Title

Access to state-funded long-term care service among low-income older Latinos: from perspective of political economy and habitus

Permalink

https://escholarship.org/uc/item/974742dk

Author

Nonaka, Kumiko

Publication Date

2007-05-21

Peer reviewed|Thesis/dissertation

Access to state-funded long-term care services
Among low-income older Latinos:
from perspectives of political economy and habitus

by

Kumiko Nonaka

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Sociology

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Acknowledgments

My first thanks go to my parents, Kazuaki and Aki Shimizu, who have been supportive of me finishing the doctoral program in Sociology at UCSF throughout. Without their unconditional love and support, it would have been impossible for me to finish my dissertation and graduate with a Ph.D. in Sociology.

I owe special thanks to my friends Nury Mayen, Edwina Newsom, Carrie Friese, and Gail Dobell. I have had an ongoing, stimulating dialogue with them about many of the ideas that appear in this dissertation. In addition, with their help, I even enjoyed doing all the hard work associated with graduate school.

Many thanks are due to my great mentor, Charlene Harrington, who has guided me as I have learned the necessary skills and knowledge to complete this dissertation. The analytical framework of the dissertation is strongly influenced by her training. In addition, she has provided continual supported to help me overcome many problems I encountered while in school.

I would like to acknowledge and thank my dissertation chair, Robert Newcomer, who agreed to Chair my dissertation after I lost my initial Chair, Gay Becker. He has provided much advice and support across my years in the Sociology program.

I owe special thanks to my dissertation committee member, Jeanne Tschann, who gave me many thoughtful insights and much advice as I have developed my dissertation. I have learned a lot about how to construct logical arguments as well as do statistical analysis under her guidance.

Many thanks go to Carrie Friese and Stephanie Miller, who have edited this dissertation and most of the papers I wrote during school. I am sure that it must be time and energy consuming work because English is my second language. They were always

helping me despite their own busy lives. Their kindness has always encouraged me to complete not only this dissertation, but all sorts of school-related work.

I would like to thank my husband, Gen Nonaka, who has been supportive as I have pursued my degree and life goals. He has been also patient with me, even when I was not a particularly pleasant person to deal with during those difficult times in writing a dissertation.

Finally, special thanks go to my mentor, initial dissertation Chair, and friend, Gay Becker. Gay supported me in many ways to complete this degree. By working with her, I have learned to analyze issues of interests from both macro and micro perspectives. I really hoped that I could show Gay my complete dissertation. However, it was one of the greatest experiences of my life to study and work under her mentorship, and I will always remember her.

Abstract

This is an exploratory study to understand how use of state-funded community-based long-term care services (e.g., Medicaid waiver programs and Personal Care Services optional benefit) and other social resources (e.g., financial assistance and housing services) among low-income, older Latinos are influenced by individuals' lived experiences, which are largely constrained by macro-structural forces.

This study uses both qualitative and quantitative data sets collected for an ethnographic study about the roles of culture in management and experiences of illness and old age among low-income, ethnic minority, elderly populations. Data were collected during 1996 to 2000 through semi-structured, in-depth interviews about management of illness and old age. Quantitative data collected consisted of participants' physical functional ability and demographic characteristics.

The purpose of this study is to suggest other factors that may influence access to social services. More precisely, I try to show how life experiences, which are partly the results of class-related conditions, influence the ability to access to social services. Toward this end, I examined service use from the expanded behavioral model for vulnerable population perspective using statistical analyses. I also explored how additional factors influence service using the qualitative data, which was analyzed from the theoretical perspectives of political economy and habitus.

Drawing on the perspectives of political economy and habitus, this study suggests that older Latinos' access to social resources is influenced by their ability to deal with bureaucratic systems in the U.S. society, especially Social Security. Their ability to negotiate with such systems is largely shaped by their life experiences, which are largely influenced by class-related conditions in the U.S. and their home countries. In this sense,

this study tries to show the ways in which macro- and micro-factors relate to shape

individuals' abilities to access social resources.

Table of Contents

List of Tables

Chapter 1. Introduction / Statement of the problem

1.1. Introduction

This is an exploratory study to understand how use of state-funded community-based long-term care services (e.g., Medicaid waiver programs and Personal Care Services optional benefits) and other social resources (e.g., financial assistance and housing services) among low-income older Latinos is influenced by individuals' lived experiences which are largely constrained by macro-structural factors. The purpose of the study is to suggest another way to understand factors affecting access to long-term care and various social resources among low-income older Latinos, by arguing that access can be understood not only by the availability of financial resources and social support but also knowledge about and awareness of services. Many studies have suggested that access among low-income older Latinos tends to be influenced by financial resources, knowledge about and awareness of services, availability of social support, and educational level (Wallace, Levy-Storms, & Ferguson 1995; Ailinger & Causey 1993; Talamantes, Lawler, & Espino 1995; Parra & Espino 1992; Starrett et al., 1989 & 1990; Tran, Dhooper, & Mclnnis-Dittrich 1997; Burnette & Mui 1999). These studies have used the behavioral model.

While I also consider the importance of these factors in determining access to health and long-term care services, I also suggest that these factors are largely influenced by individuals' abilities to deal with the system, which includes formal organization of the US mainstream society. The ability of an individual is largely informed by their relationship with family, their expectations of family members, and their internalized class-related behaviors and perceptions. These factors have been shaped through their life experiences, both before and after immigration to the US. Furthermore, class-related

behaviors and perceptions are largely influenced by political, economic, and socio-cultural forces. In short, I examine factors influencing the use of social services among low-income older Latinos by looking at the relationship between macro and micro forces.

<u>1.2. Statement of the problem</u>

In 2002, there were 37.4 million Latinos in the U.S. representing 13.3% of the total population. Latinos were more geographically concentrated than non-Latino Whites, as 44.2% live in the West and 34.8% live in the South (Ramirez & Cruz 2002). In California, Latinos 65 years and older represented 13.1% of the Latino population in 2002 (IUPLR 2002). Although the 2002 Census reported a relatively small proportion of Latino 65 years and over (5.1%) within the total population of those 65 years and older (Ramirez & Cruz 2002), older Latinos are projected to be the most rapidly expanding ethnic elderly population in the US (Ailinger & Causey 1993; U.S. Bureau of the Census, 2000; Peng, Navaie-Waliser, & Feldman 2003). In 2004, 11.6% of older Latinos age 65 and over needed help with personal care as compared to 5.6% for non-Hispanic Whites and 8.6% of non-Hispanic Blacks (Administration on Aging, 2005).

In order to meet with these growing policy trends, the US have encouraged the expansion of home and community-based services since the 1980s, preparing for the upcoming aging society. Home and community-based service refers to long-term medical or supportive services, which are provided in individuals' homes and communities, for the elderly or people with disabilities who need help with activities of daily living such as eating, bathing, and dressing. Home and community-based service includes adult day care programs, respite care for family caregivers, residential services and assisted living facilities, home health for nursing care, personal assistance services, care planning and

case management, and other services necessary to avoid institutionalization (National Conference of State Legislatures, 2002). Despite the growth of home and community-based service, not all eligible people who need assistance in their daily lives are receiving services because of the shortages of service slots (Miller et al., 2000; Harrington et al., 2000).

Under these shortages, studies have reported lower utilization of home and community-based services among older Latino populations (Wallace, Levy-Storms, & Ferguson 1995; Ailinger & Causey 1993; Talamantes, Lawler, & Espino 1995; Parra & Espino 1992; Starrett et al., 1989 & 1990; Tran, Dhooper, & Mclnnis-Dittrich 1997; Burnette & Mui 1999). For instance, Osacar (2004) reported lower utilization in four programs serving San Francisco's senior and disabled adult population. These programs include cash assistance, personal care service, housing assistance, and meal delivery. She reported that eligible older Latinos underutilize these services, compared to other racial/ethnic population. For instance, in 2003, only 9% of the 14,417 personal care recipients in San Francisco were Latinos, despite the fact that Latinos consisted of 14% of the eligible population (Osacar, 2004).

Although the results vary based on types of services assessed and the characteristics of the samples, previous studies suggest that barriers for older Latinos' access to health and long-term care services include: lack of financial resources (Starrett et al., 1989; Parra & Espino 1992; Ailinger & Causey 1993; Tran, Dhooper, & Mclnnis-Dittrich, 1997), lack of knowledge and awareness about services (Starrett et al., 1989; Parra & Espino 1992; Ailinger & Causey 1993), language barriers and a lack of bicultural/bilingual service providers (Gavaria & Stern 1980; Sotomayor & Randolph 1988; Tran, Dhooper, & Mclnnis-Dittrich, 1997), and a lack of access to services,

specifically transportation (Richardson et al., 1987; Ailinger & Causey 1993). In other words, they will use services effectively if: 1) they are aware of available services for them; 2) they know about services or know how to access them; 3) bicultural services are provided; and 4) they have some financial resources through out-of-pocket or public assistance.

However, overcoming these barriers is not always easy for political and economic reasons. Current cost containment policies make it harder for state governments to increase the availability and amount of cash assistance, which may allow low-income older Latinos to purchase services. Additionally, cost containment policies limit the expansion of home and community-based service as well as other services. The availability of bicultural service cannot always improve access to services among older Latinos. At the same time, it is questionable if enhancing these issues could increase service use among older Latinos.

In summary, I argue that access to home and community-based services is influenced by structural and individual factors, including knowledge about and awareness of services, financial resources, availability of transportation, and the availability of bicultural services.   The organization of this paper is as follows. First, I will introduce the three conceptual frameworks of this study, which are widely used to understand the use of health and long-term care services. These theories include the behavioral model, political economy, and habitus. Although the concept of habitus has not been used to understand the use of health and long-term care services in general, I contend that this concept is necessary to understand why individuals' life experiences effect service use by influencing one's ability to deal with a bureaucratic system. Political economy is important in understanding how individuals' life experiences shape one's ability to deal

with the system, which in turn influences their ability to access services. Additionally, the political economy perspective is helpful for understanding the ways in which individuals' access to social resources can be influenced by macro structural forces, such as long-term care and social welfare policies. After introducing these concepts, I will discuss long-term care issues among the Latino population, including informal care and formal long-term care services. Then, I will introduce the methodology of this study. The methodology section includes an introduction to the types of services on which I will focus. Before moving into the analysis, I will first describe the lives of study participants in order to give a brief picture of who they are. The analysis consists of two sections. First, I will examine the use of home and community-based long-term care services from the perspective of the behavioral model, using quantitative methods. Then, I will examine how other factors that the behavioral model does not usually suggest influences older Latinos' access to home and community-based services and other social services, using narrative analysis. This point will be further discussed in the concluding section from the perspectives of political economy and habitus.

1.3. Research question

This is an exploratory study about how the use of home and community-based services and social resources among low-income older Latinos are influenced by both macro structural and individuals' lived experience. More precisely, I try to show how their lived experiences have been influenced by cultural, economic, and political factors. This lived experience in turn affects their ability access to home and community-based long-term care services and other social services. The purpose of the study is to suggest

another way to understand factors affecting access to long-term care and other social

resources among low-income older Latinos. I argue that access cannot be understood only

through the availability of financial resources, but also social support and knowledge

about and awareness of services. In this study, I will focus on access to Medicaid Home

and Community-Based Services (HCBS) and various social services, which include

financial assistance (Supplemental Security Income and General Assistance) and housing

assistance that is provided by various formal organizations, such as churches and the

Social Security Administration.

Chapter 2. Conceptual framework

2.1. The expanded behavioral model for vulnerable population

The current sociological approach to "access" is largely conceived through Andersen and Newman's behavioral model (1968), within which access to health care services is believed to be dependent on needs for services (need factors), availability of social and economic resources (enabling factors), and any factors that influence attitudes and beliefs toward health care services (predisposing factors). It was originally developed to predict the use of health care services (Andersen 1995).

Gelberg, Andersen, and Leake (2000) expanded the behavioral model for vulnerable populations in order to examine health service utilization and the effect of realized access on health outcome among specific vulnerable populations. Vulnerable populations include the homeless, minorities, chronically ill, the elderly, and undocumented immigrants. In this model, they added variables specific to vulnerable populations for each domain (predisposing, enabling, and need) (Gelberg, Andersen, and Leake 2000). This dissertation uses the expanded behavioral model for vulnerable populations because the sample of this study includes low-income older Latinos.

The Expanded Behavioral Model for Vulnerable Population

Predisposing	Enabling	Need	→ Access
Demographics	User's ability to access	Perceived health	
Age	Financial resources, Insurance	Self reported health	
Gender	Transportation Knowledge about services	Interviewer's assessment of health	
		Evaluated health	
Health beliefs	Provider's ability	Barthel	
Values concerning health & illness	Availability of services	ADL	
Attitude toward social services		IADL	
Knowledge about illness	Vulnerable domain	Illnesses	
	Competing needs	Barthel Index	
Social Structure	Recipient of public benefit		
Previous Occupation	Ability to negotiate system		
Education,	Social service		
Ethnicity	resources		
	Cultural competence		
Vulnerable domains			
Immigration status			
Acculturation,			
English ability			
Psychological			
Resources			

The Predisposing domain

In general, the predisposing domain consists of demographics, social structure, and health beliefs (Andersen 1995). Demographics in the original behavioral model usually include age, gender, and marital status. Social structure in the original behavioral model is "measured by a broad array of factors that determine the status of a person in the community, his or her ability to cope with presenting problems and commanding resources to deal with these problems, and how healthy or unhealthy the physical environment is likely to be" (Andersen 1995:2). Education, ethnicity, and occupational status are often used as measurements of social structures (Andersen 1995) because these variables imply an individual's status in a society, which further influences their ability to use services.

For example, Leiyu (1996) discusses the ways in which ethnicity influences access to a primary care physician. According to Leiyu (1996), ethnic/racial minorities experienced more difficulties in accessing primary care in terms of getting appointments, finding primary care physicians, contacting physicians by phone, and having longer waits to get appointments. These findings reflect sociodemographic differences (e.g., the differences in types of medical insurance, income level, and residential areas in which services are more available or less available) that influence an individual's ability to access appropriate medical services (Leiyu, 1996). At the same time, these findings reflect a more complex relationship between providers and ethnic minorities, such as ethnically and culturally competent care. Moreover, discrimination against minority group members by health care providers may be considered a contributing factor (Harrington & Pellow 2001:59). In short, ethnicity-which is a variable of social structure

in the original behavioral model – influences an individual's status in society and their ability to cope with problems.

Health beliefs in the original behavioral model include attitudes and beliefs toward health and social services, values concerning health and illness, and knowledge about disease. These factors influence individuals' subsequent perceptions of need for services as well as service use (Andersen 1995; Gelberg, Andersen, and Leake 2000:1277). For example, Aroian and colleagues (2001) found that elderly Russian immigrants believe that a decline in their health will burden their children by undermining their ability to work if they become caregivers for aging parents. Therefore, the maintenance of good health is important, and frequent use of medical services is believed to contribute to the maintenance of good health. Moreover, elderly Russian immigrants are willing to use government subsidized programs and do not assume the commonly associated stigma with means-tested programs (e.g., Medicaid). This is in large part due to their socialization under communism (Aroian et al., 2001). On the other hand, Latino culture tends to think of arthritis, sleeping problems, and heart disease as normal parts of aging. This belief often makes them think that nothing could be done to cure them once they are diagnosed. This understanding leads them to inadequate health care use, limited health improvement, less compliance with doctors, and limited help-seeking behavior (Talamantes, Lawler, & Espino 1995; DuBois, Yavno, & Stanford 2001).

The predisposing domain of the expanded behavioral model for vulnerable populations includes country of birth, the degree of acculturation, immigration status (i.e., illegal or legal status), length of time in the community, literacy/English ability, living conditions (e.g., running water, heat and air conditioning, and unsafe structures), mobility (e.g., moves between communities and dwellings), victimization, mental illness, and

10

psychological resources (e.g., mastery, cognitive ability, and self-esteem) (Gelberg, Andersen, and Leake 2000:1276). For example, literacy/English ability, predicts health care use. Fiscella et al., (2002) found that the health care use pattern for English-speaking Hispanics was not significantly different from that of non-Hispanic whites. On the other hand, Hispanics who speak only Spanish were significantly less likely than non-Hispanic whites to have a physician visit, mental health visit, or influenza vaccination.

The Enabling domain

According to Andersen (1995), the enabling domain should indicate both <u>users' means and ability to access services</u> and <u>providers' availability to offer services</u>. The enabling domain measures <u>users' ability to access services which</u> generally consists of *financial resources*, *means to access service*, and *knowledge about or awareness of services* (Coulton & Frost 1982; Mui & Burnette 1994; Starrett et al., 1990). The expanded behavioral model for vulnerable populations also includes in the enabling domain measures of <u>users' ability to access services.</u> <u>Providers' ability to offer services</u> generally consists of *institutional factors* that are suggested by the expanded behavioral model for vulnerable populations.

Financial resources generally refer to income and insurance status, which are important to predict one's service use (Coulton & Frost 1982; Mui & Burnette 1994; Starrett et al., 1990). For instance, an uninsured person has difficulty accessing necessary medical services. *Means to access service* are generally measured by the availability of transportation and perceived difficulty in obtaining transportation to service locations (Wan and Odell, 1981).

11

Knowledge about or awareness of service is a critical factor in the enabling domain. It is often predicted by the availability of social and informal support networks because social networks provide information about services for individuals who need them (Starrett et al., 1989; Starrett et al., 1990; Wallace, Levy-Storms, & Ferguson 1995; Tran, Dhooper, & Mclnnis-Dittrich 1997). Thus, social and informal support networks are often measured by neighborhood cohesiveness, relationships with family members, living arrangements, and organizational memberships, such as attendance at church and at senior centers (Starrett et al., 1989; Starrett et al., 1990; Wallace, Levy-Storms, & Ferguson 1995; Tran, Dhooper, & Mclnnis-Dittrich 1997).

Additionally, *knowledge about or awareness of service* includes an understanding of the service structure/system, the ability to access available services, and eligibility for a service. For example, Long, Liu, and Black (2005) compared individuals who participated in Medicaid Home and Community-Based Service (HCBS) with those who refused to participate (despite eligibility) in order to understand the reasons for non-participation. They found that lack of knowledge about eligibility is one of the major reasons why individuals did not receive Medicaid HCBS. Despite being qualified for Medicaid HCBS they decided not to use it because they did not think they would meet the financial eligibility criteria for Medicaid (Long, Liu, and Black, 2005). In addition, availability of transportation and perceived difficulty in obtaining transportation to the service location was included in the individuals' ability to access services (Wan and Odell, 1981).

Under the expanded behavioral model for vulnerable populations, users' abilities to access services are generally measured by the number of recipients of public benefits, the ability to negotiate with system, and competing needs of individuals (Gelberg, Andersen, and Leake 2000:1277). For example, Long, Liu, and Black (2005) indicate the

significant influence of competitive needs in their study of Medicaid HCBS use. Some

people who were actually eligible for Medicaid HCBS decided not to use services because

they felt that they would lose too much by participating, such as the ability to pay for

other critical living expenses due to the need to meet required spend-down levels.

Therefore, they appeared to get by through a combination of reliance on informal care,

use of Medicare home health, and going without needed services (Long, Liu, and Black,

2005).

The provider's ability to offer services includes *institutional factors* and *factors

that are suggested by the expanded behavioral model for vulnerable populations*.

Institutional factors are measured by the volume of service and the extent to which

providers can adequately serve. Shortages in services present a barrier for elderly to

utilization (Swan & Estes 1993). In addition, the lack of providers in areas close to

people who need care undermines individuals' ability to access adequate care. This is

particularly a problem for those who live in rural and inner-city areas (Harrington &

Pellow 2001). Another institutional barrier is providers' avoidance patients with

Medicaid due to low reimbursement fees for those (Himmelstein & Woolbandler 1997).

