that these women developed in their younger years have created an on-going sense of self who is fiercely independent. These characteristics made these immigrant elder women less likely to ask their children for assistance and to be family care givers.

Another unexpected finding regarding culture is that competent care giving trumped cultural concerns in their long-term care planning. This may reflect similar findings that cultural factors alone do not lead to quality of life satisfaction by immigrant elders in ethnic-specific nursing homes (Hikoyeda & Wallace 2001). Nevertheless, since belief and practices in ethnic and minority family care giving are rooted in cultural understanding (Gelfand, 2003; Dilworth-Anderson, Williams & Gibson, 2002; Scharlach, Fuller-Thomson & Kramer, 1995), this is an unexpected finding. Since these immigrant elder women are long-term residents and naturalized citizens and have English fluency, these findings may be more true for immigrant elders with more years living in the United States and higher levels of assimilation or integration. These immigrant elder women described what Kim (2001) called a multi-cultural identity, in which an individual embraces multiple cultures. These women described an identity that embraced not only American culture, but also the culture of their country of nativity, and a deeper ethnic heritage. Each woman had a unique combination of cultures that underlies her individuality. It is unknown what may be true for immigrant elders who are newer residents with other immigration statuses or with language isolation. To further understand this phenomenon, the research design would need to include multi-lingual data collection and a larger sample.

Another interesting aspect of competent caregiving for these immigrant elder women was that their care givers were not only technically competent in caregiving, but also treated them with dignity and respect. An individual's ideas of how to be treated with dignity and respect are rooted in cultural understanding. While these women indicated that cultural concerns, like food, were not so important to them, culture would still be embedded in their understanding of dignity and respect. So, while these immigrant elder women did not identify cultural concern, having a

care giver who had cultural sensitivity in understanding dignity and respect was part of their concept of a competent care giver.

The findings provide a mix of themes that provide insight into older adulthood for these immigrant elder women. These findings give us pause in some previous conception of culture in relations to these immigrant elder women's long-term care needs, wants and expectation, but also their social supports and sense of identity. While these findings highlight some of the uniqueness of immigrant elder women and their issues of older adulthood, they draw attention to the universality of some issues of older adulthood, such as: independence, family social support and access to service, and being treated with dignity and respect. These themes are so universal that they are embedded in the *United Nations Principles for Older Persons* (UN, 2007), which focus attention on the situation of older adults world-wide, such as principles of: independence, care and dignity.

6. Limitations and Research Recommendations

As with all research, there are limitations to this study. These limitations include various aspects of the research design, such as: participants' projection of future long-term care use, issues of bias in sampling and generalizability, and financial constraints. Each will be explored below and recommendations given in how to better address these limitations.

In regards to long-term care planning, participants are asked to project what services they would likely utilize. No one can truly predict what services that they most likely would utilize. This is still a reasonable question considering that all of the participants are already older adults and their health status could change unexpectedly. Likewise, if a participant had a change in cognitive or physical functioning, decisions regarding services may be made with or by others. Although their perceived need is important, a longitudinal study would better answer this

question by comparing the anticipated utilized services to the actual services utilized throughout their older adult years.

This research design has bias in sampling based upon language. There was a sampling bias based upon the selection criteria, which included being conversational in English and living in the local population. Likewise, immigrant elder women who were not fluent in English would not meet the research selection criteria. In addition, English fluency can be used as a measure of acculturation to American society. So, the participants were more likely to have higher levels of integration and assimilation to American society to those who are language isolated. To gain the full spectrum of acculturation in immigrant elders, research would need to be conducted in English and in the immigrant elder's native language. While conducting research in multiple languages with translators would provide greater heterogeneity in level of acculturation, it would create other methodological issues.

Additional sampling bias was based upon location. Immigrant groups tend to disperse in different manners to different locations, primarily based upon their job prospects and family reunification. Likewise, each community will have a different mix of immigrant elders. In addition, this research interviewed immigrant elders who had stayed in the United States during older adulthood. Immigrants who arrived as children or adults, but emigrated from the United States prior to becoming 65 years older did not meet the research selection criteria. To gain a fuller picture of immigrants' desire to stay in the United States in older adulthood, longitudinal studies would be needed that would track immigrants from adulthood through older adulthood to see if they emigrate or stay in the United States.

Additional bias in sampling most likely occurred due to self-selection not to participate. There are many reasons why immigrant elders may self-select not to participate in this research.

With the changes in social welfare policies in the 1990's, some immigrant elders may fear that they could lose services or benefits by disclosing their national origin or year of immigration. Since this research occurred after the 9/11 terrorist attacks and changes to immigration policy, some immigrant elders may have self-selected not to participate due to fears of being targeted or discriminated against due to their national origin. In addition, the research selection criteria excluded undocumented immigrant elders.

Like qualitative studies, this research has limited generalizability of its findings. As a primarily qualitative study, this research had a small sample size. In addition to being small, the sample had limited heterogeneity based upon country of origin and socio-economic status. Nevertheless, the U.S. Census (He, 2002) reported a similar distribution based upon country of origin for foreign-born older adults, nationally. While this research may not be generalizable to all immigrant elders, it still gives insight into long-term care issues and heterogeneity of the older adult foreign-born population.

If given adequate funding, this research could be expanded to address some of these methodological issues. While this research did receive two small grants, they were used for participant stipends, mileage, and software. If this research were funded, the researcher would have been able to focus on this research project full-time instead of constantly seeking new sources of income. Additional funding could have been used to increase participant recruitment efforts and possibly recruit from a broader region. Even with more funding, some of the limitations of this study would remain.

7. Lessons Learned

Aside from the content of the research findings, the research process provided new insight. This dissertation research was on immigrant elder women and their long-term care needs. This is fairly new topic, which added to the current research, but was riddled with challenges. The

initial challenge was the limited to non-existent literature on immigrant elders to discuss their use of long-term care services. The literature that was used was related to the older adult population in general or more specifically, ethnic and minority elders.

The next challenge was where to recruit and find immigrant elder women to participate in the study. According to U.S. Census data, Allegheny County, PA, is consistently ranked in the top 2-3 counties of the nation in density of the older adult population. Pittsburgh has a wealth of ethnic neighborhoods, which reflect the history of the area. Monroeville, a suburb of Pittsburgh, had its own International Women's Club. Although I attended this group out of personal interest, this became my primary recruiting site. While an American, the women were gracious in allowing me, and other American women, to come to meetings and/or join as member. The International Women's Club's members were from around the world and varied in age. So, when recruitment began, I had a core group willing to volunteer. The women, who did volunteer, often encouraged and referred others to participate. Likewise, the younger women, also, took information to older adults in their communities. Nevertheless, I was an "outsider" to the immigrant community, so, it is unknown how many others self-selected not to participate because I was not an immigrant. Further, I learned that recruiting from the community is a labor intensive activity that does not guarantee reaching the proposed number of participants.

The next challenge was how labor intensive the research itself would be. There was the travel time to and from the participants' home. Then, the interviews themselves, typically, lasted several hours. While generating significant data from the qualitative questions, the transcription process took a minimum of 6-8 hours, followed by several hours of auditing the transcription against the recording for accuracy. Coding of the interviews took several hours and then, the iterative coding of the previous interview took a minimum of 1-2 hours, which grew to almost 20

hours by the last interview. I realize that I was fortunate to have a qualitative researcher review my coding schema and was able to confirm the core codes with her in early on in the research process. The moving from coding the qualitative data to broader themes was another labor intensive process of thinking and cross-checking ideas that came from pouring over the data to clearly defining patterns. Even though I had conducted qualitative research projects for classes, I had not predicted the labor intensity of this work. The entry of the quantitative data went quickly as did its data analysis. From this process, I understood why doctoral candidates are drawn to secondary data analysis for their dissertation; it is an efficient way to complete a research project. On the other hand, conducting community research that uses qualitative and quantitative methods is a labor intensive process, which may better be pursued through a funded project.