*Factors that are suggested by the expanded behavioral model for vulnerable

populations* consist of availability of social services that may assist individuals in using

health services (e.g., transportation services) (Gelberg, Andersen, and Leake 2000:1277).

Gelberg, Andersen, and Leake (2000) found that homeless individuals living in shelters

have better access to services for skin/leg/foot problems than people who commonly slept

on the street or in places not meant for shelter. This may be because some shelters offer

services designed for the homeless, such as on-site health services, provider referral,

and/or transportation to health care facilities.

Additionally, cultural barriers that prevent ethnic minorities from accessing services can be seen as *factors that are suggested by the expanded behavioral model for vulnerable populations*.   Cultural barriers are exemplified by language differences between providers and users as well as insensitivity to cultural customs (Parra & Espino 1992; Harrington & Pellow 2001; Gavaria & Stern 1980; Sotomayor & Randolph 1988; Tran et al., 1997). For instance, in a study about the influence of English proficiency in health care utilization among Latinos, Derose & Baker (2000:85) mentioned that lack of bilingual services becomes a barrier for people who only speak Spanish, in communities where there are few Spanish-speaking providers, or where there is real or perceived discrimination against Spanish-speaking patients.

Need domain

According to Andersen (1995), need variables in the original behavioral model should be understood as "how people view their own general health and functional state, as well as how they experience symptoms of illness, pain, and worries about their health, and whether or not they judge their health problems to be of sufficient importance and magnitude to seek professional help" (Andersen 1995:3). In general, need factors are measured by ADL, IADL, perceived need for health services (Coulton & Frost 1982; Wan & Odell 1981; Bowling, Farquhar, & Browne 1991; Choi 1994; Mui et al., 1994; Tran, Dhooper, & Mclnnis-Dittrich 1997; Mayoralas et al., 2000), and self-reported health status. The need domain of the expanded behavioral model for vulnerable populations includes perceptions and evaluated need regarding conditions of special relevance to vulnerable populations, such as AIDS and sexually transmitted diseases (Gelberg, Andersen, & Leake 2000). The need factor is often considered to be the strongest

determinant in using services (Coulton and Frost 1982; Bowling, Farquhar, & Browne 1991; Choi 1994).

In summary, the behavioral model is a multidimensional model that considers both individual and societal determinants of service use (Roy, Dietz, & John 1996). This model has been criticized for not fully integrating external factors such as health policies, providers' availabilities and characteristics (Phillips et al. 1998). Indeed, this model tends to focus on variables, that are related to individuals' conditions and characteristics, such as the availability of financial resources, social networks, educational level, demography, and physical functional ability. Furthermore, this critique may be applicable for the expanded behavioral model for vulnerable populations. Both the original behavioral model and the expanded behavioral model for vulnerable populations do not fully integrate external political and economic factors into consideration.

2.2. Political Economy

Because the behavioral model is criticized for not integrating external political and economic factors into consideration, the political economy perspective is useful to understand how macro-structural dynamics, effect individuals' abilities to access health and long-term care, the availability of services, and individuals' cultural beliefs about using services.

The political economy perspective draws on the works of Karl Marx (1978) and Max Weber (1967). In this perspective, social structures and arrangements are produced through interactions among socio-cultural, political, and economic forces and processes (Estes 1999; Estes, Linkins, & Binney 2001). The intersections of these processes affect power relations, including class, sex/gender, and race/ethnicity. These, in turn, produce

15

social structures and arrangements, which lead to social policies. In this sense, social policies are viewed as reflections of the "structure and culture of advantage and disadvantage embodied in social class, racial, ethnic, gender, and age relations" (Estes 1999: 17). Thus, social policies are "seen as products of economic, political, and socio-cultural processes and forces that interact in any given socio-historical period" (Estes, Linkins, & Binney 2001:40). Furthermore, social policy is itself, a powerful social arrangement of a time, a powerful determinant of the life chances and conditions of individuals and population groups such as the elderly and ethnic minorities (Estes 1999; Estes, Linkins, & Binney 2001:40).

The political economy perspective tries to understand individuals' conditions by looking at how political, economic, and socio-cultural dynamics influence to shape ones' class conditions. Political, economic, and socio-cultural forces are composed of diverse fields involved in the production, reproduction, and maintenance of social structure. Although there are diversities in interests and conditions among members of a class/group, members in each class also share certain interests and conditions (Navarro 1995). Common interests and conditions lead to power struggles among various classes in order to realize their own class interests, to maintain a condition that is favorable to a class, or to enhance conditions of members in a class (Alford 1972; Navarro 1987 & 1995; McKinlay 1984). Power struggles occur at the site of the state through politics because each class/group seeks to realize their own interest in policies, such as tax, economic, and social policies (O'Connor 1973; Habermas 1975).

Because the state has the power to allocate resources through social policies (i.e., taxation and social welfare), politics are viewed as the most powerful determinants of social structure. In addition, economic sectors, particularly large-scale capital, are viewed

16

as another powerful determinant of social structure because the growth of economic sectors is believed to solve social problems (i.e., unemployment and crimes) by generating employment and financing the state to implement social and welfare services (O'Connor 1973). Therefore, these two actors are considered the primary determinants of individuals' and social groups' life chances and conditions (O'Connor 1973; Habermas 1975; Estes 1999).

On the other hand, the public, particularly those who are the low-income and ethnic minorities, are considered to be the most disadvantaged (O'Connor 1998). Among the disadvantaged, minority elders are among the most disadvantaged (Wallace & Villa 1999). This is partly because the elderly population constitutes a smaller portion within a minority group, while younger cohorts constitute the largest portion. The smaller portion of the elderly in populations makes this group into a smaller number of voters, which limits politicians' motivation to act for elderly populations. In addition, the assumptions that minority elders are well cared for by extended family members contributes to limited policy attention (Wallace & Villa 1999).

As an example, McKinlay (1984) offers four major groups/classes that influence the formation of the health care system in the U.S. The most influential group is the medical industrial complex[1]. The state is another influential actor, which tends to align with the medical industrial complex by generating conditions that make capital accumulation possible. Another actor is medicine itself, which includes research, training of medical laborers, and epidemiological rationalizations for the existence of medicine. Lastly, groups of people who are loosely termed 'the public' influence the formation of

---

[1] The medical industrial complex refers to the health industries, which are composed of multibillion-dollar congeries of enterprises including hospitals, nursing homes, insurance companies, financial industries, and other related industries (Estes, Harrington, & Pellow 2001:136.)

the health care system in the U.S. They are the potential users of medicine and the most vulnerable to the activities of the other three groups. They tend to experience difficulties accessing health care services, which have developed over time as a result of the activities of the medical industrial complex, the state, and corporations (McKinlay 1984).

With this perspective, many scholars examined insufficiencies of health and long-term care services in the US (Wiener and Illston 1994; Navarro 1995 & 2001; Feldstein 1997; Himmelstein & Woolbandler, 1997; Harrington and Pollock 1998; Estes and Linkins 1999; Estes, Harrington, & Pellow 2001; Wiener et al., 2001). For instance, in the case of long-term care policy, the interests of the medical industrial complex influence the fate of government sponsored programs. They are commonly in opposition to public financing of health care and long-term care because it strengthens governmental control over health care (Navaro 1995). Instead, the medical industrial complex supports the initiative of the economic sector to provide health and long-term care services. These groups attempt to realize their interests through various ways. One strategy is financing members of Congress who sit on powerful committees that draft health legislation in order to control the behaviors of Congress. For example, insurance PACs (political action committees) contributed $60 million to members of Congress from 1981 to the first half of 1991 (Navaro 1995). They also seek to influence legislation through lobbying. Moreover, their interests effect the processes of proposal formation. The medical industrial complex works to block any effort to enact government-sponsored, health care insurance and long-term care insurance.

In addition, the political economy perspective gives more attention to how providers' ability to offer health and long-term care may influence individuals' access (Swan & Estes 1993; Harrington & Pellow 2001). For example, the Commonwealth Fund

Quarterly (2001) reported decreasing access to health care services among Medicare

Choice subscribers because of managed care's withdrawal and physicians' high turnover

rates (averages 30% or more of physicians' turnover in some states). From 1999 to 2001,

a total of 151 of 346 plans terminated their Medicare Choice contracts and another 165

plans reduced their service areas. This withdrawal is attributed to the low payment rates

by Medicare, providers' unwillingness to accept plans' payment levels, the increasing use

and costs of medical services, and local market dynamics. Market dynamics motivated

providers to leave Medicare in favor of more profitable, employer-based enrollment.

Physicians' high turnover is caused by insufficient reimbursement rates to cover the cost

of care, frequent claim denials and payment delays, both of which have resulted in

contentious relationships between plans and their provider networks (The Commonwealth

Fund Quarterly 2001). Thus, external political and economic processes influence access

and utilization in health care services.

The political economy perspective offers ways to understand how access is

influenced by external political and economic factors as well as class-related factors. The

perspective is useful to see how structural factors shape social systems, including long-

term care policies, which in turn influence providers' ability to provide services and

individuals' ability to access services. At the same time, the perspective takes into

account the ways in which individuals' class conditions are shaped through macro-

structural forces, which also influence individuals' ability to access services.

2.3. Habitus

Habitus is a concept that was developed by Pierre Bourdieu. It provides a means to

consider the role of internalized class-based practices and perceptions in relationship to

access and use of long-term, home and community based care among elderly Latinos. Bourdieu conceptualizes class within "social space", which "is a practical space of everyday life" (Yr,405). For each individual, their own social space or a practical space of everyday life is their objective space. Individuals' objective space depends on their position, which reflects their class condition. Thus, habitus is developed based on ones' class conditions, and it is another way to consider class.

Within this objective position/space, individuals produce practices as well as perceptions, and judgments of other agents' practices. This is called habitus. In Bourdieu's words, habitus is "both the generative principle of objectively classifiable judgments and the system of classification (principal divisions) of these practices. It is in the relationship between the two capacities which define the habitus, that the capacity to produce classifiable practices and works, and the capacity to differentiate and appreciate these practices and products (taste), that the represented social world, i.e., the space of life-styles, is constituted" (Yr,405).

In short, habitus produces and reproduces class structures by producing class-related practices and works among individual actors. In addition, habitus provides a mechanism to differentiate and appreciate class-related practices and tastes among individual actors. By taking the concept of habitus into his class structure analysis, Bourdieu made it possible to understand class-based practices and their reproduction.

Furthermore, Bourdieu considered habitus as an internalized form of class-based economy and social condition. An individual's class condition is internalized, which generates meaningful practices and meaning-giving perceptions. Individuals carry these practices and perceptions out in their everyday lives. Bourdieu states:

"The habitus is not only a structuring structure, which organizes practices and the perception of practices, but also a structured structure, the principle of division into logical classes which organizes the perception of the social world is itself the product of internalization of the division into social classes. Each class condition is defined, simultaneously, by its intrinsic properties and by the relational properties which it derives from its position in the system of class conditions, which is also a system of differences, differential positions, i.e., by everything which distinguishes it from what it is not and especially from everything it is opposed to; social identity is defined and asserted through differences. This means that inevitably inscribed within the dispositions of the habitus is the whole structure of the system of conditions, as it presents itself in the experience of a life-condition occupying a particular position within that structure. The most fundamental oppositions in the structure (high/low, rich/poor etc.) tend to establish themselves as the fundamental structuring principles of practices and the perception of practices" (408).

In short, Bourdieu considers class as not only constituted by outside factors, such as economic conditions, prestige, and status, but also as internalized perceptions, practices, and manners of inter-relating with others as well as society. Although this concept focuses on cultural consumption, such as taste for food and arts, it also indicates how perceptions and practices based on class conditions are embedded into individuals' daily lives. This concept is a key factor in understanding disparities.

Habitus is not usually used to examine issues related to access and use of health and long-term care services. However, this concept is useful in understanding how individuals' behavior and perceptions have been shaped throughout one's life, which in turn influences access to and use of long-term care and social services. While the political economy perspective focuses on individuals' conditions as an outcome of structural dynamics in economic, political, and socio-cultural fields, the concept of habitus focuses on how individuals' internalized class condition influence their practices and perceptions.

Chapter 3: Substantive issues: Literature reviews

3.1. Informal Care and the Culture of Familism

In general, Latino elders are assumed to be well cared for by family members and they are recognized as having a preference for family care over formal support because of a culture of familism (Andersen et al., 1986; Greene & Monahan 1984; O'Donnell 1989; Sotomayor & Randolph 1988; Purdy & Arguello 1992; Starrett, Mindel, & Wright 1983; Cox & Gelfand 1987). Familism is a defining characteristic of Latino family structure (Sotomayor & Applewhite 1988; Aranda & Knight 1997) and it is important to introduce this concept to understand practices in informal caregiving, utilization of formal long-term care service, and the utilization behaviors of this study's participants. In terms of informal caregiving, familism is one of the fundamental concepts that sustains informal care giving among Latinos and helps to explain the greater practice of informal care giving among Latino families when compared with non-Latino white Americans. Familism helps us to understand why older Latinos use or do not use formal long-term care services and the role of family members in the delivery of these services. Familism allows us to understand why some people use services while others do not.

Familism is a cultural belief that values strong identification, attachment, and feelings of loyalty, reciprocity, and solidarity amongst members of the same extended family (Sabogal et al., 1987). Structurally, familism promotes multigenerational households and extended family kin networks that provide support to family members (Maldonado 1979; John, Resendi, & Vargas 1997). According to the census of 2002, 26.5% of Latino households were made up of five or more people, compared with 10.8% of non-Latino White. Reciprocally, family households with only two people represented

25.9% of Latino family households compared with 48.7% of non-Latino White family households (Ramirez & Cruz 2003:4).

Familism provides Latinos with a strong sense of filial obligation (Johnson et al., 1997). Several studies suggest that Latino elderly receive support from family members, particularly from adult children (John, Resendi, & Vargas 1997; Sotomayor & Randolph 1988; Aranda & Knight 1997). Indeed, elderly Latinos often consider family, particularly adult children, a major source of assistance and expect adult children to remain geographically close to them in order to provide assistance (Cox & Monk 1990). Sotomayor and Randolph (1988) found that the majority of their study participants received a good deal of support with transportation, shopping, and housekeeping from their adult children.

Moreover, Latino caregivers are motivated to take primary responsibility in caring for their elderly parents (John, Resendi, & Vargas 1997). Studies have found that Latino caregivers express distrust of formal care services and want to care for their elderly family members within the family context regardless of the personal cost or consequences (Madsen 1969: 224; John, Resendi, & Vargas 1997).

Informal care giving among family members is not limited to instrumental support. Becker and colleagues (2003) and Beyene and colleagues (2002) found that Latino elderly tend to place more value on emotional rather than instrumental support. John, Resendi, and Vargas (1997) documented frequent contacts and interactions among Mexican American families. This kind of emotional support is fostered by either an adult child living with the elderly person or by the elderly parents living near to adult children. In the case of children not living with the elderly parents, children make efforts to contact their parents regularly through visits and telephone conversations. Family members often

make efforts to communicate with older parents who live away from them through telephone calls (Dietz 1995).

At the same time, many studies have pointed out changes occurring in the Latino family and raise questions about the notion that elderly Latinos are well cared for by their family members (Miranda 1991; Wallace & Facio 1987; Dietz 1995; Hall 1987; Hanson, Sauer & Seelbach 1983; Markides, Martin & Gomez 1983; Maldonado 1985; Hogan, Eggebeen & Clogg 1993). For example, Markides, Martin, and Gomes (1983) studied intergenerational solidarity in San Antonio, Texas and found that elderly people believed that children should provide instrumental and financial support for their elderly parents when they needed them to. However, less than 50% of the elders interviewed actually receive these supports from their adult children, even though some of their children offered assistance (John, Resendi, & Vargas 1997). Dietz (1995) found that 57% of Mexican elders who needed assistance did not receive any help from the family. In addition, Hall (1987) found that 80% of elderly Mexican Americans included in his study had no family caregiver at all.

These researchers have identified several reasons for this change among Latino families. One reasons is that adult children have less ability to provide care due to their own financial constraints, multiple responsibilities in their paid work and to their own family, geographic distance due to their work, and increased participation in the labor force amongst Latino couples (Cox & Monk 1990; Maldonado 1985; Johnson et al., 1997; Beyene, Becker, & Mayen 2002; Hogan, Eggebeen & Clogg 1993). Additionally, the acculturation of younger Latinos is believed to change or erode familism amongst Latino families who have lived in the US for longer periods of time, as these families have not shown as much perceived obligation to assist their family members (Sabogal et al., 1987)

and are less likely to live in multigenerational households (Lee & Angel 2002; Wilmoth 2001; Glick & Van Hook 2002; Burr & Mutchler 2003; Zsembik 1993). Furthermore, despite their preference for family care, elderly Latinos are aware of their children's busy lives and they do not want to be a burden to their children (Beyene, Becker, & Mayen 2002; Johnson et al., 1997; Talmantes, Lawler, & Espino 1995).

Familism and mutual assistance among family members are still defining characteristics of Latino culture. However, according to Facio (1996), familial networks among the aged no longer constitute the 'romanticized' extended family so often described in Latino aging literature because of the socioeconomic factors affecting adult children. Usually, females, particularly daughters or female relatives, leave the workforce to take care of their older family members. However, "for Chicano families such decisions are further complicated by assessing one's financial status in light of one's family obligation or the ideological force of familism" (Facio 1996:87). With more and more people residing in nursing homes, older Latinos often feel very insecure about their own immediate futures when they think about their decline in functional ability as a consequence of illnesses. They fear being placed in a nursing home, yet they do not want to be a burden to their children. Thus, the issues surrounding long-term care are increasingly important for the Latino population as more and more Latino elderly live into old age (Facio, 1996).

3.2. Formal Long-Term Care

Home and Community-Based Long-Term Care Services in the US

Home and community-based services (HCBS) refers to long-term medical or supportive services, provided in and individual's homes and community. Services including assistance with activities of daily living such as eating, bathing and dressing are provided to elderly or people with disabilities (National Conference of State Legislatures, 2002). HCBS also includes adult day care programs, respite care for family caregivers, residential services and assisted living facilities, home health for nursing care, personal assistance services, care planning and case management, and other services necessary to avoid institutionalization (National Conference of State Legislatures, 2002).

The development of home- and community-based long-term care services has been supported by many factors. Some policy makers see HCBS as less costly than institutional care; therefore, it is considered a way to contain spending. In addition, HCBS is considered preferable to the elderly and family members than institutional care. Moreover, some HCBS may be the only option for older people who lack available or appropriate informal care networks and who are not impaired enough to require institutional care (Goins & Hobbs, 2001).

The growth of HCBS was also supported by various legal acts, such as *the Americans with Disabilities Act* in 1990 and *Olmsted case* in 1999. The Americans with Disabilities Act outlawed the practices of private and public entities that unreasonably restrained the participation of individuals with disabilities in society (Americans With Disabilities Act. 1990). The Supreme Court ruled in the Olmstead case in 1999 that individuals living in institutions who are able to live in the community have the right to live in the least restrictive setting (i.e., home and community). Thus, states may not

discriminate against persons with disabilities by refusing to provide community services when these are available and appropriate (Harrington et al., 2000:673; Harrington et al., 2001:63). These various factors have contributed to the growth of HCBS since the 1990s.

Major ways to provide HCBS are through Medicaid-sponsored programs and state-funded programs. State-founded HCBS can offer services that are not provided by Medicaid HCBS as well as for people who are not eligible for Medicaid (Kassner, 2005). Most commonly provided services include homemaker, meal delivery, adult day care, respite care, and personal care assistance (Kassner 2005). State-funded HCBS programs are financed through general and other revenues (e.g., state lotteries or tobacco settlement monies) (National Conference of State Legislatures, 2002; Kitchener, Willmott, and Harrington, 2004). Currently 48 states provide a total of 157 state-only funded programs (Kitchener, Willmott, & Harrington, 2004). However, states tend to use these programs to supplement Medicaid-funded programs because it is less of a financial burden for states (Weiner et al., 2002; Kitchener, Willmott, and Harrington, 2004:2).

Medicaid is the primary payer for long-term care. In 2002, Medicaid paid 47% of nursing home and home care services. Medicaid long-term care costs in 2002 were $84.7 billion (34%) of total Medicaid expenditures (Health Policy Institute, 2004). About half of Medicaid long-term care spending is for the elderly (Health Policy Institute, 2004). States share responsibility with the federal government for Medicaid, paying on average 43% of total Medicaid costs. As states have flexibility to set eligibility and service criteria, spending varies across states.

As Medicaid provides coverage of long-term care costs for poor people, individuals must meet strict income and asset rules. In most states, aged or disabled adults who are eligible for Supplemental Security Income (SSI) are also eligible for Medicaid. In

2005, the federal SSI limits for individuals were $579 per month in countable income and no more than $2,000 in countable assets. Individuals whose income is not adequate to cover their health and long-term care costs, but exceeds the SSI standard, can usually qualify for these long-term care services. However, these individuals must contribute nearly all their income to pay for their care. In addition, participants must meet the state's functional eligibility criteria to receive Medicaid-covered long-term care services. States' criteria vary, but generally include health status as well as physical and cognitive functioning (Kassner, 2005:1).

Medicaid HCBS are offered in three ways: Medicaid home health, Medicaid Personal Care Services (PCS) optional benefit, and the 1915 (c) waivers. Medicaid home health services include personal care for assistance with daily activities for Medicaid participants (National Conference of State Legislatures, 2002). Medicaid Personal Care Services (PCS) allows states to fund non-medical assistance with ADLs such as bathing and eating as well as instrumental activities of daily living (IADLs) such as shopping and preparing meals (LeBlanc, Tonner, and Harrington, 2000). States have had the option of offering PCS as a Medicaid state plan benefit since 1975 and receive federal matching funds for services provided. States are given considerable discretion in determining the amount, duration, and scope of covered services (Kitchener et al., 2005). Although programs cannot solely involve housekeeping or chores, programs typically involve non-medical assistance with ADLs and IADLs for participants with disabilities and chronic conditions (Kitchener, Ng, and Harrington, 2005).

States can obtain waivers from the federal government, which allow then to design HCBS programs for specific target populations for service not traditionally covered by Medicaid (National Conference of State Legislatures, 2002).   The Medicaid waiver

HCBS program was established by Section 2176 of the Omnibus Budget Reconciliation

Act (OBRA) of 1981 and was incorporated into the Social Security Act at Section 1915

(c). Through this authority states receive Medicaid matching funds to provide HCBS that

are not otherwise covered under Medicaid program, as an alternative to institutional care,

to individuals who otherwise would receive care in a nursing facility (Duckett and Guy,

2000; Miller 1992:163).

Under the 1915 (c) waiver, seven specific services can be provided: case

management service, homemaker service, home health aid service, personal care, adult

day health care, habilitation service, respite care, and adult day care (Health Care

Financing Administration 1996; Duckett & Guy, 2000:123). Additionally, other services

(e.g., transportation, in-home support service, delivered meals, minor home modifications,

and adult day care) may be provided at the request of the States if approved by HCFA.

Such services must be cost effective and necessary for waiver participants to avoid

institutionalization (Health Care Financing Administration, 1996; Duckett and Guy,

2000:124).

Medicaid HCBS programs expanded during the 1990s in terms of the volume of

programs and participation as well as inflation-adjusted spending. The 1915 (c) waiver

contributed much to this growth. Only six states participated in the 1915(c) waiver

program in 1981. By 1997, every state had the 1915(c) waiver program reflected in a

total of 221 approved waiver programs (Miller, Ramsland, & Harrington 1999:139). On

the other hand, Medicaid home health and PCS experienced little growth from 1992 to

2001. The number of Medicaid home health programs remained 31 throughout this period.

Although the data for the number and growth rate in PCS by 1998 are not available, PCS

increased from 28 in 1999 to 29 programs in 2001 (Kitchener et al., 2005:209). The

number of waiver participants increased from 235,580 in 1992 to an estimated 842,906 in 2001, which is a 258 percent increase. Estimated numbers of participants in home health and PCS from 1992 to 1998 are not available. Home health grew 1.3 percent from 2000 to 2001. The participation in state-plan PCS declined by 0.4 percent from 2000 to 2001 (Kitchener et al., 2005:209). Total Medicaid HCBS spending increased from $5,772 million in 1992 to $21,992 million in 2001, which is a 281 percent increase. During this period, waiver spending increased by 553 percent, home health grew 127 percent, and the growth of PCS was 281 percent (Kitchener et al., 2005).

In 2002, 2.3 million individuals were served through these programs. Of these recipients, over 729,500 individuals (31%) received care through the home health benefit, 683,000 individuals (29%) were served through PSC, and 920,833 individuals (40%) received services though the waiver (Kitchener, Ng, and Harrington, 2005). The total Medicaid spending on HCBS was $25 billion, consisting of $16.9 billion (66%) in waiver spending, $30 billion (12%) in home health, and $5.6 billion (22%) in PCS spending (Kitchener, Ng, and Harrington, 2005:5).

Although Medicaid HCBS has grown during the 1990s, shortages of HCBS waver slots have been reported since the 1990s, 42 states had waiting lists in 1999 (Miller et al., 2000; Harrington et al., 2000; Kassner and Williams, 1997). Therefore, not all Medicaid eligible people who need assistance in their daily life are receiving HCBS.

The availability of HCBS varies from state to state based on various factors, such as the proportion of people aged 85 and over and the economic condition of states. This is because states with better economic conditions or a larger portion of people aged 85 and over tend to offer more HCBS (Harrington, et al., 2000; Miller 1992). However, many

states try to limit the availability of HCBS while they attempt to meet the growing demands for HCBS.

The most frequently used cost control strategies in Medicaid HCBS are: 1.) setting limits to benefits per participant; 2.) limiting the availability of service slots; 3.) setting more stringent financial eligibility than institutional care, and; 4.) using waiver waiting lists (Kitchener, Ng, and Harrington, 2004). For example, 33 percent of states were using more stringent financial eligibility standards than those used for institutional care in 2002. Those states used various eligibility standards, such as 100% or 150% of SSI as the financial eligibility criterion (Kitchener, Ng, and Harrington, 2004). Consequently, a national total of 74,526 people were on the elderly/disabled waiver waiting lists in 2002 (Kitchener, Ng, and Harrington, 2004:65). These cost control strategies result in limited access to HCBS for Medicaid eligible people. Those who cannot use HCBS usually depend on informal caregivers, particularly family, or live within limitations.

Since the slowing of the U.S. national economy in late 2001 and consequent budget shortfalls, as well as escalating Medicaid expenditures, availability of HCBS was further limited as many states began to look for ways to control or reduce Medicaid spending (Coleman, Fox-Grage, & Folkemer 2003). According to The National Association of State Budget Officers, more than 30 states experienced the excess in preliminary estimates of Medicaid expenditures for 2002 than the states' original appropriations by $2.8 billion (Ku, Ross, and Nathanson, 2002:3).

In summary, policy trends have encouraged the expansion of HCBS under states since the 1980s, while cost control strategies have limited access to HCBS for all Medicaid eligible people who need assistance. With this policy trend in mind, in the next section, I will review studies of the use of long-term care services among Latinos.

Use of formal services among older Latinos

Given the projected growth and increasing demand for formal long-term care

services among Latinos, a number of researchers have studied service use among older

Latinos and their underutilization is well documented (Wallace, Levy-Storms, and

Ferguson, 1995; Ailinger and Causey, 1993; Talamantes, Lawler, and Espino, 1995; Parra

and Espino, 1992; Starrett et al., 1989 & 1990; Burnette and Mui, 1999).

Although the results vary based on types of services assessed and the

characteristics of the samples, research suggests that barriers for elderly Latinos access to

health and long-term care services include: 1.) lack of financial resources (Starrett et al.,

1989; Parra & Espino 1992; Ailinger & Causey 1993; Tran, Dhooper, & Mclnnis-Dittrich

1997); 2.) lack of knowledge and awareness about services (Starrett et al., 1989; Parra &

Espino 1992; Ailinger & Causey 1993), and; 3.) language barriers and a lack of

bicultural/bilingual service providers (cultural sensitivity) (Gavaria & Stern 1980;

Sotomayor & Randolph 1988; Tran et al., 1997).

Lacking financial resources to utilize services poses difficulties for many people.

Economic means refers to income, assets, and the availability and adequacy of

government sponsored insurance (i.e., health care insurance and long-term care insurance)

(Swan & Estes 1993; Harrington & Pellow 2001). According to the US census of 2002

(Ramirez & Cruz 2003), Latinos age 16 and older are in a poorer financial status than

non-Latino Whites. Latinos have a higher unemployment rate than non-Latino Whites,

representing 8.1% and 5.1% respectively. Moreover, Latinos were more likely than non-

Latino Whites to work in the service sector (22.1% and 11.6%, respectively) and as

operators and laborers (10.8% and 10.9% respectively). Consequently, Latinos are more

likely to be in a poorer financial status than non-Latino Whites, as 26.3% of Latinos earn

$35,000 or more annually compared with 53.8% of non-Latino Whites. Furthermore, 21.4% of Latinos were living in poverty compared with 7.8% of non-Latino Whites (Ramirez & Cruz 2003).

Because of their poorer economic status during their working year, many older Latinos tend to also be in a poor financial status (Du Bois, Yavano, & Stanford 2001). The portion of Latino elderly receiving SSI is lower than the general population because of their employment in agricultural and other unskilled sectors, which carry limited or no pension plans. For those who receive social security, it tends to be the sole income or a major source of income. However, their lower paying job histories result in a lower benefit level of social security than non-Latino populations (Garcia 1988).

Wallace, Levy-Storms, and Ferguson (1995) showed how limited financial resources influences service use among older Latinos by comparing the use of paid in-home assistance among disabled Latino and non-Latino white elders. Their findings suggest that there is a similar prevalence of paid care use for elderly Latinos and non-Latino Whites, which suggests that Latinos do not have a cultural aversion to paid functional assistance. However, they found different patterns of paid care use. In terms of non-Latino Whites, variables that increase the probability to use services are higher need and higher income. On the other hand, among Latino elderly, higher need decreases the service use. While Latinos pay for low-intensity paid assistance involving IADL, they shift to solely informal care when their functional ability decreases, because of their limited financial resources (Wallace, Lavy-Storms, and Ferguson 1995).

On the other hand, Freedman et al., (2004) found that those with the least financial resources at their disposal were more likely to have home health visits. This is because Medicare managed care plans may minimize access difficulties for those of the poorest

socioeconomic status. However, it is unclear why wealthier individuals are less likely to use home-visit service. Thus, the authors assume that these people may tend to pursue better options, such as assisted living (Freedman et al., 2004).

Knowledge and awareness of services are considered important factors that determine the use of services among minority elderly populations (Wan & Odell 1981). This view contends that minority elderly will utilize more services effectively if they are knowledgeable about available social resources. Therefore, it is important for social service agencies and providers to make efforts to provide information to the elderly (Yeatts et al 1992).

Knowledge about services is often assessed in relation to social networks and living arrangements. Knowledge and awareness of services are directly affected by social support, English literacy, and living arrangements (Starrett, et al., 1990). For example, Latino elderly who live with a spouse or adult children are more likely to use formal services because family members provide information about services and organize the service use for the elderly person (Wallace, Levy-Storms, and Ferguson 1995).

Another example is a study done by Starrett, Mindel, & Wright (1983) that showed that knowledge about services was the strongest direct predictor of service use when related to perceived needs and availability of informal supports, including living arrangements. In this study, the availability of natural support systems were measured by living arrangements, participation in senior centers, and the frequency of contact with friends, neighbors, family, relatives,. Among those who perceive their needs to be met in their daily living arrangements, elderly who have access to information about services are more likely to use services. For example, the person who lives alone, visits frequently with kin, friends and neighbors, and participates in senior centers or churches is more

likely to use formal support services. This finding is interpreted to suggest that those with natural support networks provide information and organize service use for the elderly. On the other hand, those elderly who live with their spouses, visit infrequently with friends and neighbors, and do not participate in senior citizen activities are less likely to be knowledgeable about services, and thereby use fewer formal services. This finding indicates that the Latino elderly with a less extensive support system does not have information about services, which results in underutilization.

At the same time, some elderly who live with a spouse or family member perceive a need for services and have knowledge about services. However, they do not have contact with providers because they prefer informal family caregiving (Starrett, Mindel, & Wright 1983; Purdy & Arguello 1997). Both Latino elderly and family members prefer family care to formal support (Andersen, Giachello, & Aday 1986; Greene & Monahan 1984; O'Donnell 1989; Sotomayor & Randolph 1988; Purdy & Arguello 1992; Starrett, Mindel, & Wright 1983; Cox & Gelfand 1987). Here it is argued that Latino children are in a better position to access and provide information about services when compared to other immigrant groups [2] because they are the most assimilated and have a higher income level (Cox and Gelfand 1987). Therefore, Purdy and Arguello (1997) suggest that "the family provides the elderly with the information but they chose not to make use of the information presented to them" (35) because they prefer to use informal support.

Education is often examined as a measurement of both knowledge and financial status (Andersen, Giachello, & Aday 1986; Greene & Monahan, 1984; O'Donnell, 1989). For example, Ailinger and Causey (1993) conducted a longitudinal study of Latino elders'

---

[2] Cox and Gelfand (1987) compared among Hispanics, Vietnamese, and Portuguese.

use of home health services. They found that those who have a lower education level are less likely to use home help services than those with higher education, which implies that higher educational levels provide opportunities that affect knowledge of health services and access to them (Ailinger and Causey 1993). In addition, education implies the types of job they held, which affects their retirement income.

Although knowledge is an important aspect that shapes or influences the use of services among the Latino elderly, Cho (1998) argues that knowledge about services will not increase the service use unless cultural sensitivity is achieved for the minority elderly. Cultural sensitivity can be viewed as an institutional barrier, including racial discrimination, the lack of Spanish speaking staff, and insensitivity to cultural customs by providers (Parra & Espino 1992; Johnson et al., 1997). In terms of health care use, Latinos with limited English ability have significantly limited access physician visits and medical insurance when compared to Latinos who speak English (Derose & Baker 2000). Similar findings were shown by Fiscella et al., (2002) in their study, which found that Spanish-speaking Latinos were significantly less likely than non-Latino whites and English-speaking Latinos to have physician visits, mental health visits, and influenza vaccinations.

However, the lack of English proficiency alone cannot be a barrier to access social and health care services among Latino populations. Schur, Albers, and Berk (1995) found that a lack of English proficiency did not appear to independently influence health care use among a national sample of Latinos. The lack of English proficiency may become a barrier along with other cultural and institutional factors, such as lack of an interpreter and real/perceived discrimination against Spanish-speaking patients (Derose & Baker 2000:85).

The findings of research vary and sometimes conflict with one another because of differences in the types of services and in the Latino populations researchers focused on. Regardless of the characteristics of services, as previous researchers identified, the lack of knowledge, financial constraints, and cultural insensitivity may be major barriers to access of social and health care services among Latinos. In other words, they will use services effectively if: 1.) they are aware of available services for them; 2.) they have some social network to assist them to use services; 3.) bicultural services are provided, and; 4.) they have some financial resources through out-of-pocket or public assistances.

Chapter 4: Methodology

<u>4.1. Data</u>

This study uses the Latino population sub-sample data set that was collected for an ethnographic study (Minority Aging Study) about the roles of culture in management and experiences of illness among low-income, ethnic minority elderly populations. The ethnic populations under study included African Americans, Latinos, Cambodians, and Filipinos (R01number: NGA5R37AG11144**)** (Becker et al., 1998 & 2003; Becker, 1997 & 2002; Becker, Yewoubdar, & Ken, 2000; Yewoubdar, Becker, & Mayen, 2002). The original study sought to explore: 1.) their experience of illness, the interpretations they place on illness, cultural models for understanding illness, and use of biomedical and indigenous health care; 2.) cultural meanings minority elders and their families attach to old age; 3.) the role of the family in illness management and recovery in decreasing functional ability, and; 4.) perceptions and experiences in using or considering use of community resources, both formal and informal, that are considered or utilized in specific situations, and decreased functional ability. This dissertation will focus on the fourth point, which is the perceptions and experiences in using and considering use of community resources among elderly Latinos.

Data were collected during 1996 to 2000 through semi-structured, in-depth interviews about interpretations of illness, cultural meanings of old age, the role of the family, and community resources. Additionally, quantitative measurements were used in order to assess the samples' functional ability and gain demographic information, which included a survey of socioeconomic status and living arrangement of study participants. Functional ability was assessed by using ADL, AADL, Barthel, IADL, and self-reported

health status. The sample of the original study consisted of 85 older Latinos aged 51 and older who have one or more chronic illness.

Participants were recruited through physicians, acute care hospitals, home care services, and community health clinics in two counties. In addition, some subjects were referred by other participants. Criteria for entry into the study was the presence of one or more chronic illnesses. Exclusion criteria were known or observable presence of confusion or dementia. The study protocol and consent form were approved by the Institutional Review Board, Committee on Human Research, University of California-San Francisco. The research protocol calls for participants to be interviewed 4 times in every 6 month. The qualitative analysis of this dissertation uses every interview that was conducted. The quantitative analysis reports baseline data only.

4.2. Services

In this dissertation, I will explore whether older Latinos use state-funded long-term care service and other social services. In terms of state-funded programs, I will look at use of following eight services: 1.) home health; 2.) outpatient rehabilitation therapy; 3.) adult day health care; 4.) personal care; 5.) home delivered meals; 6.) transportation services; 7.) senior information referral, and; 8.) senior center. Other social services include financial assistances, such as SSI and GA, and government housing services.

Home health emphasizes post-acute rehabilitative services, not long-term and custodial home care (Harrington and O'Meara, 2004). It provides skilled nursing or related services in a recipient's own home by a state licensed provider. Under Medicaid, services provided can be preventative, treatment, rehabilitative and maintenance, which include nursing services, occupational, physical and speech therapy, home health aid,

medical and social service, personal care, and dietary counseling. Service is ordered by a

physician and paid by Medicaid, the Part B Medicare benefit, private insurance, and

personal/family resources (Hernandez and Zawadski, 2003:21).

Adult Day Health Care is a licensed Medicaid certified health program, which is

funded as a Medicaid state plan optional benefit. The program provides a variety of

health, therapeutic, and social services to those at risk of being placed in a nursing home.

Provided services include medical services, nursing services, physical therapy,

occupational therapy, speech therapy, psychiatric/psychological services, social services,

recreational activities, transportation to/from center, if needed, noontime meal and

nutritional counseling (Hernandez & Zawadski, 2003:20).

Personal care provides personal assistance services for low-income people with

physical disabilities. Services include assistance with ADL and IADL. In California,

personal care service is mainly provided through *the In-Home Supportive Services (IHSS),*

which covers the cost of in-home personal and chore services to frail elderly, disabled, or

blind persons who are low-income and have limited financial resources (Hernandez &

Zawadski, 2003:21). Services consist of four domains, including Personal Care Services

(e.g., ambulation, bathing and grooming, dressing and bowel and bladder), Paramedical

Service (e.g., administration of medications), Domestic and Related Services (e.g., meal

preparation, shopping, heavy cleaning, accompanying medical appointment, routine

laundry, and other errands), and Protective Supervision Service. The program is financed

through a combination of federal funds through Medicaid and state and county funds

(Waterstone et al., 2004).

Eligibility requirements in *IHSS* include being 65 and over or disabled, being a

recipient of Supplemental Security Income/State Supplementary Payment (SSI/SSP), or

meeting all the eligibility criteria for SSI/SSP except for income limits (Waterstone et al., 2004:5; California Department of Social Services, 2001). County social workers conduct assessments to determine eligibility as well as types and amount of services provided, according to state and federal policies (Waterstone et al., 2004:6). A doctor must authorize Paramedical Service (Waterstone et al., 2004).