On a positive note, I learned that I can create an interview schedule that appears age appropriate and generally well structured. In older adulthood, individuals are faced with Erikson's (1997) psychosocial crisis of integrity versus despair that is resolved through the central process of introspection (Newman & Newman, 1984). Introspection can be completed through reminiscence and life review. Beginning the interview with their immigration story allowed the participants to reminisce and provide a life review. While this met their developmental need for introspection, their immigration stories gave them a sense of being the expert by allaying anxiety about the interview. In addition, the researcher built rapport with the participants during these immigration stories. Most of the participants continued their immigration stories to current day that made an easy segue to discuss current social support systems. Then, there was a slight shift in content to more specific questions related to their exposure to long-term care followed by their perceived need. This approach was similarly replicated in the quantitative questions. When asked specifically about long-term care planning

to date, none of the participants needed clarification of any of the terms used in these quantitative questions. This most likely is due to their developmental stage and previous exposure to those terms, like annuity, living will and power of attorney. So, when the interview progressed to the situations that may require care, they were not disconcerted by questions relating to hallucinations, risk of violence or harm to self or others, and continence of bowel and bladder. Lastly, to finish the interview, the final set of quantitative questions focus on paid care giving and provided them one more chance to clarify the importance of culture and other factors in receiving long-term care services. This flow of questions continued to provide comfort and support to participants as they were asked to answer more detailed or harsh questions.

Of the whole interview two quantitative questions regarding income proved problematic. These were the two questions regarding income—your annual income and your household's annual income. The women would become somewhat distressed and concerned when asked these questions. Initially, I interpreted this distress as information that was too confidential to disclose. This was not the case. The women were concerned that they could not actually answer the question correctly and what proof did I want or need. Most of the women could describe the kinds of income that they received. The difficulty arose from trying to generate a monthly or annual amount. While their Social Security check and pension checks were fairly set, that was not the case for their other incomes, such as: part-time work, rent, dividends, and interest. While most of these participants considered themselves financially stable and secure, these interviews were completed prior to the United States economic crisis, and their answers may have changed considerably based upon the economic upheaval.

Overall, the researcher can learn a lot about the research design and implementation, as well as individual skills and abilities when critiquing the research process. This critique provides

invaluable information to a developing researcher well beyond the specific data of the research findings. My weakness was not recognizing how large of a research project I had undertaken for my dissertation. My strengths are that I can create solid interview instruments, as well as design and conduct community research utilizing qualitative and quantitative methods. For my on-going research agenda, I will need to be more discerning in evaluating the scope of a research project, and to be more diligent in ensuring that I have adequate time and resources to complete it efficiently and effectively.

8. Implications and Future Research

While the study is small, it supports the U.S. Census (He, 2002) report that foreign-born older adults are more likely to be naturalized citizens and have lived in the United States for over 20 years. This has far reaching implications for immigration and naturalization policies as well as social welfare policies. First and foremost, immigration and naturalization policies should not be analyzed and evaluated in a vacuum. It is not only important that our current immigration and naturalization policies meet the current needs of the nation and its citizenry, but also recognized the potential long-term impact of those policies. This is not to advocate closing the United States borders, but to advocate for immigration and naturalization legislation that integrates projection costs of future social welfare supports, such as: English as a Second Language for education for new comers and their children to Social Security and Medicare for older adults who have become naturalized citizens. Currently, the process appears reversed. The social welfare policies have created the equivalent to immigration policies by restricting benefits to immigrants (Weaver & Hackman, 2009; Fix & Passel, 2002; Fremsted 2002). In addition, states have significant control in restricting or in expanding social welfare benefits to immigrants (Tumlin & Zimmerman, 1999; Fix & Tumlin, 1997). This current method makes it difficult to assess the

full impact of immigration, regardless of the age upon immigration, and recognizing their on-going impact as they become citizens and lifetime residents of the United States.