The IHSS program consists of two components: *the Personal Care Services Program (PCSP)* and *the Residual IHSS program*. *IHSS* was supported entirely by state and county funds from 1973 (when the program was funded) to 1992. In 1992, California Legislature passed AB 1773 in order to receive Medicaid funds. *PCSP* is the portion of *the IHSS* program that are funded by Medicaid. Services that do not qualify for Medicaid are retained within *IHSS* as the "Residual" Program and are paid for using state and county funds (Waterstone et al., 2004:7). *Residual programs* can cover the cost of *IHSS* services provided by a spouse or services for consumers who require only domestic and related services, including preparation of meals, meal clean-up, routine laundry, shopping for food, other errands and shopping, heavy cleaning, accompaniment to medical appointments, accompaniment to alternative resources of care, removal of grass, weeds, and rubbish, removal of ice and snow, and domestic services (Waterstone et al., 2004).

Home delivered meals are provided by Local Area Agencies on Aging, a local program that prepares and delivers meals to homebound seniors. Transportation services are also provided by Local Area Agencies on Aging. With transportation services, local agencies secure escort and travel vouchers or provide a vehicle to assist in transporting older persons to essential services. Local Area Agencies on Aging also provide senior information referrals as well as assistance and follow-up to link older persons and their

families to specific community services (California Association of Area Agencies on Aging 2005).

Although there is no standard definition of a senior center, comprehensive senior centers typically provide nutrition, recreation, social and educational services. Many senior centers are funded by local non-profit organizations and governments, while others are supported with funds raised by national charitable, volunteer, and for religious organizations such as the YMCS (Administration on Aging 2004). Senior centers are different from other county-provided services for two reasons. First, senior center often do not have any eligibility requirement. Thus, anybody can participate in them. Second, participation in senior centers requires higher functional ability while other service uses are expected to occur with the decline in health. I will examine how the use of these services are influenced by macro structural and individuals' life experiences.

Other Services in this study consist of various types of financial and housing assistance that are provided by formal organizations, such as governmental and religious organizations. Government-sponsored financial assistance includes SSI and GA. SSI is a federal cash benefit program administered by the Social Security Administration under Title XVI of the Social Security Act. Disabled individuals or those 65 and over can receive SSI if they have limited income and resources. Another financial assistance is GA, which provides a varying set of assistance programs for low-income people who are not eligible for federal assistance. GA is funded and administered entirely by the state, county, and/or local agencies where the particular program is operated (Uccello and Gallagher, 1997).

This dissertation employs the mixed method approach, using both qualitative and quantitative analyses. Although these two methods are rooted in distinct logics, the two methods can compliment each others strengths and limitations. Quoting Charles Ragin (1994:92), Neuman (1997:14) introduced one in which qualitative and quantitative methods differ:

> *The key features common to all qualitative methods can be seen when they are contrasted with quantitative methods. Most quantitative data techniques are data condensers. They condense data in order to see the big picture..... Qualitative methods, by contrast, are best understood as data enhancers. When data are enhanced, it is possible to see key aspects of case more clearly.*

Quantitative method seeks to find causal relationships that can be generalized to some group of people with statistical analysis (Neuman, 1997). On the other hand, qualitative research seeks to understand individuals' points of view as well as constraints and experiences in everyday life from a case-based position (Denzin and Lincoln, 2000).

In order to utilize the advantages that qualitative and quantitative methods offer, my analysis procedure takes the following steps.

Method	Objective
Quantitative analysis	Analyze 85 participants in order to see if their service use is influenced by same factors that previous studies have suggested.
	↓
Quantitative analysis	Analyze 34 key participants to see if there are differences in their characteristics. Selection criteria for these 34 participants are described in Chapter 7.
	↓
Qualitative analysis	Explores 34 key participants to see how their service use is influenced by their life experiences, which are partly the result of macro-structural factors.

First, I attempt to see whether use of and access to HCBS and other social services can be explained by the expanded behavioral model for vulnerable populations. More

specifically, I examine if elderly Latino's access to services is influenced by factors that previous studies have suggested. These factors include individuals' physical functional ability, the availability of financial resource, knowledge and awareness about services, the availability of social support, and English language proficiency. The detail variables used in this analysis and statistical procedures will be introduced in Chapter 6.

At the second stage, I will focus on 34 participants who are considered key participants. The selection procedure of these 34 participants will be introduced in chapter 7. In this stage, I compare their characteristics to see if there are differences or similarities in terms of their financial resources, the degree of acculturation, the availability of social networks, and physical functional ability. This is another step to see if there are differences in their service use from what previous studies have suggested.

At the third stage, I use narrative analysis, a particular mode of research, to see if factors other than those in previous studies influence service use among this study's participants. In this step, qualitative analysis helps to capture other key factors that are unidentified or ignored by quantitative analysis and previous studies.

Qualitative/narrative analyses

As an overview, narratives are the stories that people tell about themselves to reflect their experiences (Becker 1999). It is a fundamental human way of giving meaning to experience (Garro & Mattingly 2000:1). Stories are ways of thinking about the past and making sense of ongoing situations, which guides further actions (Garro & Mattingly 2000:14). As people talk about their experiences, past events are reconstructed in a manner congruent with current understandings and the present is explained or interpreted with reference to a reconstructed past. These two processes are used to generate

expectations about the future (Garro & Mattingly 2000:11). Furthermore, narratives are stories that represent how the narrator wants people to see them (Becker 1999). Therefore, narratives can provide us with important insights into peoples' experiences and their perceptions on them (Becker 1999). In short, narrative is a way to see and understand study participants' lives through "the lens of story" (Randall 2001:34).

Narrative analyses make it possible to see the multidimensional aspects of people's lived experiences . According to Kenyon and William (2001:7), stories consist of four interrelated dimensions that are structural, sociocultural, interpersonal, and personal dimensions. Structural dimensions refer to structural constraints (i.e., social policies, power relations, and economic realities) that constrain stories, silence voices, and set limits to one's sense of possibility.

Sociocultural dimensions refer to social meanings that are associated with issues (i.e., aging, life course and care) within a given cultural context. This dimension of stories includes sociocultural meanings of being female/male and of a certain ethnicity. Both structural and socio-cultural dimensions indicate that people perceive and interpret cultural and social conditions in which they are situated through stories(Garro & Mattingly 2000).

Interpersonal dimensions refer to "how our life stories are shaped by and entwined with the life stories of other individuals, whether in our families and our friendships or in our intimate relationships" (Kenyon & William 2001:7). The personal dimension "involves the creation and discovery of meaning and coherence within each of us uniquely, that is, the way in which the pieces of our lives do or do not make sense to us" (Kenyon & William 2001:7). People's stories are an appreciation of the intertwining of

the structural, sociocultural, interpersonal, and personal components (Garro & Mattingly 2000:24).

Stories about experiences and events seen from the perspective of particular actors reflect larger social contexts. Therefore, stories can tell us something about social worlds (Garro & Mattingly 2000:24). Pollock (2000) provides us with an example about how narrative reflects political economic and socio-cultural conditions of the time in his social history of medicine through an analysis of physicians' autobiographies in the 20th century. In this study, Pollock used female physicians' autobiographies that describe the difficulties in establishing professional competence because of pervasive gender stereotyping. Through female physicians' autobiographies, Pollock (2000) sees the social conditions that produced their struggles. These conditions included male physicians' resistance to including female physicians and the overproduction of physicians with consequent concerns about misdistribution of physicians. Moreover, these barriers reflect a social issue of a time. Pollock notes that the ways in which female doctors "construct a kind of social history of feminism mirrors the struggles of women in other professions" (Pollock 2000:124). In addition, his example shows the dynamics of the medical industrial complex and the culture of U.S. biomedical model in that time period. Psychiatrists' biographies show how their treatment plans were structured and limited by bureaucratic factors that included insurance systems, the availability of beds, and organizational characteristics. Moreover, the biomedical model considers the body external from

emotions and other aspects of individuals' lives, which constitute 'illness'[3].

Narrative analysis contributes to understand individuals' views and constraints under particular social, political, and economic conditions. The participants talked about their experiences and interpretations of: 1.) illness; 2.) role of social support in managing illness; 3.) declining physical abilities and,; 4.) using or considering the use of community resources. These stories contain their individuals' views that reflect social, political, economic, and cultural positions within which they locate. Understanding their views will help to understand how the factors of each domain influence their experiences.

---

[3] For detailed discussion, please see Donald Pollock (2000). "Physician Autobiography: Narrative and the Social History of Medicine." in Narrative and the Cultural Construction of Illness and Healing. Edited by Cheryl Mattingly and Linda C. Garro. University of California Press.

Chapter 5: Description of Study Participants

This chapter introduces the study participants. The sample consists of 64 women and 21 men. The mean age is 73 years old and the age range is from 51 to 97 years old. The demographic characteristics are shown in Table 1 on page 80. Overall, they are low-income, have multiple chronic illnesses that cause them difficulties in daily living, are unable to speak English, reside in a Spanish-speaking community, and have little support from adult children. Despite their physical functional disabilities, they live in the community independently.

5.1. Functional disabilities

First, I will describe how study participants live with their functional limitations that are the result of old age and multiple chronic illnesses. All participants in this study have one or more chronic illness. Major chronic illnesses include arthritis (58.8%), diabetes (32.9%), and hypertension (38.8%). About thirty-seven percent of them have more than one of these illnesses. For instance, thirty-one percent of the participants have all three illnesses and 14% of the participants have both arthritis and diabetes.

Their illness affect their ability to perform daily activities and their self-evaluation. For instance, arthritis is not a life threatening illness, but the severe pain caused by this illness impacts the ability to engage in many daily activities. In addition to the pain from arthritis, some participants have to contend with vision problems. Although vision problems and pain are not life-threatening, these conditions restrict what participants can do. These activities include going out alone, climbing up and down stairs, walking, and doing household chores. Their inability to do these things sometimes affects their self-

image. Some participants tried to accept their condition live within their limitations,

while others felt sad about not to being able to do what they used to do.

For example, a 65 year old woman who has arthritis and depression described her

pain and the consequent disruption to her daily living as follows:

I: Do you think that these illnesses have affected your daily life?
P: Yes. Right now, for example, it hurts me a lot if I touch cold water, do the dishes, being standing up, my legs hurts, the waist. The pain is strongest in right side on my back. The pain is in the leg, the heel and it goes up to my back.
I: So, can you do the things you did before.
P: No I can't.

Another woman describes feeling old and sad for being unable to do what she used

to do. She is a 78 year old woman who lives with her husband. She came to the U.S. for

30 years ago and had never worked outside the home.

Participant (P): "I was a woman that loves to embroider, I liked to do fine things and I was always trying to do ... if I saw furniture that was old I cleaned it. I shined it. It looks so new that the persons ask me, " when did you buy it?". I was like that but not anymore.
Interviewer (I): You don't have any desire?
P: No, no I don't want to. I can't because I can even bend my knees, I can't do it.
I: Have you started a new activity?
P: A new activity? Me? How? No.
I: Don't you have any new activity.
P: No, I can't. I would like to do something so I can be entertained. I could have busy my mind. But I can't.

She feels that she is confined at home, and her activities are limited due to her physical

hardship. She wants be helped, but she cannot find it. She states:

P: That's what I want. I need help but I don't have anybody. I applied one time and I don't know if it was because I went to the Centro Latino and they didn't help me. But I really need help.

Because of her severe pain, it is hard for her to do household chores. However, she has to

do them because nobody else can do them for her. Thus, she manages her chores as

follows:

"I don't have anybody. But one day I do one thing and tomorrow I do another thing. If I get tired I sit down, then I start again."

Because she and her husband are low-income and have little help from their family,

despite their financial and physical difficulties, they depend on the U.S. government.

P: He (her husband) doesn't have any money to help my family. I have to do everything. He cannot count on his brother either. This is confidential; I don't want you to put this information in that thing (tape recorder). I am everything (she sounds angry). I don't know what is going to happen in 10, 20 or 100 years later. I don't know what will happen. He depends on me and I am depending on God and on this government. That is the only help. My husband can't do anything. We are living this situation. This is something personal. I don't talk about this to anyone. It's a very hard situation.

All participants are experiencing some level of restriction in their activities

because of their chronic illnesses. Yet, they continue to live in a community

independently with assistance from others, which includes family members, friends,

community organizations, and formal long-term care services. Some participants have

informal support from family, which helps participants to remain in the community. Other

participants do not have much informal help from family members. These participants are

either giving up what they used to do or pushing themselves to continue their everyday

lives. For instance, an 83 year old woman ignores her memory and vision problems and

continues to live alone without having enough assistance from her family and publicly

funded programs. She describes her cooking strategy as follows:

Interviewer (I): Can you cook?
Participant (P): Yes I can. Even when sometimes the food got burned because I forget that I am cooking (laughter). Oh, no. At least I still can smell. My grand-daughter brought me apples and she told me that she wanted baked apples. Well I told her, just get them ready

and put them in the oven. Well, she did it but then she left. Then, I add them cinnamon and I put them in the oven. And then I went to the bathroom and I forgot all about them (laugh). After a while I remembered that I was baking apples..... they were black all burned out. One time I was baking bread and burned it too. It was in the oven when I heard the smoke detector but it was too late! At first, I didn't know why it was making that noise. The kitchen was full of smoke and I said what's going on? Oh, no it was the bread. I try to clean it up but no it was all burn" .

Here, the burning smell is a sign that food was cooking. Although she prefers to maintain her independent living, sometimes it poses a risk for herself as well as neighbors because of the potential of a fire. In addition, to keep her house clean, she does nothing.

I: That'll be a little hard. Do you need a household helper?
P: No, I don't need it. I don't cook too much to keep the stove clean. It is hard for me to clean it. The stove is new and I don't want it to be dirty. I try to keep it clean. The best way is not cooking.
I: You should ask for house helper.
P: Yes, I know.

A 78 year old woman who lives with non-relatives goes about daily life with a combination of self-effort, formal long-term care service, and family support. She is suffering from pain in her hands, legs, and back, which make her tired. Her pain and tiredness causes her difficulties in many activities, but she continues to live independently with assistance from her sons who live away and a homemaker who comes four hours a week. When the interviewer asked about her physical condition and living condition, she replied as follows:

I am feeling worse. Because I remember that six month ago when we talked, well I know I had this pain but it wasn't like this. Did my hand was this shrink and tight before? It wasn't too bad, huh? My doctor says that I need to keep my hand moving and use this bandage all day. No. I have to cook my food. The house help [homemaker service] I have doesn't work more than four hours every week. She can come two days, [but]she want four hours in one day. I understand that because she has to pay the bus, plus the time coming back and fourth.

The interviewer asked her whether her pain affects her daily activities and her ability to do the things she used to do. She answered, "*I believe so because I feel tired. But I push myself to come to this center because I will be tired anyway.*" She pushes herself to come to a senior center because she does not want to eat alone at home. She can eat with other people and can socialize in the center. Family support also allows this woman to continue to be active. Her sons encourage her to go to the center. She is motivated to push herself to go the center because she knows that her son will pick her up at the center to go home. In other words, she is motivated to go out as her son provides her with transportation. At the same time, her son's affection and care for her encourages her to be active.

Some participants live with help from family members. For example, an 88 year old woman who has suffered from arthritis and severe headache stated:

P: Yes, it has affected me because I was very active in everything and now I can't do anything. However, it has affected everything. I have to depend on other. I am not used to let other people help because I did everything as I wanted but now I have to accept what they [her extended family members] do even if I don't like it.

I: Do you need help to take a shower?
P: No I don't. They [her family] fixed my bathroom. So far I don't need help to take a shower. ……... Just to cook and clean the house.
I: Also when you need to go out.
P: Yes, I can't go out alone. I have a daughter who helps me. I go to mass every Sunday she pick me up and bring me back. That is the only place where I go and from time to time I visit them and they come to pick me up and everything. Those are the only places where I go and the church.

Regardless of the degree of disability, all participants are dealing with restrictions in their activities due to their health problems. They stopped doing what they used to do. Regardless of the availability of formal or informal support, all participants continue to live in their community independently. Moreover, their health conditions and functional

abilities have declined over time. In addition, those who did not have many problems at the first interview often had to give up activities after six months or a year later.

5.2. Immigration process, work, and Latino community

In this section, I will describe how study participants live outside of the U.S. mainstream society because of multiple factors of their immigration status, lack of English proficiency, work history in the US, and financial constraints. These factors relate to each other. English ability and immigration status often result in low-paying jobs, which in turn results in financial constraints. In addition to financial constraints, these factors have made positions them outside of mainstream society.

Work histories

The immigration status of many study participants and corresponding lack of English language proficiency that is necessary to gain better paying jobs often resulted in employment in low-paying jobs. This contributes to the failure to be fully integrated into the U.S. mainstream society. Although some participants came as legal immigrants, most of participants came illegally and received residency later. Therefore, their illegal immigrant status resulted in the avoidance of formal agencies and authorities, and employment in low-paying jobs, which together resulted in the failure to be integrated to the U.S. mainstream society. For instance, a 72 year old woman described her work history in the U.S. as follows.

At foremost, making ice cream. At the fish baler machine cleaning fish. I also worked as a house keeper. The last job was as a janitor. I worked for an American Building and for other companies that I don't remember the name at this time."

Another a 74 year old Salvadorian man described his immigration process and preceding life in the U.S. as follows. He crossed US-Mexico border using a "coyote" 14 years ago. He received legal status four years ago through his daughter. His immigration status, lack of English language skills, educational level, and occupational skill-level make it difficult for him to get a better paying job. He was a farmer and had no education in El Salvador. He worked in low-paying manual jobs, such as a grocery store, which did not provide him with benefits (i.e., Social Security). He describes his migration experience as follows:

Well… the guerrillas were everywhere and they took our places. We didn't have houses to live in or land to work. The planes were throwing bombs everywhere so we start looking for somewhere to move. Then I was shot and beat, so I decided to come over here. I came in 1985. ……… I came to Mexico. I got a Mexican visa. I was working in Mexico for a while. Then, this person with whom I was working recommended me with a "coyote" to bring me here.
JC: I was the first one to come and then my kids came. They were forced to leave the country too. They came as refugees. I haven't done anything because I was scared of the authorities. I came first but the problem is when you don't know how to read or write.

An 84 year old woman came from Panama and worked as a domestic laborer for Spanish-speaking employers. Because both she and her son came to the U.S. as illegal immigrants and could not study English to gain stable employment, it was hard for them to start up life in the U.S. She describes this experience as follows:

P: Well I had to work because my son wasn't a legal and nobody gave him job. One of my nieces gave him a fake Social Security and he started working. I knew that wasn't right but we needed to eat and pay the rent. After that I went to live with my sister but she kicked me out after a few weeks. She told me to leave her house. The reason was that I didn't help her enough at her house. Every day when I came back from work I was really tired so I laid down on the couch and I got sleep. It was late night and my boy and I wanted to rest because we were working hard [they were sleeping in the living room]. She didn't like that, she always said "Oh, look you're sleeping.." "Oh, Nelly", I told her, "remember I came from work and I am very tired and I am old beside is late. It's 12 midnight and I need to sleep". She sat down watching TV until midnight. We have to wait until she finished watching TV. So finally she told me to leave her house.

P: I was cleaning houses but it was too hard for me. The first job I got was with a Nicaraguan lady ironing tons of clothes. It's true that she paid me good money but it was too hard for me because after I finish ironing for hours and hours I had to go out under the rain or the wind. I got sick and couldn't work any more. When I felt better I started cleaning houses and I couldn't make it either. When I came back from work I told him [her grand-son] to go help me to clean the windows and doors. He went just two times and then he stopped because it was too hard for him. Then he told me to stop working and stay home while he was working.

Illegal immigration status often results in employment in low-paying jobs, which did not provide study participants with benefits, such as Social Security and health care insurance. These jobs often include being a janitor, a baby-sitter, house cleaner in private households, a manual labor, or working in Latino-owned small businesses. Moreover, these jobs further served them to keep them in the Latino community.

Study participants' lack of English language ability also resulted in employment in low-paying jobs. Only six participants speak English and two of these six are not confident with their English proficiency. However, they do have the ability to communicate with doctors in English.

The rest of the participants do not speak English. The length of time in the U.S. varies among those who do not speak English. Some participants immigrated to the U.S. in their 50s, while other participants immigrated to the U.S. before their 30s. Several participants explained the reasons they did not learn English. Since they had to work to support their family, they did not have time to go to school to learn English. Additionally, many participants worked within a Spanish-speaking community, thus, they did not need to learn English. For instance, a 72 year-old woman from Panama did not have the chance to study English due to her health problems, the need to work, or her work environment.

I: Did you come to the U.S. in order to work?
P: My idea was to study and work but I couldn't study. Because when I went ... I was
going to the school...
I: In Panama ?
P: No, here. So I got sick. After about four months of being here they had to take me to
the hospital in Santa Monica. The doctor told me if you work you can't go to the school.
If you go to the school you can't work. You cannot do both things. I had to work at that
time. Now that I can go to the school I go. I feel ... I don't know if is due to the nervous
but I get sick with high temperature, fever and I can't. If I go one day I cannot go more.
I: You didn't need English to work?
P: No, because where I was working the lady was Jewish-Cuban and she was very good
with me.

Although participants struggled to assimilate into mainstream society through their

work, it was often difficult to find a job because of their lack of English proficiency, old

age, immigration status, and lack of skills. For instances, a 70 year old woman came from

Nicaragua 9 years ago to have a better life in the U.S. She was a nurse's aide in Nicaragua.

She wanted to work in the same profession in the U.S. However, she could not do that

because of her health problems and lack of licensure. Because she could not learn English,

she could not get a license. In addition, she was too old to be hired as a nurses aide. Thus,

she has been living in the Latino community with her roommate. Her daily routine is

limited to visiting a senior center. A 72 year-old man came to the U.S. in order to work in

electric installation and to be with his sons. However, he could not find a job because of

his age.

In this country they don't want to hire me in electric installations. Because I told my
younger son, I am 72 and I want to work. I don't feel tired. But the companies in this
country don't like to hire old persons.

Study participants' initial conditions affected their lives in old age. Their low-income

status caused them more severe financial conditions after their retirement. Living in a

Latino community made it harder for them to learn how the U.S. society works.

However, it is important to note that staying in the Latino community does not always have negative effect. Many participants chose to remain in the Latino community. This is because the Latino community offers them various advantages. For instance, a Latino community provides them with a culturally consistent living environment in a new country. Moreover, living in a Latino community becomes a buffer from discrimination due to language, racial, and cultural differences (Cota-Robles, 1980; Maldonado, 1988). Additionally, many community organizations tend to provide culturally sensitive programs, such as Spanish-speaking events (Burr, & Mutchler, 2003). Furthermore, a Latino community allows them to keep living in their cultural environment (Maldonado 1988:139). Moreover, for the current elderly generation, the Latino community can be an extension of home, in which they have developed lifelong networks of family and friendship (Maldonado 1988:139). In this type of environment, older Latinos with less English language ability can maintain independent living.

Financial problems

Because of their immigration status and lack of English ability, study participants are low-income, which also translates into financial difficulties in old age. Indeed, Latinos in general are more likely to be in poorer financial status than non-Latino whites because of higher unemployment and higher rates of employment in the service sector (e.g. as operators and laborers) (Ramirez & Cruz 2003). Their poorer financial status at working age transfers through into their old age because of less assets, pension, and Social Security benefits. Moreover, the portion of Latino elderly receiving Social Security is lower than the general population because of their employment in agricultural and other unskilled sectors, which carry limited or no pension plans (Garcia 1998). Therefore, old age among Latinos involves dependency on social programs for the aged poor, particularly Supplemental Security Income (SSI) and Medicaid (Facio 1996).

With the exception of a few participants who own a house, most participants in this study are of low-income status (73.4%) and are relying on means-tested financial assistance programs, such as SSI and GA. One person did not have any source of income at the time of the interview. Qualitative interviews reveal that their average income is around $600 per month. Their poverty is traced in their descriptions of work histories that provided them with limited income and pension plans. The majority of participants worked in unskilled (45.9%), and semiskilled (23.5%) sectors. Additionally, 14.1% of the participants had not work in the paid labor market in the US.

Participants' spending generally consists of rent, medication, food, and utilities. In other words, they spend money only on a minimum of necessities. Despite their frugality, participants often have difficulty paying for these minimum necessities, which threatens their daily living. Conditions differ between those who have support from

extended family and those who do not have support. The situation is harder for those who have no support from their extended family members.

Rent is one of the primary hardships participants are facing. The majority of their income goes to rent. They generally pay around $400 for their rent from an average income of $600 to $700. During the time of the interviews, the San Francisco Bay Area was experiencing rapid rent increases due to the booming economy. The changing economic environment put them under pressure to leave their long-time residences because their income could not catch up with their rent increases. However, it is extremely difficult for participants to find a new place to live because of their limited income. Thus, they are faced with the choice of inventing strategies to keep paying for their current residence or living on the streets, which is not an acceptable choice. The ideal solution is living in government sponsored housing, but this is not always easy to get. One participant states:

We are expecting a change in the rent. We were told that they will raise the rent. We pay $400 for a studio and we get $600 (from SSI). How much left we will have? Do you know what I was told by an employee in our building office? "Be getting ready with your cart" like those people on the streets. Very cruel comment.

In order to avoid being homeless, many participants developed creative strategies to survive. One woman, who is sharing a two-bedroom apartment with a non-kin person, decided to have a third person move in, in order to deal with a $100 rent increase. She and her roommate decided to make a two-bedroom apartment into three bedrooms by using a separator to divide one room into two rooms. Another strategy participants use is to contain spending on food. Saving money on food, however, can result in not having an

adequate diet to maintain their health conditions. A statement made by a female

participant demonstrates this point.

My diet is expensive too. Since I didn't have money I was having rice and beans but the doctor asked me "N what are you eating?" I said, "the same you told to eat" but he said "No, no N, you are not. You know you have to have at least three ounces of meat, fruit and vegetable." How do you think I will afford that diet?

Another way this participant saves money is by isolating herself from her extended

family members who live away from her. Since money goes to food, rent, utilities, and

medication, she cannot spend money to phone her family. Although her extended family

members live in Mexico and the West Coast, she cannot call them because she cannot

afford to pay for long-distance calls.

I don't call them because it is too expensive. Don't call me and I am not going to call you because this month I will pay $34 for two calls I made to NY and another one to Mexico. I said this month I am not going to call to anybody.

Money and Health Care

In these hard financial situations, Medicare and Medicaid are important financial

resources for study participants to access costly medical service. Additionally, access to

medical services is important to maintain their independent living, which will be

discussed in a later chapter. Medication takes a large portion of their expenses because

Medicare did not offer prescription drug benefits when interviews were being conducted.

Yet, participants are often aware that they cannot miss their medication despite the cost.

Look how many we have bought. We have $10 here and more here. They are very expensive. I am crazy, Chica, imagine this. I should have a better life now that I don't have so many debts, I should have some money in my saving and I can't because all my money is going into medicines and more medicines.

However, the stories are different for the ten uninsured participants. These people do not

have any health care coverage because either they are under 65 years old or they have not

lived in the U.S. long enough to qualify for Medicaid. These people often wait to see

physicians until they are brought to emergency care. They also skip medications due to

the inaffordability. For example, one woman who has diabetes and hypertension did not

take her medications for hypertension for two weeks because she could not buy them,

resulting in further crisis in her illnesses later on. People often tried to control their

illnesses with alternative medications.

In order to live and have medical care services, study participants want to work.

By working, they will have money to purchase medical care services, medications, and

food. However, their illnesses prevent them from work. In fact, many study participants

perceive that their limited English language ability is a less serious barrier for them in

finding a job when compared to their health problems because they are looking for an

unskilled job within the Spanish-speaking community. For instance, a 65 year-old man

immigrated to the U.S. four years ago and is receiving some support from welfare to pay

his rent, which is not enough for him to live on. He describes his desire to work to support

himself and his difficulty in finding a job because of his physical problem as follows:

Yes, it is about three hundred dollars. It is a kind of pension like and emergency help. It is little and is not enough to rent a room. One room costs $250 or $300. And right now, they [the government] say that they are going to take that support away, you cannot imagine how I am feeling. I would like to work but due to the pain that I have in my back I cannot work. I can wash, clean. I have the desire of working but I know that if I go to work I will get worse and I will have to take three times the quantity of medicine I am taking now to feel a little bit better of my bones.

Financial Assistance

Despite their hardship, participants tend to appreciate the U.S. government for giving them financial help, which includes SSI, Medicare, and Medicaid. Some participants also receive General Assistance. These formal assistance programs are not available in their countries of origin. One woman expresses her appreciation to what she receives from the U.S. government as follows:

I am not complaining about this country. Thanks to God we worked here, and now, they are helping us because in our countries we don't have this kind of help. If you want to eat you have to work or live on the streets. That is why I thank God every day.

"Help" or "assistance" from formal institutions, particularly the government, means financial assistance. Financial assistance makes it possible for them to get medical care and to make ends meet. An 85 year old woman who migrated to the U.S. at the age of 55 elaborated how Medicare and Medicaid are her life-line because she and her husband cannot access medical services without them. In their countries, they would be at risk of homelessness because they receive little help from their adult children.

I feel happy. Look, first of all, if I were in my country, I would have to work because over there I don't have anything to live out of. Here, I have my little money and I have a doctor, which is so important, at this age. I don't work and I have my doctor and my little money that they give me. Thanks. I don't tire of saying thanks to god for bringing me to this country. I am here, happy.

Lastly, financial help from the state provides not only a means to live but also a sense of independence. Facio (1996) describes that older Latino women get a sense of independence for the first time by receiving financial assistance from the state because they have some of their own money that is not from her husband.

Well because I don't depend on my daughters or anyone so I am an independent woman. Just for my check (laugh)………I depend only on it (Social Security). When I want to go outside, I don't ask to anyone. My husband was the only one and now he is dead.

62

It is not clear whether their appreciation of the U.S. should be viewed as proof that the U.S. is providing good care for older immigrant populations. Instead, I think that this appreciation comes from their lack of knowledge about what is available to them and their low expectations of government. This is because their expectations are set through the years of socialization in their old countries, which do not offer any help for the elderly population. In addition, not all participants are grateful to the U.S. government. For instance, the youngest participant in the study who is in her mid 50s and has an elder mother living with her voices discontent. Her evaluation of the U.S. government and society is based on her observations of her mother and other elders in the center as a coordinator at the center.

I have noticed that among the seniors in this center. "Where will I go? How can I become a citizen?" There are solutions but they are so worried that they don't see the solution. The other problem with them is that they are being exploited. If they are renting a room they can't take a shower everyday, they can't cook or use the fridge. They are victims in this country. Then the landlord evicted these people because they can't pay the rent. They don't have money because the program for legal resident is changing. They are forced to become U.S. citizen or lose everything. It is a chain of problems that the senior is carrying. Maybe behind that senior there is a family but they don't want to carry with that responsibility. That is hard. But don't you think that the seniors have already invested their efforts, and time raising their families? At this time they should be getting the benefits from that.

The financial condition of those who have support from adult children is better than those who do not. However, they and their children are still struggling to make ends meet. However, mutual support among family members makes their situation better. Mutual support is an important aspect of familism that is a traditional cultural value among Latinos. Familism promotes a moral obligation to support family members. Mutual support benefits both older Latinos and their adult children.

In some cases, older Latino parents and their children share households to help each other financially. By living together, adult children and elderly parents support each other emotionally, instrumentally, and financially. A 76 year-old man shares a house with his spouse and two adult children's' families. It helps both sides financially and instrumentally. He picks up his two grandchildren every day, which helps his adult children financially because they can focus on working.

We [family] are very united. We are renting one house together. We pay $1025 for a four-bedroom house. We share the bills. I don't pay for the phone because I don't use the phone. My daughter pays $410, I pay the same; the only one who pays $205, she is single and she has two kids. Her salary is about $2,000. She makes more money but she is single. But she helps her mother at home.

Some participants receive support from adult children who do not live with them. This form of help is done through gifts or paying for medication. A 74 year-old woman who has lived in the U.S. for 53 years and is living with a child receives financial support from her adult children who do not live with her. The children get together to contribute money in order to buy her furniture and medications.

5.3. Family relationships

The Latino culture of familism provides a strong sense of filial obligation (Johnson et al., 1997). Latinos often expect their children to provide both financial and emotional support, especially during a time of illness. Latino elderly feel disrespected when this expectation is not fulfilled by family members (Facio 1996:79). The concept of respect (`respeto') for people by the virtue of age, experience, or service is important in Latino culture (Beyene, Becker, & Mayen 2002). Beyene, Becker, and Mayen (2002) describe the status of older Latinos as, "[elders] generally occupy a highly respected and

secure role within Latino family support systems. Latino elderly continue to be highly valued for their role and function as well as their ability to contribute their knowledge and experience to their society. In contemporary Latino culture, it is still common practice to seek out the elderly for advice in matters such as child-rearing and family relations (Beyene, Becker, & Mayen 2002). Thus, older Latinos expect not only emotional and instrumental assistance from their children, but also a culturally proper place within the family as a way to show them respect. Furthermore, Latinos give more value to the feeling being emotionally connected to their family than to being financial supported. Perceived closeness with adult children is viewed as important for older Latinos (Becker et al., 2003).

The familial situation in this study is mixed. In some participants' families, familism is a defining characteristic, upon which intergenerational mutual assistance is active. The participants from this type of family receive emotional, instrumental, and financial support from family members, particularly from adult children. On the other hand, some participants have little help from family members. These participants feel that they are left behind by children who are Americanized. Other participants receive some level of supports, including financial, instrumental, and emotional ones. Nonetheless, they are not fully satisfied with the level of support they receive, and they feel disrespected.

In the families in which intergenerational support is actively exchanged, older Latinos receive a good deal of emotional and instrumental support from their extended family members, particularly adult children and grandchildren. The support is provided both in cases where elderly are living with children and where they are not. When older Latinos live with extended family members, he/she receives financial, instrumental, and emotional support within the household. A 79 year old man's statement characterizes this

65

type of relationship. He said, *"I feel relax. I don't worry for anything; my family gives me everything. Shoes, clothes, food, and shelter."*

Some participants live alone or with a non-kin person, but are still satisfied with the support they receive from family members. In this case, family members often live near by and they visit and call frequently to see if their mother/father/ grandmother/grandfather is doing okay. Family members visit them, take them out to entertain them, or communicate with them regularly. Moreover, older Latinos feel confident because they are sure that their family members will be there when they need help. Family members provide transportation when they go out, such as to doctor visits or doing errands. When they have difficulties doing house chores due to their illnesses, family members come to clean the house, cook for them, and do other household chores. They are satisfied with the affection and respect they receive from their family members on the basis of their culture.

Other older Latinos in this study receive some kinds of instrumental support from family members, particularly adult children, but not enough or as much as they expect. Their children support them in certain ways, such as taking them to the hospital or doing errands. Their adult children come once in a while to help them, and provide assistance by, for instance, writing checks for them. However, they are not satisfied with the treatment they receive from their family members.

In addition, there are some participants who are completely isolated from their extended families. In some cases, participants' extended family members live away from them. Other participants are ignored despite living close to their family members. They attribute their isolation and the lack of support from children to their children's economic hardship and the U.S. culture. They are aware of their children's economic hardship and

the obligation to raise their own family. A 72 year-old woman describes a financial

hardship both she and her son are facing, and the consequently limited communication

between them, as follows:

I told him, don't call me every day on the phone, not even one day yes and one day no, call me every three days. Because the job that he has pays him so little that he does not have money to pay rent, he pays $500 for the little apartment, only one room. And he can't be paying so much money to call me, only to ask me how I'm doing. If I feel sick, I told him, because I have cut the phone, the long distance.

Additionally, the U.S. culture gives more value to material success and money

than family unity and the elderly. One participant compared the U.S. to her country of

origin as follows:

Family and neighbors treat you with dignity (in her home country) but in this country (the U.S.) people say, "Feed her anything because she doesn't even know who she is." On the other hand, in your country (her home country) family feed you with chicken soup, oatmeal but in this country life is money.

In the eyes of older Latinos who feel isolation from their family members, the elderly are

disrespected in the U.S., and the U.S. is a sad place to be old. Moreover, people are too

busy to take care of their older family members because of their work and their own

family obligations. Participants understand that everybody is struggling to fulfill their

multiple obligations. Everybody has to work in order to pay rent and utilities, to raise their

family, and to educate their kids. Consequently, children cannot think about their older

family members. Furthermore, younger people think that older parents are fine because

they receive help from the government through Social Security and health care insurances

(Medicare and Medicaid).

These participants, who do not have enough instrumental and emotional assistance

from adult children, often developed alternative support networks with friends. However,

in general, older Latinos cannot fully provide for each other because of their own physical

conditions. Although they cannot provide enough instrumental support for each other, friends provide emotional support by visiting and calling during a friend's illness (Facio 1996:82). Even though they have developed alternative support among elderly friends, those who do not have enough family assistance often fear becoming severely disabled and being unable to do household chores because they do not want to go to a "rest home" or nursing home.

In this section, I introduced how participants of the study live in order to provide a picture of who they are and what their living conditions are like. In general, they are struggling to live in the community. Some people are struggling with their family, while others are struggling by themselves without family help. For those who do not have enough family support, the situation is harder than for those who have family support. With these pictures of their lives in mind, I will now describe the issues around accessing social resources.

Chapter 6: the use of HCBS from the expanded
behavioral model for vulnerable population

This chapter examines access to Home and Community-Based services (HCBS) within the framework of the expanded behavioral model for vulnerable population, using quantitative methods.   This section analyses 85 participants.

6.1. Variables

Dependent variables

Five services are measured in this chapter including: 1.) personal care; 2.) home delivered meals; 3.) assistance with transportation; 4.) senior information referrals, and; 5.) senior centers. The interviewer asked each participant whether they use these five community services. Although respite care was included, no participants used this service. Therefore, respite care was excluded from the analysis. Similarly, hospital-related services (e.g. home health, outpatient rehabilitation therapy, and adult-day health) were excluded from this analysis because only 6 participants used these services.

The five services are computed to three types of services based on their service and eligibility characteristics including: 1.) personal care; 2.) county-provided services, and; 3.) senior center. Personal care provides personal assistance and this category is not combined with other services. County-provided services consist of home delivered meals, assistance with transportation, and senior information referrals. Senior center is also not combined with other categories.

I categorize services in this way because different factors influence utilization behavior based on "the discretionally characteristics" (Mitchell and Krout, 1998:159) of services. "Discretionally characteristics" (Mitchell and Krout, 1998:159) refers to

69

eligibility and the characteristics of services. Service use may be facilitated or hindered

by these factors. For instance, use of home health or rehabilitative services may be

motivated by different factors from personal care services or delivered meal. Home

health or rehabilitative services need to be authorized by a doctor; therefore,

participants' physical functional ability may have significantly influenced their

eligibility. Furthermore, the recipient and his/her family members see few alternatives in

medical services. On the other hand, personal care assistance needs to be authorized by

a social worker, which also requires functional disability. However, a family can

provide alternative support if it is available (Mitchell and Krout, 1998). Moreover,

participation in a senior center often does not require any eligibility and anybody can

visit a center if they want to. Therefore, use of personal care services and participation

in a senior center may be motivated by different factors.