As with the general older adult population, these immigrant elder women had similar long-term care concerns and plans, specifically—to stay at home and not to depend upon family members. This further supports the on-going need for home health care services and greater flexibility in spending healthcare funding. The current policy trends support additional financing for home health services as well as greater patient-centered care (Hackman, 2008; Mulvaney & Hackman, 2008). As states begin to rebalance their healthcare dollars, these needs should be better met. On-going program evaluation will be needed to assess if the programs are being implemented and are being effective in meeting older adults' needs.

One specific long-term care need voiced by immigrant elder women was to have competent paid care givers that treated them with dignity and respect. This concern was even greater than any cultural concerns related to long-term care. A recommended plan to better ensure that direct care staff are providing competent care would ideally include training as well as more supervision. In regards to training, regular in-service trainings on intergenerational communication, diversity consciousness and cultural sensitivity would increase understanding of older adults' expectations regarding dignity and respect across cultures. In addition, certified nursing assistance and home health aides could have more training prior to certification and employment. Likewise, more supervision of certified nursing assistance and home health aides would provide increased monitoring to assess individual's competencies to determine what additional trainings may be indicated. Through the Centers of Medicare and Medicaid, the government has the ability to make these changes in regulation that could benefit all older adults as well as collect data and evaluate the success of these changes.

Of all the implications of this study, the most direct is the need for more research in the related areas of immigration and long-term care. In regards to immigration, more longitudinal studies are required to better predict citizenship patterns as well as lifetime goals and needs, such as the following questions:

1. What are individual's migration patterns across borders over the life course?
2. What lifetime goals and needs are met through migration?
3. What factors predict citizen naturalization for immigrants?

In regards to immigrant elders, larger studies are needed to make more generalizations regarding being foreign-born across the life span, recognized more heterogeneity, like socio-economic status, but also to make more comparisons across country of nativity, such as the following questions:

1. What similarities to immigrant elder have with other older adult groups?
2. How does culture translate for immigrant elders?
3. Does ethnic allegiance present differently for immigrant elders than for ethnic and minority elders who are native United States citizens?
4. What are the characteristics of immigrants tend to become citizens?
5. What impact does socio-economic status have on immigrant's plans for older adulthood?
6. How does country of nativity act as a predictor for citizenship, remaining in the United States during older adulthood, and long-term care planning?

Also, additional studies of long-term care that focus on intercultural-intergenerational care between staff and residents, such as the following questions:

1. Which ethnic groups report having unmet needs in long-term care services?

2. What training do foreign-born, ethnic, and minority older adults recommend for staff providing them services?
3. According to foreign-born, ethnic, and minority older adults, what situations in care giving require special cultural attention?
4. What gaps in training do staff self-identify regarding care giving older adults of a different ethnic group?
5. What issues arise in intercultural-intergenerational dementia care?

While there has been on-going research on ethnic and minority older adults for decades, research on foreign-born older adults is a relatively new field of research. There remain many research questions to answer. Most importantly, research in this area is critical to better understand the foreign-born older adults as a heterogeneous group and identify how they are similar to other groups of older adults.

9. Conclusion

As the U.S. population ages, the diversity of its older adult population is becoming more complex. As a country built by immigrants, how should the United States plan for its foreign-born aging population? The immigrant elder women in this study represent a small fraction of that group. Nevertheless, the insights that they gave regarding their long-term care plans and their concerns echo those of the U.S. older adult population, and diverge from some other minority ethnic older adult studies. In general, older adults more likely wish to stay at home, not to be a burden to their family, and to have competent care givers. The current long-term policy trend is to support a more flexible system to better meet those needs. Nevertheless, these policy trends need to be supported with adequate funding for implementation and to create an adequate infrastructure of appropriate and affordable housing for our older adults and of long-term care service providers for home care. Arising from the on-going changes of long-term care policy

and programming is the need for more research, such as: community needs assessment, policy analysis, and program evaluation. Throughout the process, efforts should to be made to assess if the diverse needs of all older adults are being met. This research is a small contribution to that cause.