Personal care services: The first service is personal care service, which is not

combined with other services. Personal care services provide personal assistance for low-

income people with a physical disability, and service includes assistance with the ADLs

and the IADLs. A personal care service often provides assistance with ambulation,

bathing and grooming, administration of medications, meal preparation, shopping, heavy

cleaning, accompaniment to medical appointments, routine laundry, and other errands.

Personal care service requires an individual to meet strict eligibility criteria for Social

Security Income/State Supplementary Payment (SSI/SSP) and Medicaid physical

functional disability.

County-provided services: The second category is county-provided services,

which consist of home delivered meal, assistance with transportation, and senior

information referrals. These services are provided by Local Area Agencies on Aging and

70

have less strict eligibility criteria than personal care services. Therefore, it is easier for the elderly to access to these services.

Senior centers: The third category is senior centers, which usually has no eligibility requirements to participate. Therefore, accessing a senior center is the easiest activity for elderly persons. Moreover, it usually requires a relatively good health status to participate in the various activities and to get to a senior center. If an individual cannot get to a senior center by himself/herself, he/she needs to be assisted with transportation.

The three categories consist of the following values. Personal care is a dichotomous variable, 0 (no use) and 1 (use). County-provided services is also a dichotomous variable, 0 (no use) and 1 (use). Senor center is a dichotomous variable, 0 (no use) and 1 (use).

Independent variables

The independent variables used in this section are limited due to the lack of measurements. The independent variables are organized based on the expanded behavioral model, including the predisposing domain, enabling domain, and need domain.

Predisposing domain: The predisposing domain is measured by demographics and structural factors. It also includes variables from the vulnerable domain. Demographic variables include *age* and *gender*. Variables that measure structural factors include *previous occupation* and *education*. *Previous occupation* refers to the participant's occupation before retirement, which are ranked from 1 to 9 using the Hollingshead Social Index. The scale consists of farm/menial labor (=1), unskilled labor/homemaker (=2), machine operator/semiskilled labor (=3), skilled manual (=4), sales/clerical worker (=5), technical worker/semiprofessional (=6), business manager/minor professional (=7),

71

administrator (=8), and higher executive/major professional (=9). For the analysis, these nine scales are combined into three scales (0 to 3) because each scale consists of a small sample size. The three scales consist of farm/menial/unskilled labor or home maker (=0), machine operator/semiskilled or skilled laborer (=1), and sales/clerical/technical/semiprofessional/business manager/ minor professional/ administrative worker (=2). *The education* scale consists of 0 (= no education and grade school education), 1 (= high school education), and 2 (= college education).

Vulnerability factors in the predisposing domain *are immigration status* and *level of acculturation*. *Immigration status* consists of permanent resident (=0) and citizen (=1). Although the initial survey included an unknown status, this category is excluded from the analysis because only 5 participants belong to this category. Unknown status is a self-reported status by the participant, and they chose this category because they did not want to answer or were not sure about their status. It can also include illegal immigrants, although, I cannot validate whether or not these participants are illegal or legal immigrants. *Level of acculturation* is measured by the years lived in the US. Although English language ability is a measurement of acculturation, I do not include this variable because only two participants are bilingual. Psychological resources and health beliefs cannot be included in the statistical analysis because of a lack of measurements.

Enabling domain: The enabling domain in this study examines the influence of the participants' abilities to access Home and Community-Based services (HCBS). Participants' abilities to access HCBS are measured by *insurance status* and *availability of social network*. In addition, *recipient of public benefit* is included to measure the influence of this vulnerability factor in the enabling domain.

Insurance status is important to access personal care services because Medicare and Medicaid pay the cost of these services. For instance, In-Home Supportive Service (IHSS) is covered by Medicaid with the exception of a Residual program. Medicaid eligibility is the first step to get this service. Furthermore, being eligible for Medicaid indicates that the person is a recipient of public benefits, which is an indicator of respondents' access to some social resources that leads them to further services. *Insurance status* is a dichotomous variable, consisting uninsured (=0) and insured (=1), which includes Medicaid, Medicare, and private insurance. Those who have private insurance are combined with those who have Medicare or Medicaid because only 4 participants have private insurance.

The availability of a social network is considered as a measure of knowledge about service. This is based on the literature that discusses how social networks bring people information about services. At the same time, a social network itself is an important resource because it helps people organize services. Social networks are measured by *living arrangements*, *marital status*, *the frequency of informal socialization*, and *church attendance*. *Living arrangement* consists of not living with family members (=0) and living with family members (=1). *Marital status* includes married (=1) and unmarried (=0), which includes widow and divorced. *The frequency of informal socialization* and *church attendance* are measured by the frequency an individual participates in these activities during a month. The frequency of informal socialization ranges from 0 to 30. Thirty means that the participant engages in informal socialization almost everyday during a month. The church attendance ranges from 0 to 20. Twenty indicates that a participant participates in church activities 20 times a month.

Recipient of public benefit is a vulnerability factor of the enabling domain, and it

refers to whether individuals receive Supplemental Security Income (SSI) or GA.

Receiving these welfare benefits indicates that they have an opportunity to access some

social resources (e.g., social worker), which brings them Medicaid and financial

assistance. Recipients of public benefits consist of non-receiver (=0) and recipients of SSI

or GA (=1).

Some variables of the enabling domain cannot be measured by statistical

procedures because of a lack of adequate measurements. These variables are perceived

barriers, availability of transportation, competing needs, self-help skills, and ability to

negotiate within the system. These variables will be examined using narrative analysis in

the next chapter.

Need domain: The need domain is measured by *the ADLs* (Katz, et al, 1963), *the*

IADLs (Lawton & Brody 1969), *the Self-Reported Health* (Idler, Hudson, Leventhal,

1999), *the Barthel Index Score* (Mahoney & Barthel 1965), and *the Interviewer's Overall*

Assessment. The respondents reported on their functional health status, using *the ADLs*,

the IADLs, *the Self-Reported Health*, and *the Barthel Index Score*. *The ADLs* (Katz et al,

1963) contain 6 items, which are eating, getting out of bed or a chair, walking around the

house, toileting, dressing, and bathing. Each activity is scored yes (1) or no (0) and is

computed to a scale ranging from lowest function (0) to highest function (6). *The IADLs*

(Lawton & Brody 1969) contains 9 items that measure the ability to perform activities.

The scale includes preparing meals, doing laundry, doing light household chores, going

grocery shopping, managing money, taking medicine, making telephone calls, driving,

and taking public transportation. Each item is scored as yes (1) or no (0). The computed

score ranges lowest (0) to highest (9). The higher score represents better functioning.

Self-Reported Health (Idler, Hudson, Leventhal, 1999) is a single item with possible

responses ranging from poor health (=1) to excellent health (=4). *The Barthel Index*

(Mahoney & Barthel 1965) measures the ability to move around the house and do daily

routines independently. The activities include eating, bathing, toileting, dressing,

relieving bowel and bladder, getting out of bed or a chair, ambulation, and climbing stairs.

The score consists of increments of 5 points, for a total possible score of 100. A higher

score represents better functioning. *The Interviewer's Overall Assessment* is rated by the

interviewer's personal observation and is a single item created for this study, with scores

ranging from low (= 0) to high (= 3). A higher score represents better functioning.

6.2. Statistical procedures

First, descriptive statistics are conducted in order to show the characteristics of

this study's participants. Then, each dependent variable is tested using correlation

analysis separately in order to see if there is an association between each independent and

dependent variable.

6.3. Results

Descriptive statistics

This section analyses 85 participants to find the overall utilization behavior of

these study participants. The descriptive statistics are shown in Table 1.

Service use: Fifteen people (18%) use personal care services. Seventeen (19%)

people use county-provided services. Fifty-seven people (67%) participate in a senior

center.

Predisposing domain: Participants' ages ranges from 51 to 97 and the mean age is 72.78. Sixty four of the participants (75%) are female. In terms of social structure, the majority (50%) have an educational level of grade school or less. Twenty-nine percent have a high school education, and twelve percent have a college education. In terms of previous occupation, sixty percent of the participants worked as farm worker, unskilled laborer, or homemaker. Twenty-four percent of the participants were skilled laborers and 16% were clerical workers, sales workers, and/or administrative or technical workers. The length of time in the U.S. ranges from 0 to 76 years. Forty-six people (55%) are permanent residents and 33 participants (39%) are citizens. Five participants (6%) are of unknown status.

Enabling domain: The majority of participants (42%) have both Medicare and Medicaid. Fourteen percent have Medicaid only and eleven percent have Medicare only. Five percent have private insurance and twelve percent are uninsured. The majority of participants (73%) receive SSI or General Assistance. The frequency of informal socialization ranges from 0 to 30 and the mean score is 7.42 times per month. The frequency of church attendance ranges 0 to 20 and the mean score is 3.39. The majority of participants (78%) are unmarried, including individuals who are widowed, divorced, or separated. Fifty-seven percent of study participants live with family members and the rest either live alone (31%) or live with non-kin persons (13%).

Need domain: Participants have a wide range of functional health scores. The IADL scores ranges from 0 to 9 and the mean score is 7.78. The ADL scores range from 5 to 6 and the mean score is 5.94. Interviewer's overall assessment consists of 22.4% at low functioning, 63.5% at moderately functioning, and 14.1% at highly functioning. The Barthel Index ranges from 15 to 100, and the mean score is 95.38. The participant's self-

reported health status varies. Almost 13 percent (12.9) reported their health status as poor

and 23.5% reported as fair. The majority consider their health as good (36.5%) or

excellent (27.1%).

Table 1. Descriptive statistics (n = 85)

Characteristics	n	%
Dependent variables		
Personal care service	15	18
County-provided services	17	20
Senior center	57	67
Predisposing domain		
Demography		
Age		
Age range	51 – 97	
Mean age	72.78	
Gender		
Women	64	75
Men	21	25
Social structure		
Education		
Grade school or less	50	59
High school	25	29
College education	10	12
Current & Previous Occupation		
Administrative/professional/semiprofessional/ technical /clerical/sales	14	17
Machine operator/semiskilled or skilled labor	20	24
Farm/menial/unskilled labor/homemaker	51	60
Vulnerable domain (level of acculturation)		
Years live in the US		
Mean	28.26	
Range	0 – 76	
Status		
Permanent resident	46	55
Citizen	33	39
Unknown	5	6
English language ability		
Spanish only	83	98

Table 1. Descriptive statistics (n = 85)

Characteristics	N	%
Enabling domain		
Financial ability		
Health Insurance		
Medicare & Medicaid	50	59
Medicaid	12	14
Uninsured	10	12
Medicare	9	11
Private/HMO	4	5
Recipient SSI/GA (receiving SSI/GA)	58	73
Social network		
Frequency of informal socialization		
Mean	7.42	
Range	0 – 30	
Church attendance		
Mean	3.39	
Range	0 – 20	
Married	19	22
Live with family members	48	57
Live alone	26	31
Live with non-kin persons	11	13
Need domain		
IADL		
Mean	7.89	
Range	0 – 9	
ADL		
Mean	5.94	
Range	5 – 6	
Barthel Index Score		
Mean	95.38	
Range	15 – 100	
Self-reported health		
Poor	11	12.9
Fair	20	23.5
Good	31	36.5
Excellent	23	27.1
Interviewer's assessed health		
Low functioning	19	22.4
Moderately functional	54	63.5
Highly functional	12	14.1

Table 2: Correlation analysis

	Personal care services	County-provided services	Senior center
Age	.316*	.158	.168
Gender	-.265*	-.014	.053
Education	-.042	-.042	-.042
Current & previous occupation	-.019	-.128	-.171
Years live in the US	.085	.122	-.298**
Insurance status (insured or uninsured)	.169	.091	.133
Immigration status (Citizen or permanent resident)	.113	-.108	.266*
Recipient of public benefit	.129	-.001	.391
Frequency of informal socializing	.285*	.151	.091
Frequency of family exclusion	-.120	-.037	-.031
Church attendance	-.131	-.169	.079
Marital status	-.248*	-.127	-.165
Live with family members	-.341**	-.036	-.161
The IADLs	-.229*	-.348**	.347**
The ADLs	.116	-.125	.038
The Barthel Index Score	-.008	-.030	.269*
Self-reported health	.011	.143	-.032
Interviewer's assessed health	.115	.167	.029

$* = < .05$ $** = < .01$

Association between service use and the behavioral model

The result of the correlation analysis is shown in table 2.

Personal care service: The correlation analysis indicates that gender, marital status, living arrangement, frequency of informal socializing, age, and the IADLs have a statistically significant relationship with use of personal care service. Female participants are more likely to use personal care and a higher age predicts more personal care service use. This finding may reflect the larger portion of females in this study. Lower IADL scores are associated with more personal care service use. In addition, there is a negative association between marital status and living arrangements, indicating that those who live alone are more likely to depend on personal care service. In addition, there is a positive association between service use and the frequency of informal socializing, which indicates that those who have more contacts with their friends and neighbors have better access to personal care service.

County-provided services: County-provided services include home delivered meals, assistance with transportation, and senior information referrals. The correlation analysis indicates that only IADLs have a statistically significant relationship with the use of country-provided services. This result indicates that those who are experiencing a declining health status seek some kind of assistance, to compensate for their declining ability to cook with delivered meals, seek more resources to get by, or go to medical appointments with transportation services.

Senior Center: The correlation analysis indicates a significant relationship between participation in a senior center and the length of time living in the U.S., immigration status, recipient of welfare benefit, the IADLs, and the Barthel Index Score. Unlike other services, there is a positive association between center participation and functional health

status. Therefore, people who have better physical functional ability are more likely to participate in senior centers.

<center>6.4. Discussion</center>

The results show that use of these three types of services varies based on the characteristics of the services.

Personal care service: Fifteen participants use personal care service. The results show that these people tend to have difficulties in performing the IADLs, are living alone or with non-kin person, and frequently socialize informally. In other words, it may be that important factors are actual disability in the IADLs, perceived need due to lack of family support, and having contacts with friends or neighbors as information resources. Perceived need and availability of informal support network influences service use and these two factors may be related. This result is consistent with the study done by Starrett, Mindel, and Wright (1983). Their study suggests that a person who lives alone, visits frequently with kin, friends and neighbors, and participates in senior centers or churches is more likely to use formal support services (Starrett, Mindel, & Wright 1983). This is because they may perceive needs with assistance in household chores, such as cooking, laundry, grocery shopping, and other errands when their functional ability declines. They seek assistance through formal support systems because family care is not available . The positive association with frequent informal socialization indicates that their friends or neighbors may bring them information about services. The frequency of church attendance, which does not have a significant relationship, may be attributed to declining health status. Once their health began to decline, they may feel too tired to participate in

<center>82</center>

church activities. Therefore, this does not accurately measure the degree of their social support networks.

At the same time, this result implies that those who live with family are cared for by family members, which is consistent with previous studies that contend both Latino elderly and family members prefer family care to formal support (Andersen, Giachello, & Aday 1986; Greene & Monahan 1984; O'Donnell 1989; Sotomayor & Randolph 1988; Purdy & Arguello 1992; Starrett, Mindel, & Wright 1983; Cox & Gelfand 1987). Furthermore, this result raises a concern about those who have less informal support from family or friends and have little information about services. This is because these people may be left alone without any means to cope with declining functional ability when they begin to have difficulties performing the ADLs and the IADLs.

County-provided services, includes home delivered meals, assistance with transportation, and senior information referral. Only the IADLs had a significant relationship with these services. This result may indicate that those who begin to experience a decline in their physical functional ability try to compensate for their disabilities in using social resources. Although no other variables show a significant relationship with the services, it is important to examine how other variables influence service use with the qualitative analysis.

In terms of senior centers, the results imply that participation in a senior center requires better health and those who lived in the U.S. for less time tend to use centers in order to seek more social resources, such as Medicaid and SSI. A positive association between the IADLs and the Barthel Index suggests the importance of better functional ability to participate in a senior center . Many participants in the study walk to senior centers. Therefore, declining health prevents them from going to the senior center. A

negative association between participation and years living in the U.S. suggests that those who have lived in the U.S. for less time may be more likely to participate in senior centers in order to seek out social resources and friendship. This is because they tend to have fewer resources and are less acculturated to the U.S. society. Moreover, senior centers may be easier for them to come to because this service does not have any eligibility requirements or complex knowledge for participation. Centers in this study provide services for a Spanish-speaking population. There is a significant relationship between immigration status and participation in a senior center, which indicates that those who are citizens are more likely to participate in a senior center than those who are permanent residents. It may be contradictory that those who have lived in the U.S. for a shorter period of time are more likely to participate in senior centers than those who have lived in the U.S. for a longer period. However, the length of time in the U.S. does not always indicate the likelihood of being a citizen in this study sample. It is not clear why those who are citizens are more likely to come to senior centers. One possible reason may be that these people may obtain citizenship with the assistance of senior center personnel, who may assist them with paper work for the citizenship application. Moreover, senior centers often provide classes for the citizenship test.

In general, health status seems to be a significant factor in the use of all three categories of services, which includes personal care services, county-provided services, and senior centers. This is because the variables that measure physical functional ability have a significant relationship with service use in all areas. However, it is not clear whether other variables are less important because of the small sample size. In addition, it is not clear whether the frequency of informal socializing indicates more knowledge or awareness of available services. These two points will be examined with the qualitative

analysis in the next section.   In the next chapter, I will analyze the differences between service users and non-users qualitatively in order to see: 1.) if non-users are really healthier than service users; 2.) how those who do not have informal help from family and friends live without any assistance, and; 3.) if there are other factors that prevent or facilitate service use.

Chapter 7: Familism, life experience, and ability to access to social resources

<u>7.1. Introduction</u>

In the next two chapters, I compare service users and non-users in order to see: 1.) if non-users are really healthier than service users; 2.) how those who do not have informal help from family and friends live without any less assistances, and; 3.) if there are other factors that prevent or facilitate service use. Thus, I limit my analysis to 34 key participants in order to compare the differences between service users and non-users. Within the 34 participants, twenty participants use some kind of service. I selected the rest of the 14 participants based on their life stories from the in-depth interviews. In-depth interviews with these 14 participants indicated that they cannot access services despite their perceived need for assistance in order to maintain independent living in their community. These thirty-four participants are further divided into three groups, which consist of: 1.) participants with formal and family support; 2.) participants with formal support only, and; 3.) participants with low support.

A selection criterion of the first two groups (the participants with formal and family support) is using some formal services, which include personal care, meal delivery, housing assistance, transportation service, and financial assistances. The Participation in senior center is not included for this selection process. Then, these service users are further divided into two groups based on the availability of family support. The selection criterion of the third group (participants with low support) is based on the desire to get assistance from formal organizations. These people mainly express their needs of personal care service and housing assistance, and I select these people as the third group.

 I extend the dependent variables of Home and Community-Based service (HCBS) to various social resources, such as housing and financial assistances that are provided by

various organizations (i.e., church and the government). These services are necessary for the elderly to manage their daily problems caused by health problems. Some participants deal with not only health-related problems, but also housing and financial problems. For these people, HCBS is not the primary issue, as housing and financial problems are more immediate impediments to maintaining independent living in their own community. Moreover, those who access HCBS often actively sought other services, while those who cannot access HCBS often struggle to receive other services, such as financial and housing services. Comparing service users and non-users may help us gain a more detailed understanding of the factors that facilitate or prevent service use.

In this section, I will discuss how older Latinos' access to social resources is influenced by their life experiences, which have contributed to their ability to deal with the U.S. welfare system. More specifically, I will argue that access to social resources is influenced by factors proposed by previous studies, including availability of financial resources, knowledge and awareness of services, language barriers and lack of bicultural/bilingual service providers, and the lack of access to services (e.g., transportation). But, significantly, their access is also influenced by their ability to deal with formal organizations of the U.S. mainstream society. The ability is largely determined by their relationship with family, their expectations of family members, and their habitus, which I introduced in the theory section. Both expectations of family members and habitus are shaped throughout life, both before and after immigration to the U.S.. Furthermore, their habitus, which shapes their life experiences, is largely influenced by political, economic, and socio-cultural forces. The purpose of this chapter is to explore other factors that may contribute to some Latinos' inability to access social resources.