APPENDIX A

Multiple Methods Interview Schedule

Hello, my name is Ruthanne.

I want to thank you for your time and willingness to participate in this research.

I want to make sure you understand that your participation in this research is purely voluntary and you can stop at any time. No identifying information will be kept with your answers. All information will remain confidential and will not affect any services you receive or your status in country.

All of the questions in the interview are about you.

There are no right or wrong answers.

The interview takes about one hour depending upon the length of your answers.

We can take a break at any time. Just let me know.

The first portion of the interview will be recorded to better document your answers in full.

Do not become overly concerned about the recorder. As long as the light is on, we are recording.

Are there any questions you have before we begin?

Part I: Qualitative Questions

1. Tell me the story of your immigration to the United States.

Note to interviewer: These are additional probes to assist the participant in telling the person's story.

- a. What is your country of birth?
- b. How old were you when you immigrated?
- c. With whom did you immigrate or did you immigrate alone?
- d. Do you have friends/family living in the U.S.?
- e. Why did you leave your homeland?
- f. Why did you choose to immigrate to the United States?
- g. Tell me about your initial experiences upon arriving here. Where did you first arrive? Were you scared? Did you have any preconceived notions about life in the U.S. or was it a complete surprise?
- h. When you think about your life in the U.S., what things do you like most about living here? What things do you like least?
- i. Do you celebrate any of the traditions or ceremonies from your country?
- j. Are you involved in social groups or clubs with other people from your country?
- k. What languages do you know? Which ones do you speak conversationally?

2. There are people who help us in many different ways in our daily life. This help can be “doing favors” such as giving a car ride or running errands, “in kind gifts” such as a cup of sugar, hand-me-down clothes, and financial assistance. I would like you to describe to me who are the people who help you, what do they do for you and how often?

Note to interviewer: These are additional probes to assist the participant in explaining the person’s social support.

- a. Who provides you help or assistance? List: spouse, kids, friends, neighbors, religious and social groups, organizations.
- b. What kinds of tasks do these people do to help you?
- c. How often do these people help you?

3. As people get older, they may require help. This can include homemaker services, home health care services, hospice services, adult day care services, continuing care retirement communities, personal care facilities, and nursing homes. Describe your knowledge and understanding about these kinds of facilities and services in the United States. This would include your personal experiences as a patient, staff person or volunteer as well as from being a family member or friend of a person receiving care.

Note to interviewer: These are additional probes to assist the participant in telling the person's understanding of long-term care services.

- a. What personal experiences have you had with long-term care services and facilities?
- b. What do know about long-term care services and facilities based upon being a family member or friend of a person receiving care?
- c. What are your thoughts about services that help older adults stay at home?
- d. What are your thoughts about facilities, like: personal care homes, nursing homes, and continuing care retirement communities?

4. You may have thought about what care you may need in the future. What are your hopes, concerns or fears you have about your future care needs? These may include financial issues, expectations of family members, immigration concerns, and cultural needs. What long-term care planning have you completed to date?

Note to interviewer: These are additional probes to assist the participant in telling the person's issues regarding individual planning and anticipated use.

- a. Who have you talked to about your hopes, concerns or fears about your future?
- b. What type of long-term care planning, if any, have you done for yourself?
- c. What type of arrangements have you made for services or facilities?
- d. How do you see your current legal immigrant status affecting your long-term care planning?
- e. What activities, if any, of [INSERT: the participant's homeland's] culture are important to you in your long-term care planning?

Part II: Demographics

This set of questions asks your personal identification information. You may have already told me some of this information previously. This list is to make sure that I have all the same personal information for each person interviewed.