7.2. Selecting focused participants

Thirty-four participants were selected through intensive analysis of the in-depth interviews. The rest of the 51 participants are excluded from this qualitative analysis because their perceived need for assistances in their daily living is low. Although these 51 participants have some functional disabilities and face financial and housing problems, they evaluate their conditions as "no-need for assistance" and they perform their daily chores. Also, some participants are well cared for by adult children. I evaluate the 34 participants who need assistance in order to avoid institutionalization. These thirty-four participants are further divided into three groups, which consists of: 1.) participants with formal and family support; 2.) participants with formal support only, and; 3.) participants with low support.

I categorize these 34 participants based on their life stories told in in-depth interviews. The in-depth interviews with the participants tell us about their perceived difficulties managing their daily routine, the perceived severity of pain, and their descriptions of managing household chores, such as cooking and going groceries. These stories indicate that they have difficulty maintaining a stable life by themselves. Although most participants are trying to maintain their independent living in their own community, I see risks associated with having a more severe health problem, such as a fall, due to their declining functional ability and lack of assistance. Additionally, some participants are facing immediate problems as they continue to live in the community. It is important to stress that this categorization cannot be validated objectively because this is a subjective categorization for exploratory purposes.

The first group, <u>participants with formal and family support</u>, consists of 11 participants (32%). These participants live with a combination of family and formal

assistance. Ten participants use multiple services. The most used service is a personal

care service through Medicaid HCBS and 9 participants use this service. Four

participants use hospital-related services, such as outpatient rehab and home health. Four

participants use a meal delivery service in addition to personal care services. Three

participants use transportation services, in addition to personal care service.

The second group, <u>participants with formal support only</u>, consists of 9 participants

(27%). They have less family support, but use formal long-term care services in order to

compensate for their functional disabilities. For instance, six participants use personal

care services and three participants use community-based services. Three participants use

multiple services, such as a combination of personal care and transportation services.

Two participants who received no services at the first interview were included in this

group because they have access to formal services. These two participants were offered a

personal care service by their social worker several times and they also received various

community services not included in quantitative measurements. These services include

government sponsored senior housing and cash assistance.

Fourteen participants (41%) – <u>the participants with low support</u> – are included in

the third group. These are participants with less formal and family support. These

participants have less support despite their functional disability and hardship in managing

several daily activities. Only two participants receive formal services. One participant

receives referral services, and another receives both referral and home health services.

However, they are included in this group because they do not receive other necessary

assistances, such as personal care and/or cash assistance.

7.3. The differences and similarities: statistical analysis

Before discussing the findings from the narrative analysis, I first introduce differences and similarities using quantitative methods. This step is necessary for me to show whether there are statistically significant differences between service users and non-users, in terms of financial status, health status, the availability of informal social networks, all of which are shown as significant factors in the previous chapter. As the sample size is very small, the statistical results of this section may not be valid. However, it may give us a certain idea about how service users differ from non-users from the standpoint of the behavioral model.

Statistical procedures

One-way ANOVA (analysis of variance) are conducted in order to see differences among three groups, in terms of age, the ADLs, the IADLs, the Barthel Index Score, frequency of informal socializing, and frequency of church attendance. One-way ANOVA is employed because these variables are scales.

Chi-square analyses are conducted in order to see group differences in gender, educational level, previous occupational status, immigration status, the length of time living in the U.S., marital status, and living arrangement. Educational level is computed into dichotomous variables of grade school/less (0) and high school/college education (1) because each value contains a small number. Similarly, years living in the U.S. is computed into a dichotomous variable of less than 20 years (0) or more than 20 years (1). Additionally, medical insurance status is recorded into three values, which include Medicare/Medicaid (2), uninsured (0), and private insurance (1).

90

Results

One-way ANOVA: Table 3 shows the means of the ADLs, the IADLs, the Barthel Index Score, frequency of informal socialization, and frequency of church attendance. One-way ANOVA analyses are conducted in order to see differences among the three groups in terms of age, the ADLs, the IADLs, Barthel Index Score, frequency of informal socializing, and frequencies of church attendance. Only the IADLs ($p = .00$) have a statistically significant difference at .05 level of error. The participants with family and formal supports tend to have lower IADL when compared to the participants from the other two groups. The mean IADL of the participants with formal and family supports is 5.09. On the other hand, the mean IADL of other two groups are 8.56 for the participants with formal support alone and 8.36 for the participants with low support. There are no statistically significant variations in the other variables.

Chi-square analyses: Table 4 shows the frequencies and percentages of age, gender, educational level, previous occupation, immigration status, years living in the U.S., health insurance status, recipient of SSI/GA, marital status, living arrangement, the interviewer's assessed health status, and the self-reported health. Chi-square analyses suggest that only insurance status has a statistically significant association with group variation ($p = .034$). Those who have formal services all have either Medicare or Medicaid, while 57% of participants with low support have either Medicare or Medicaid. Thus, the availability of Medicare or Medicaid can be considered as a significant predictor of formal service use.

Table 3. Mean of ANOVA analyses (n = 34)

Characteristics	The participants with formal & family support (n = 11)	The participants with formal support only (n = 9)	The participants with low support (n = 14)
IADL	5.09	8.56	8.36
ADL	6.00	6.00	5.93
Barthel Index	85.64	100	95.36
Informal socializing	9.60	11.44	7.08
Church attendance	1.55	2.78	3.69

Table 4. Descriptive statistics of Chi-Square analysis (n = 34)

Characteristics	The participants with formal & family support (n = 11)	The participants with formal support only (n = 9)	The participants with low support (n = 14)
Age			
Age range	69 – 94	72 – 81	65 – 95
Mean age	79.00	76.22	76.14
Gender			
Women (=1)	9 (82)	8 (89)	11 (79)
Men (=2)	2 (18)	1 (11)	3 (21)
Education	8 (73)	6 (67)	7 (50)
Grade school or less	3 (27)	3 (13)	7 (50)
High school/college education	0	2 (2)	0
Previous occupation			
Skilled labor	4 (40)	2 (22)	9 (64)
Farm/unskilled labor/homemaker	6 (60)	7 (78)	5 (36)
Immigration status			
Permanent resident	6 (60)	2 (22)	8 (57)
Citizen	4 (40)	7 (78)	5 (38)
Unknown	0 (0)	0	1 (7)
Years live in the US			
0 – 20	1 (9)	3 (33)	4 (28)
21 +	10 (90)	6 (67)	10 (71)
Health insurance status			
Medicare & Medicaid	11 (90)	9 (100)	8 (57)
Uninsured	0	0	3 (21)
Private/HMO	0	0	3 (21)
Recipient of SSI/GA (received)	7 (78)	9 (100)	8 (62)
Marital status			
Married	1 (9)	1 (11)	5 (64)
Living arrangement			
Live with family members	4 (36)	1 (11)	5 (36)
Live alone	5 (46)	7 (78)	7 (50)
Live with non-kin persons	2 (18)	1 (11)	2 (14)
Interviewer's assessed health			
Low functioning	1 (9)	1 (11)	4 (29)
Moderate functional	9 (82)	7 (78)	9 (64)
Highly functional	1 (9)	1 (11)	1 (7)
Self-reported health			
Poor	2 (18)	0	2 (14)
Fair	4 (36)	2 (22)	1 (7)
Good	4 (36)	3 (33)	5 (36)
Excellent	1 (9)	4 (44)	6 (43)

93

It is important to note that the results of this section cannot be validated because of the extremely small sample size. Thus, it is a shortcoming of the sample when I say that there are less characteristic differences among participants from three groups in terms of the ADLs, the Barthel Index Score, the years living in the US, recipient of SSI or General Assistance, marital status, frequency of informal socializing and church attendance, educational level, and previous occupational status. However, I use these statistics to give the reader an idea about how little discrepancies there are among these people.

7.4. Familism and expectations toward adult children

In this section, my focus is on how service users with family support access services because extended family plays a critical role in the organization of formal long-term care services and other formal assistances among older Latinos. The role of the family may be discussed in relation with familism, which is an important element for understanding the lives of older Latinos. As I have discussed in the chapter 3, the substantive issue of familism is a defining characteristics of Latino family structure (Sotomayor & Applewhite 1988; Aranda & Knight 1997). Familism is a cultural belief that values strong identification, attachment, and feelings of loyalty, reciprocity, and solidarity amongst members of the same extended family (Sabogal et al., 1987). This cultural belief is a basis for older Latinos to expect family members, particularly adult children, to provide emotional and instrumental support to them in their old age.

Given that the family is the essential unit for the study participants, their relationship with extended family members largely influences their ways of managing old age and illness as well as consequent declining physical functional ability. Thereby, family arrangements are instrumental to the arrangement of formal and informal long-

term care. Qualitative data suggests that the older Latino sample with family support

tends to depend on their family for illness management and modification of life style as

consequences of declining health. For instance, extended family members try to

compensate their older parent's inability to cook or clean by doing these tasks for him/her.

Extended family members try to accompany older parents to doctor appointments . In

addition, they try to arrange for various services, such as state funded HCBS, for when

their parents get older and they cannot provide full instrumental support. The older

Latinos with family support perceive these acts as love and rewards for being old. On the

other hand, those who have less family support need to make these efforts by themselves

in order to resolve their daily problems that result from declining physical functional

ability. Their ability to deal with problems seems to relate with the concept of familism,

which I will explain later in this section.

Family as a critical tool to deal with the system: people with family support

Nine participants have both family and formal support through which they

maintain their living conditions. Except for one participant, eight participants who have

both family and formal support use personal care services. While adult children and older

participants exercise the traditional culture of familism, they accommodate this culture to

the U.S. lifestyle. More specifically, adult children try to practice their cultural value in

many ways, such as visiting, giving rides, cleaning, cooking, and going grocery shopping.

They also try to give companionship to their elderly parent. Adult children help their

elderly parents as much as they can by providing instrumentals well as emotional support.

However, adult children are limited because of their financial condition, family

obligations, and work responsibilities. In addition, many adult children of the participants

95

began to form a nuclear family. Of the nine participants, three people live with adult children and one participant lives with a spouse. The rest of the five participants live alone or with a non-kin person. Thus, extended family members also utilize HCBS in order to compensate for what they cannot do.

Overall, the participants of this group have little knowledge about social services, including state-funded HCBS. The interviewer asked them about how they started to receive services, from where their services are provided, and how their services are paid. However, they could not answer these questions clearly. By analyzing the qualitative interviews, it may be that they have little knowledge about the services they receive because their adult children arranged for services for them. Because we did not collect data from adult children, we do not know if adult children actually organized services for them in order to reduce the burden of informal care. However, the interviews indicate that these participants receive a good amount of family support, while they also receive HCBS in order to support their daily routine.

For example, I will turn to a 73 year-old woman who came to the U.S. 46 years ago from Nicaragua. She is illiterate in both English and Spanish. She is even afraid to take a taxi by herself because of her lack of English language skills. She does not have Social Security because she was a homemaker. Thus, she relies on Supplemental Security Income (SSI) for her income. Because of her arthritis, she has difficulty doing activities, such as getting to the senior center. Although she lives alone, her sons live in the Bay Area and come to see her every morning in order to check if she is doing ok. Furthermore, her sons give her a ride to the center because her severe arthritis makes her walking difficult. Her two sons and daughter take turns helping their mother do daily activities.

"My kids were helping me. The first to come pass the vacuum, the other one do the dishes. It is nice that I feel okay about that".

However, this person's adult children cannot do everything for her because they live outside of San Francisco, have their own families, and are busy at work. Thus, they arranged for personal care service for her. She receives personal care service three times a week, for help with grocery shopping, cleaning, laundry, and cooking. She does not have a clear understanding of how the service was organized. She describes the process as follows:

"The doctor, specialist in bones (recommended her to have homemaker services) …. Because I couldn't get up I was like the dove I told you……". "It was the specialist in bones….. because I told …..my kids asked the specialist in bones and he did not know……no, I mean the cardiologist….after they ask to someone else and finally God help me with this doctor" .

It should be interpreted that her children looked for the "specialist in bones" because of their mother's severe arthritis and her difficulty doing many activities. It was not easy for them to find a specialist, but they did manage to find a specialist who recommended they have household help in order to reduce their mother's burden. Thus, her children talked with a social worker to organize the personal care service. This woman said in the interview that only her children know these details. She only knows that her doctor recommended she have help. Her sons actively sought the "specialist in bones," suggesting that this participant depended on her children for her illness management as well as for her doctor visits.

Another case similarly shows how services are arranged by family members. A 75 year-old woman who used to be an active volunteer at the Red Cross is now completely dependent on her granddaughter who comes almost every day to do her grandmother's household chores. In this case, the granddaughter gets paid for doing so. Despite this

participant's past volunteer activities in the Red Cross, she still did not know what personal care service or formal services that she uses to provide help with doing household chores.

I: Have you started to use community service?
P: How? I don't understand.
I: For example, have you started to use cleaning house services or…
P: My granddaughter is cleaning my place. She is paid for doing that.
I: Okay, who pays her? The social service?
P: I don't know but she gets her check.

This sentence shows that she does not know about "community service" or "long-term care service," despite her knowledge about the welfare system that she gained through volunteering at Red Cross. She is getting personal care services through her granddaughter, who gets paid for this work. I assume that her services are provided by the Residual Program of In-Home Supportive Services (IHSS), which her granddaughter arranged for. This case illustrates how family caregivers use the formal service system. The participant continues:

Well there is food (delivery meal). I don't know the name (of food service) because it is my granddaughter who asks for that.

In short, she depends on her family members to receive formal services, but does not know where the services come from, how the services are paid for, and how the services were ascertained. Even though the interviewer asked these questions, their responses are unclear.

A typical case can be characterized by an 86 year-old woman who came to the U.S. 22 years ago from Mexico. She worked as a house cleaner for private households and she does not have Social Security. Thus, General Assistance is her only income. She lives with a non-kin person to save a rent. Her sons told her that they cannot help her

financially because they are also experiencing financial hardship. However, her sons help

her emotionally and instrumentally by visiting everyday, giving her a ride to a senior

center, doing grocery shopping, and eating with their mother. This participant counts on

her sons for most of her activities. For instance, she describes how she makes

appointment with her doctor as follows:

I say to any of my sons, "Son, I need to go there, he says, I take you. Just try to have the appointment after 1pm when I am out of my work". He talks to the doctors and tell them, "My mother can't come alone." I am so lucky. I count on my kids for everything.

They take me anywhere I need to go. To the doctor, "I will take you." Like today I was going to have an eye exam and I have to test with my doctor at the 18th street. My son went to talk to him, "Make the appointment for my mother at 3:00 because I get off from work at 1:00 and while I pick her up is…

 This person is happy because her sons are always "watching over" her. Cases such as

this demonstrate full dependence on adult children for arranging doctor visits, HCBS, and

other bureaucratic procedures. These situations make elderly Latinos happy, and they do

not feel a" dependency" status because this is part of their cultural expectations.

Familism and dependency on adult children

Lack of knowledge and dependency on adult children should be understood as

outcomes of familism. The traditional Latino culture of familism provides Latinos with a

strong sense of filial obligation (Johnson et al., 1997). Latinos often consider family,

particularly adult children, a major source of assistance and expect adult children to

remain geographically close to them in order to provide assistance (Cox & Monk 1990).

Adult children have social and moral obligations to provide emotional and instrumental

support for elderly parents in the Latino culture.   Moreover, providing support is

translated into respect for elderly parents by adult children (Beyene, Becker, & Mayen

99

2002). According to Beyene, Becker, and Mayen (2002), Latino culture considers old age a "period of reward for life lived" (2002:160). Support from adult children is considered as a reward for the hard work done over the years of child-rearing.

The participants of this study are continuing this tradition of familism. They grew up in a cultural environment in which grandparents lived with them. They observed that their parents took care of grandparents, and they also participated in the caring of older family members. After they grew up, they also provided their elderly parents or in-laws with assistance. When they reach old age, it is their turn to have their share for their own child-rearing, hard work, and assistance to their own parents or in-laws. One participant describe the status of grandmother as follows:

We are raised to respect our mother, the mother is the boss.

They were socialized to respect their mother and take good care of her when she reaches old age, based on the tradition of familism.

At the same time, elderly Latinos also modify their views about the culture of familism in the U.S. Some do not expect their adult children to be with them all the time because they understand their children's busy lives and the need to separate old parents from their own family. A 92 year-old woman who came to the U.S. 13 year ago describes herself and the relationship with her family as follows:

I am an independent person but when they (her daughters and grand-daughters) come they took me out. They let me alone, they come to give the satisfaction of love. So, I am happy. It is not all the time, only when they can. I can't object to them because I can't. They work.

An 86 year-old Mexican woman that I previously introduced also describes how her sons manage their busy working lives in the U.S. and the Latino tradition of caring for a parent as follows:

My son works around here (her senior center), he picks me up at noon. He tells me, "If you need tortillas or something small, walks to the corner, but what you need and I will pick up there." I am okay because he leaves his work at 1:00pm. ……. Every day. He starts working at three in the morning, he left San Pablo. I don't know at what time but he starts working at three in the morning and finish at one. I am happy because I see him every day.

Similarly, a 74 year-old woman who came from Nicaragua 53 years ago took care of her elderly mother. She described her mother as "the boss" and paid the high respect to her elderly mother. At the same time, she is aware of a change in the status of mothers in the US. She compares the status of mothers in the U.S. to her country as follows:

Interviewer: Your mother was living with you but you don't want to live with your kids. Participant: No, is because we have other customs. I bet that you have a different custom too. What the mother says was a command for us. We never talked back to our mother. In these days kids even beat their parents. In my days, the mother was very important for us.

Elderly Latinos in this study perceive instrumental and emotional support from their adult children as an expected reward in old age and their expectations are consistent with cultural traditions. At the same time, they modified these expectations to a manner that fit the reality of living in the U.S. society. Parents depend on children in old age, following their cultural tradition. They experience fewer feelings of being a burden of their children. Additionally, their children retain a good degree of appreciation for the cultural tradition of familism.

Having supports does not mean they have it all.

It is important to note that having formal and informal help does not mean these participants are better off. The families of these people are running around to manage their multiple responsibilities, such as work and their own family. Older Latinos sometimes need to get by without necessities because they cannot always receive formal

or informal support. For instance, a 73 year-old woman from Nicaragua, whom I

introduced at the beginning of this section was having severe pain in her arms from

arthritis. However, she missed her doctor appointment because *"I can't go alone"* and her

children could not arrange a time to accompany her to a doctor appointment due to their

jobs. In addition, the amount of service is not always adequate. Similarly an 86 year-old

Mexican woman describes how she has been given a limited slot of time for her personal

care services and how her son helped to compensate for her limited slot of service.

The house help I have doesn't work more than four hours every week. She can come two
days, she wants four hours in one day. I understand that because she has to pay the bus,
plus the time coming back and forth. My son helps me with the groceries, like tortillas or
something like that. What I need the most from her is the house cleaning, and the laundry.
That is what I need the most. She cleans one week and the next week she does the laundry.
I like her. The only problem is the time is too short.

These nine participants and their family members successfully gained HCBS,

while other participants did not. However, they found that these services are not enough

to maintain their independent living in terms of quantity and quality. Therefore, it is

important to stress the inadequacy of Home and Community-Based Services (HCBS) as

many previous studies have similarly pointed out (Miller et al., 2000; Kassner and

Williams, 1997; Harrington et al., 2000).

7.5. Access to social resources without family support

While adult children are key for the participants with formal and family support to

access social resources and manage daily problems that result from declining functional

ability, participants from the other two groups (the participants with formal support only

and the participants with low support) have to solve these problems and access to social

resources by themselves.