1. What is your birth date? _____
2. Where were you born? _____
3. What is your native language? _____
4. How old were you when you immigrated to the United States? _____
5. How many years have you lived in the United States? _____
6. From what country did you emigrate when you came to the US? _____
7. Did you immigrate with other family? Yes - 1 No - 2
8. Did you have family already in the U.S.? Yes -1 No - 2
9. Why did you immigrate to the United States?

10. What is your current immigration status?
 1. Refugee
 2. Naturalized Citizen
 3. Legal Permanent Resident/ “Green Card Holder”

Interviewer: Just mark the appropriate gender. Do not ask.

11. What is your gender? Male - 1 Female – 2

12. What is your race?

1. African American
2. Asian
3. Caucasian
4. Hispanic
5. Native American
6. Bi/Multi-racial
7. Other: _____

13. What is the high amount of education you have had?

1. Less than high school
2. High school graduate
3. Technical/Business school
4. Some college
5. College graduate
6. Graduate school

14. How much education did you get in the United States? (circle all that apply)

1. None
2. All
3. High school
4. Technical/Business school
5. College
6. Graduate School

15. What is your martial status?

1. Never Married
2. Married
3. Separated
4. Divorced
5. Widowed

16. Are you the head of household? Yes - 1 No - 2 Shared Responsibility – 3

17. How many generations live in your household? 1 2 3 4/4<

18. What are your living arrangements?

1. Live Alone
2. Live with Spouse/ Life Partner Only
3. Live with Family, describe: _____
4. Other: _____

19. Is your Spouse / Life Partner of the same ethnicity as you? Yes – 1 No – 2

20. What is your religious affiliation?

1. Christian
2. Hindu
3. Jewish
4. Muslim
5. Other: _____
6. None

21. What is your household annual income? _____

22. What is your annual income? _____

23. Do you currently have paid employment? Yes – 1 No – 2
If Yes, How much are you working? Part-time – 1 Full-time – 2

Part III. Quantitative Questions

1. English Fluency & Use

The next set of questions asks you to rate yourself in regards to how well you use English, where you speak English and how much.

Interviewer: Review the following scale with the participant. Circle the response for each item.

Please, use the following scale to answer the following question.

1	2	3	4	5
Very poorly	Poorly	Fairly well	Quite well	Very well

1.	How well do you <i> speak </i> English?	1	2	3	4	5
2.	How well do you <i> read </i> English?	1	2	3	4	5
3.	How well do you <i> write </i> English?	1	2	3	4	5
4.	How well do you <i> understand </i> English?	1	2	3	4	5

Interviewer: Review the following scale with the participant. Circle the response for each item

Please use the following scale to answer the following questions.

1	2	3	4	5	6
Never	Not much	Sometimes	Often	All the time	Not Applicable

5.	Do you speak English <i> at home </i> ?	1	2	3	4	5	6
6.	Do you speak English <i> with friends </i> ?	1	2	3	4	5	6

2. Individual American Acculturation

The following set of questions is about you and American culture.

Interviewer: Review the following scale with the participant. Circle the response for each item.

Please use the following scale to indicate how much you agree with the following statements.

1	2	3
No	Yes, a little	Yes, alot

1.	When I was growing up, I was exposed to American culture.	1	2	3
2.	When I was a child, my friends were American.	1	2	3
3.	I am familiar with American cultural practices and customs.	1	2	3
4.	I listen to American music.	1	2	3
5.	I celebrate American holidays.	1	2	3
6.	At home, I eat American food.	1	2	3
7.	At restaurants, I eat American food.	1	2	3
8.	American culture has had a positive impact on my life.	1	2	3
9.	Overall, I regard myself as an American	1	2	3

3. Perceived Practical Social Support

Interviewer: Review this scale with participants. Circle the corresponding number.

These questions ask about you and your relationships with various people in your life. Use the following scale for these questions.

0	None at all
1	Several times a year
2	Once a month
3	Several times a month
4	Once a week
5	Several times a week
6	Daily
9	Not Applicable

For each person listed, indicate the amount of help is available to you, such as: financial assistance, housing, transportation, reminders, and linking to resources.

1.	Spouse/partner	0	1	2	3	4	5	6	9
2.	Children	0	1	2	3	4	5	6	9
3.	Parents	0	1	2	3	4	5	6	9
4.	Sisters/Brothers	0	1	2	3	4	5	6	9
5.	Other Family Relatives	0	1	2	3	4	5	6	9
6.	Neighbors	0	1	2	3	4	5	6	9
7.	American friends	0	1	2	3	4	5	6	9
8.	Friends from home country	0	1	2	3	4	5	6	9
9.	Other international friends	0	1	2	3	4	5	6	9
10.	People from work: Co-Workers, supervisor	0	1	2	3	4	5	6	9
11.	People from my Congregation	0	1	2	3	4	5	6	9
12.	Clubs/Other Community Organizations	0	1	2	3	4	5	6	9
13.	Professionals: Healthcare Workers/Counselors	0	1	2	3	4	5	6	9

4. The Context of Care giving

The next set of questions refers to care for older adults.

1.	Through government policies and programs does your homeland promote the idea of family care giving for their older adult family members?	Yes	No	I don't know
2.	Through beliefs and traditional practices, does the culture of your homeland promote the idea of family care giving for their older adult family members?	Yes	No	I don't know
3.	Does your faith promote that family should care for their older adult family members?	Yes	No	I don't know
4.	Within your own family, had your parents and siblings promoted the idea the idea of family care giving for their older adult family members?	Yes	No	I don't know
5.	Within your own family, have you promoted the idea of family care giving for their older adult family members?	Yes	No	I don't know

4. Personal Experiences with long-term care facilities

You were previously asked about your experiences with long-term care services and facilities. This question focuses only on long-term care facilities.

1. Are you familiar with what a long-term care facility is, such as a personal care home or nursing home?

1-yes 2-no 3-I don't know

2. Interviewer: If "yes" to #1, proceed with #2; otherwise skip to next section--

What experiences have you had that you know about long-term care facilities, such as personal care homes or nursing homes?

1	Public advertisements about homes that I saw or heard	yes	no
2	Direct mailing from a home	yes	no
3	Attending an event – Bar-B-Q, Fair, Concert, Speaker	yes	no
4	Toured / Attended an Open House	yes	no
5	Visited friends at a home	yes	no
6	Volunteered at a home	yes	no
7	Worked for a home	yes	no
8	Received services for someone within my household	yes	no
9	Received services for myself	yes	no

Other (specify): _____

5. Long-term care planning to date

The following questions refer to planning that you may have done to date about your future. Long-term care planning refers to planning related future needs, such as: retirement, health care, nursing home placement, as well as legal and financial planning. You do not need to worry if you have not completed these tasks to date. If you have questions about any terms used, please, ask so that I can clarify them for you.

1.	Have you ever attended a program on retirement planning?	Yes	No	
2.	Have you ever attended a program on long-term care planning?	Yes	No	
3.	Have you spoken with family members about your long-term care concerns and plans?	Yes	No	NA
4.	Have you spoken with friends about your long-term care concerns and plans?	Yes	No	NA
5.	Have you spoken with a religious leader about your long-term care concerns and plans?	Yes	No	NA
6.	Have you spoken with professional counselors, therapists, case workers or social workers about your long-term care concerns and plans?	Yes	No	NA
7.	Have you spoken with a lawyer about non-financial long-term care concerns and plans?	Yes	No	NA
8.	Have you discussed with a financial advisor or lawyer how to get the most financial benefit from your equity & assets?	Yes	No	NA
9.	Have you created an annuity for your care?	Yes	No	
10.	Have you saved money to pay for your care?	Yes	No	
11.	Have you appointed a Financial/Legal Power of Attorney?	Yes	No	
12.	Have you bought long-term care insurance beyond the Medicare supplemental insurance?	Yes	No	
13.	Some facilities have long waiting lists, have you completed an application to a long-term care facility for the future?	Yes	No	
14.	Have you appointed a Healthcare Power of Attorney?	Yes	No	
15.	Have you created a Living Will or Advance Healthcare Directive?	Yes	No	
16.	Have you made your final arrangements?	Yes	No	

6. Receptivity to long-term care placement

In the future, there may be changes to your overall health and wellness. You may require assistance based upon these changes. The following questions are about your thoughts of going to a care home, like a nursing home or personal care home, to receive assistance.

1. Do you foresee ever using a nursing home or personal care home to be cared for?
Yes -1 No – 2

Interviewer: If Yes, skip to instructions to the next section
If No, continue

2. What are the some of reasons that you do not think that you would use a nursing home or personal care home? (Interviewer: Circle all that apply)
1. I feel that I would have better care at home.
 2. I have enough finances to pay for my care at home
 3. I believe that my family will provide all the assistance I need
 4. I feel that care at home will allow me to maintain more of my cultural and religious traditions and my native language.
 5. I believe that my neighbors and friends from my congregation and clubs will provide me some assistance.
 6. None of the above
 7. Other specify: _____

6. Receptivity to long-term care placement (continued)

The next set of questions ask you to imagine yourself in different situations in which you would require assistance. Think about your finances, home situation and practical social support that you receive from others. Based upon your overall current resources, consider if you would be able to meet that need at home.

Interviewer Instructions: Ask each item as a question
 “Do you think you would be able to manage at home,”
 Remind the person of answer choices, as needed.

1.	If you needed assistance remembering to take your medications	Yes	No	Not sure
2.	If you needed assistance taking your medications	Yes	No	Not sure
3.	If you needed assistance with managing money	Yes	No	Not sure
4.	If you were unable to drive or make arrangements for a ride	Yes	No	Not sure
5.	If you needed assistance walking indoors	Yes	No	Not sure
6.	If you needed assistance with doing your laundry	Yes	No	Not sure
7.	If you required 24-hour supervision for your safety	Yes	No	Not sure
8.	If you required 24-hour supervision due to hallucinations	Yes	No	Not sure
9.	If you needed assistance with meal preparation	Yes	No	Not sure
10.	If you were at risk of violence to yourself or others	Yes	No	Not sure
11.	If you needed hands on help with bathing	Yes	No	Not sure
12.	If you needed hands on help with dressing and undressing	Yes	No	Not sure
13.	If you needed hands on help with grooming	Yes	No	Not sure
14.	If you needed hands on help with eating	Yes	No	Not sure
15.	If you needed hands on help with getting in or out of a bed --OR-- if you needed hands on help with getting on or off a chair	Yes	No	Not sure
16.	If you needed hands on help with toileting	Yes	No	Not sure
17.	If you were incontinent of bladder and/or bowel	Yes	No	Not sure

7. Cultural Concerns and Long-term Care

There may come a time in the future that you may need assistance from a paid caregiver, at home or in a facility. As you consider a time when you may need assistance, think about what would be important to you. I am going to read you a list of items. For each item indicate how important it is to you when you consider receiving assistance from a paid caregiver. Use the following scale:

1=Not important

2=Somewhat important

3=Very important

1.	Being served food from your native country	1	2	3
2.	Being able to wear traditional native clothing	1	2	3
3.	Having the holidays of your native country celebrated	1	2	3
4.	Being able to practice your religion according to your native traditions	1	2	3
5.	Having a caregiver that speaks your native language	1	2	3
6.	Having a caregiver from your general ethnic background	1	2	3
7.	Having a caregiver from your native country's ethnic background	1	2	3
8.	Having a caregiver that treats you with dignity and respect	1	2	3
9.	Having a caregiver that is culturally sensitive to differences	1	2	3
10.	Having a caregiver that is competent	1	2	3

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