Each participant has a different reason for not having enough family support. Some participants simply do no have any children. Some have children who live geographically away from them. Other participants are left behind by "Americanized children". Here, although their children live near by, they do not have much contact. Even though they may have some contact with their adult children or extended family, participants are not satisfied with the care they receive from extended family members. They attribute this lack of contact and care from their extended family to the loss of Latino culture because of "Americanization". Some participants receive partial emotional support, but adult children cannot provide enough instrumental support because of their busy lives and own problems, such as financial problems.

Among participants who have limited family support, there is a similarity in their conditions and ideology. Participants from both groups (the participants with formal support only and the participants with low support) share similar life conditions because they all live in a low-income Latino community, are unable to speak English, and have limited knowledge about the social and welfare systems of the U.S. Moreover, the years of living in the U.S. are not an issue for some participants, although this factor is an important reason for some participants' failure to get social resources. For instance, two participants became legal residents less than 5 years ago and they do not qualify for Medicaid. They share similar beliefs about family in the U.S. and in their home countries. In general, they idealize family in Latin countries as "united" and consider families in the U.S. as fragmented.

It may be that the differences stem from expectations of adult children and their life experiences in their home countries. These experiences and expectations may influence their behaviors and perceptions toward dealing with bureaucratic agencies and

authorities to solve life problems and obtain necessary assistance. Their life problems often include financial difficulties with paying rent, utilities, food, and medication. Additionally, they experience difficulties in managing household chores as a result of declining physical functional abilities. In order to solve these problems, they have to negotiate with formal organizations that can deliver various social services, such as financial assistance and HCBS. Some people can deal with formal organizations better than others. Some people cannot deal with them at all.

Getting help and not getting help

Before I describe how life experiences and expectations of adult children influence participants' abilities to access to social resources, I will show the consequence of the ability and inability to deal with the system. There are clear differences in dealing with the system in order to compensate for declining functional ability between the participants with formal support only and the participants with low support. Some participants seek available resources actively and advocate for themselves to formal agencies despite their unclear understanding of the welfare system. On the other hand, participants with low support tend to be inactive when it comes to seeking resources and advocating for themselves, and they have less knowledge about how to do so. However, these participants with low support know that there are community services, such as personal care, by observing their neighbors.

For instance, a 75 year-old woman who has lived in the U.S. for 35 years is an extreme case of someone who does not know how to access services as well as how to deal with the system. Her IADL score was 6 and ADL 5. Her following statement demonstrates that she does not know about the systems in U.S. society.

104

Interviewer (I): Do you have a household help at home?
Participant (P): Nothing. If I want some help I have to pay five dollars and hour. Other people are being helped but not me.
I: Why is this happening?
P: I don't know.
I: Don't you qualify to receive government help?
P: No. I don't get anything. Many people have a girl working for them four hours but they don't send me anybody.
I: Why don't you apply?
P: I don't know where.
I: Do you have social worker?
P: No.
I: I remember that the last time we were talking one lady told me that she was your social worker.
P: But she never comes back. .....

This is a case in which the participant is completely unaware of services she may benefit

from. Although this is an extreme case, similar confusion is expressed by other

participants. For instance, a 78 year-old woman with Medicare and Medicaid states:

I: Do you have somebody who comes to help you?
P: That's what I want. I need help but I don't have anybody. I applied one time and I don't know if it was because I went to the Centro Latino and they didn't help me. But I really need help.

Other people do not know how to apply for personal care services:

I: So you were telling me that you don't have anyone to help you at home, have you talked to your social worker about this situation?
P: The manager of the apartments told me that he was going to talk to my social worker. The problem is that I don't even know who my social worker is. Because I spent three years home alone. Without going out at all. As soon as I tried to stand up I felt dizzy and my leg were so weak to support me.

A man describes his confusion about the health care system:

I: Do you have Medi-Cal?
P: I have. . . see I have the copies. The originals are at home.
I: Do you have Medi-Cal? How old are you?
P: 75.
I: So do you have Medicare?
P: Look here you have my papers.
YB: Yes but this is your residency.   Do you have Medi-Cal?

P: I want it but I don't know.
I: Medicare, do you have Medicare?
P: I bought this social but they said that isn't good.
I: Yes, you have all your papers but I want to know if you have Medi-Cal or Medicare.
P: Medicaid, yes I have Medicaid. But is good for nothing.
I: If you have Medicare you don't have to pay nothing.
P: Write my name down and call to the hospital to see the reason why Medicaid doesn't pay for my illness.
I: Where is your Medicare card?
P: Huh?
I: Don't you have your Medicare card.
P: No, no.
I: You need to have your Medicare card. You are 75 years old and how is that you don't have your Medicare?
P: Look this.
I: No, this is your social security card and this is your residency. That is your ID California. What is this? Don't you have a Medi-Cal?
P: No. Yes, those are all my papers, all.
I: But where is your Medi-Cal? Where is your Medi-Cal card?
P: Huh. Oh, that's the one I need.
I: What is that for?
P: Which one?
I: Okay this is for. . .
P: That is all I have.
I: You mean you don't have Medi-Cal? You need to have your Medicare. So . . .for how long have you had arthritis?

These people are often confused about health and welfare services in the U.S., and they do not know how to seek out information.

On the other hand, the participants who use HCBS or other resources (e.g., government housing and financial assistance programs) tend to manage their daily problems, such as difficulties in handling daily activities (e.g., cooking and cleaning) and financial problems. These people tend to have strong belief in dealing with their problems by themselves, without depending on family members. In other words, they often seek social resources that may help them to remain in the community and avoid institutionalization. These themes were expressed by several participants and can be seen in the following statement:

P: *Look at me I can't even wash my dishes but I try and I do it. But I want to tell you is that there are person that are waiting to be helped in everything. They feel sorry and they also want you to be worry for them. And I don't think that it's ok. …… I told them that we don't have to wait for anybody to give it to you. You have to look for it. No matter how you are. For example, my person. It is not that I can't cook but when I finish cooking this arm hurts me a lot. And also my foot. Another thing is that economically I can't because the economic help that I receive is very small. I have to stretch it. I use the meal-on-wheel to spend less money. I told them to bring me food from Monday to Friday. Saturday and Sunday I make my lunch. …………."* .

This woman decided to receive meal delivery and personal care services in order to

compensate for her difficulties in cooking, due to her arthritis, and to save her money.

She describes how she obtained these services through her social worker.

I could never find him (her social worker). I told him I need to talk with you because I am looking for you and I never find you. I called him at 8 and I left him two messages in the morning. But he didn't call me. I called him back at about 9:30 am and told him "Look Salvador, if you don't call me back, I will have to call to your supervisor because I need to talk with you"

She took a direct action to contact her social worker and even threatened him if he didn't

contact her immediately. After her action, her social worker called her to discuss her

needs. She negotiated services with him as follows.

[She said to her social worker] I'm calling you because I want that meal delivery service because I can't cook. I called to the thirteenth [the provider] but they told me that you are the one that has to talk with social worker at the thirteenth. Please help me because I can no longer cook. Don't think that I am not an active person.

Similarly, an 81 year-old woman who came from Nicaragua 24 years ago to the

U.S. describes her experiences. She is a single mother who worked in Nicaragua as an

accountant and raised her children to professionals in the U.S.

I am always looking for an opportunity. I don't waste time. I have to be updated. I saw a program in a church where they pay the rent for you. I fill out my application, I sent it and I got $100 to pay my rent. My daughter didn't go with me. I went by myself. I waited for one year, and one day I asked my daughter to go with me. I wanted to know what was happening with my application. ……. So, I went by myself. I had the address and I went to

Montgomery 72. I was walking when I saw that number and I went in. I talk to the lady and I told her that I was 'long time more than one year' and she said "just a moment". ....Tomorrow you receive one latter, she said. She meant that I will receive a letter the next day telling me the date I will receive the help.

These two quotes show how people actively look for resources and work to obtain these resources in order to resolve their problems in daily living. They act to get resources, even if they do not know for sure how they are to obtain resources. They do not fear calling or visiting an agency to ask questions.

As I mentioned at the beginning of this section, it may be that the difference stems from their expectations of adult children and life experiences in their home countries. I will introduce how these two groups differ in relation to these two points despite their similarities in the perception about family in the U.S. and their home countries.

Familism and unfulfilled expectation of family

Despite their lack of family support, participants tend to hold on to a culture of familism. Moreover, it may be that they tend to idealize family in their home countries because their expectations of adult children are fulfilled in the U.S. They often describe family in their home countries as united and family members provide elderly parents with emotional and instrumental support as well as respect and affection. On the other hand, they describe family in the U.S. as fragmented and inconsiderate of elderly parents. These perceptions are shared by participants from both groups. For instance, a 78 year-old woman who came to the U.S. 30 years ago shares her perceptions about family in Cuba and the U.S. as follows:

P: Families in Cuba are very united. The bad person in Cuba is Fidel Castro, everybody else is divine.

P: The mother? Oh, no she is the guardian of the house and the man is the gentleman, the main person in the house. Of course that the woman is important but the man is the head. The father is the main authority in the house and the woman is working at home, taking care of the family, cooking and doing everything and when the kids grow up they help in the family.
P: Oh, she (mother) is big, the bigger. She is bigger. The older she is the more respect she gets. Everybody loves her. She is very important in the family. They take care of her because she will leave the family soon. They take her out to sightseeing, and everywhere.
I: How do you see getting old in this country?
P: Chica, I will..
I: The custom.
P: I will tell you that the grand mother in Cuba dies in her home. The great grand ma dies in her home and the great great grand ma also dies in her home. In this country no, she is taken to the rest home. I don't want to go there. You know as soon you are sick and old they take you to the rest home. That is something sad because I have been visiting friends in those places and is very sad. I have felt very sad. I know they take care of them but are not the same as they were in their home. Is completely different.

Participants perceive the elderly in their home countries are happy because they are surrounded, respected, and loved by family members who take good care of them. Adult children provide food, home, medicine, and respect for their elderly parents. On the other hand, elderly in the U.S. are sad because adult children forget about their elderly parents. Similarly, another participant described family in the U.S. and her home country as follows:

P: Look, they treat you very well. When I went to visit my sister, you know, she has only one daughter and she has her mom living with her. She buys the medicines for her because my sister never worked. She doesn't have any insurance or a pension and her daughter buys her medicines. My niece works and my sister, her mom, doesn't do anything. Even when my niece has her husband and her kids she attends her mother.
I: So they gave her own place...
P: They don't put you away in a rest home like in here.

A 77 year-old woman who came to the U.S. 33 years ago from Cuba also laments how kids in the U.S. forget about their elderly parents and an old mother is left alone. This woman's daughter lives in Canada with her husband and her son, who used to live

near by, moved to a different state for his work. Thus, she feels lonely and abandoned because her son does not invite her to move with him and his family.

I: Can you tell me what does the old age means for you?
P: For means something that I have so many things to talk about. For me is a face where it doesn't matter if you are man or woman, you're alone, left behind, look down especially by the sons. When you don't have kids is okay they are better. When you are mother and old and you don't have the love from your loves one without attention. The old age for me is sad.

In short, families in Latin countries are "united" and older members are loved and respected. They have their own status as a mother or a father in a family and family members care for aged parents well. On the other hand, families in the U.S. are not united and do not give respect and love to elderly parents. In the U.S., elderly parents are placed in "rest homes" (which refers to a nursing home) and are forgotten by adult children. This belief is shared by those who have accessed social resources.

I: How is in Nicaragua?
P: Oh no over there is different. I took care of my old ones and they don't go anywhere else. They are with you all the time. All the family is together. Here is a different story, nobody wants to be seeing with an old folk. When the kids get married they don't know anything about their parents or their in-laws. They want to live alone. In my country is different. Not everybody but most of the people take care of their old ones. I am telling you what I saw in my family. In my country there is no welfare or nothing. When the person is so poor the neighbors take care of them. They collect money and give them a decent memorial.

The participants of two groups share similar perceptions with those who have both formal and informal supports regarding family in their home countries and in the U.S. Both groups live in the Latino traditional culture of familism, observing how their parents and neighbors treat elders.

Accepting unfulfilled expectation

Many participants thought that they would have the same treatment from their family, particularly from adult children, when they reached old age. However, this expectation was not fulfilled for many participants. In order to make sense of their current situation, many people attribute their unmet expectations of adult children to the U.S. culture and in turn idealize the culture and family of their home countries.

The participants who gained some social services tended to have few expectations of extended family members to help them. It is hard to state how they have developed the sense of independence that is not relational to family. However, I speculate upon several reasons. For instance, a seventy-five year-old woman from Mexico has lived most of her life with her husband who recently passed away. Her extended family is living in Mexico. She feels that she left her family in Mexico because she wanted to stay in the US. Therefore, she does not expect any family caregiving. She feels it is her decision to come to the U.S., not following her children. Therefore, it may be that she has developed a sense of independence and does not count on extended family members as much. Similarly, a 79 year-old woman who came to the U.S. 40 years ago from El Salvador describes how she is independent from family members:

I was independent even when I was working. I always live alone and I was invited to a party I was there. If somebody ask to go dancing I was there. I have always be independent but now I feel more independent because I am living my last year the way I like. On my own way.

Furthermore, some participants have modified their expectations of adult children since they came to the U.S. in order to accommodate their life conditions, such as the acculturation of their adult children and corresponding decline in the expectation that family care is a reward for efforts in child rearing. A seventy-two year-old woman

111

describes how she depended on her son when she came to the U.S. 13 years ago by

following her son. She compares this dependent self to her independent self.

*Now I am [independent]. When I just came here no, I was not independent. I had to ask
everybody to do or go anywhere with me. Don't you know that this time I didn't ask
anybody to pick me up at the airport?*

Another participant also adjusted her expectations of adult children to fit within

U.S. society. An eighty-one year-old woman who I introduced above came to the U.S. to

live with her daughter when she was in her early 60s. However, she had to leave her

daughter's house because of a difficult relationship with her son in-law. Although she

feels sad about her situation, she adjusted her expectations to suit her current situation.

She has lived her life as a single mother. So, it may be posited that being a single mother

helped her develop a sense of independence apart from family. At the same time, her

experiences in her home country also helped her develop skills to deal with the system,

which I will discuss later in this section.

While participants with formal support tended to accept their condition and try to

be independent, they did sometimes deal with loneliness because they did not have family

to depend on and experienced anxiety about their immediate future. Many participants

without family support worry about what they will do when they are no longer able to

perform many daily tasks. They are anxious about being placed in a nursing home, which

they often call a "rest home". They have a strong fear of being placed in a "rest home," as

they believe it is a lonely place where elderly die in isolation and miserably. For these

participants, being independent and self-sufficient are important in order to remain in the

community and to avoid institutionalization. These people sought the formal support

provided by the government in order to accommodate their declining physical functional

ability. These people tend to have less negative feelings about government funded

programs, particularly home and community-based long-term care. They considered it

"help" and a resource that allowed them to remain in the community and avoid the

humiliation of a "rest home".

I: I don't know how my future will be, because like I tell you, I don't have any family, I could not tell you what future I will have.

I: Yes, I'm scared of getting there (nursing home). At the same time I think "I am a lonely person, my daughters are living away from here". One is living in Pleace Hills, the other one is in Nicaragua. They have their own families to take care of. I know I am old but I can still cook, move around, I go downstairs to do my laundry. I am still having an active life. I am praying to the Lord to give strength. But when I am no longer able to my things, what is going to happen to me? To be humiliated there (nursing home)? I don't want that for me. Now I remember why I am so scared of dying. I'm scare of ending my days there (nursing home). On the other hand, I don't want to be one more problem for my daughters, I wouldn't like to do that. Because your children get bore of taking care of you. What can I do? Maybe one of these days I will go to those places (nursing home) and maybe I have better luck than those people and they will take care of me. I don't want to be a problem for my family. In the hospitals is different because they take turns. That was the topic I wanted to talk about.

Many participants fear being institutionalized. However, they do not want to be a

burden on their children. Therefore, some participants without family support perceive

government sponsored HCBS, Social Security, other financial assistance programs, and

other community programs that assist community-dwelling elderly as resources which can

help them avoid institutionalization. Indeed, for some participants, the formal assistance

programs for the elderly are the only resource they can depend on.

P: Yes. I don't depend on nobody. I have never depended on nobody. The only one I depend on in this country is the government because I have pension.

In short, they are anxious about their future because they do not have family to depend on.

Thus, they seek a solution with social resources. They accept their situation and act on

behalf of themselves.

Not accepting unfulfilled expectation and the *inability to deal with the system*

On the other hand, participants with low support tend to have more expectations of their extended family members, particularly to adult children. Therefore, it is hard for them to accept their situation and some participants have severe depression. Their expectations may be developed throughout their relationships with family members and life experiences. In this sense, they tend to be deeply engaged with the traditional culture of familism. They believe that they did their share, such as childrearing and caregiving for aged relatives. As Beyene, Becker, and Mayen (2002) pointed out, older Latinos except to collect their rewards for struggling. However, this cultural expectation is not fulfilled in the U.S. society, which has different cultural values and social systems.

Because these participants expected to depend on their adult children, they did not develop the skills needed to deal with bureaucratic systems, which is necessary to receive home and community-based services and other social resources. This can be demonstrated by comparing this group with the participants who have both family and formal support. The participants with family support fully depend on the arrangements provided by home and community-based services and other services. However, they have little knowledge about how they access these services and how these services are paid for. Therefore, these people do not need many skills to deal with the bureaucratic systems, nor knowledge about how the services have been as certified. I assume that participants with low support expect a similar condition with the participants with family support. While their expectations and degree of knowledge in dealing with systems may be similar to the people with family support, the difference is that they do not have family who can arrange these services for them.

For instance, an 82 years old woman came to the U.S. 16 years ago from Nicaragua in order to live with her son, who planed to take care of her. Her Barthel Index Score is 80, which is lower than mean score of 95. She has Medicare, SSI, and General Assistance from the state. Although her sister and son live in San Francisco, she has been forgotten by them. Thus, she is suffering from loneliness and depression. She used to live with her son's family, but had to leave because of her son's financial hardships in taking care of her and discomforts with her daughter-in-law.

Before, I was living with my son but I left him. I took my clothes and my personal things because I knew that he couldn't pay higher rent. He didn't have a good job. We as mothers, we know our kids and we rather suffer alone and let them live their own life. I couldn't live with him because of his wife. She was older than him……… He needed to live with his wife. So, I left him and left all my belongings there. The only things I took were my clothes and my bed. That is another thing that make me feel sad because he is my son and I love him. Now, he doesn't look for me. He didn't even call me.

I was suffering of my nervous since I was living in Nicaragua. I worked hard. I worked day and night in Nicaragua to support my daughter who got sick. Her father left me alone. He told me he was going to look for a job and he never come back so I had to support all the expenses in my house with my family. I was sick since I left Nicaragua but the illness hadn't developed yet until I was here.

She worked hard to support her daughter without having her husband's support. After her daughter passed away, she worked hard to raise her grandson who forgot her after they immigrated to the US. She thought that she would receive assistance, respect, and affection as rewards for her hard work when she got old, and she counted on her grandson in her old age. It was hard for her to accept that these cultural expectations were not fulfilled in the US.

In addition to feeling sad, the participants have to deal with the U.S. health care system and Social Security in order to manage their old age. For instance, the same person I described in the above paragraph now has to deal with everything by herself in the U.S.

society, of which she has less knowledge. Her old age and inability to speak English prevented her from working in the U.S. and to be integrated into the mainstream society. As a result, she could not learn how to negotiate U.S. social systems. The situation is hard for her and causes depression, which has become a serious problem for her health condition.

P: My niece. She helps me when I need to go to the hospital. She also takes me to the bank because I don't like to go alone to get my money. She takes me in her car. She is special with me. They have their own houses but nobody ask me to live with them.

P: I would like someone to be giving me the things I need to eat. I would like a person like that. But since, no, there is no one.

Her unfilled desire and cultural expectations cause her severe depression. In addition , her health condition got worse across the three interviews. While she could boil vegetables at the first interview, she lost this ability over the time frame of the study. She seems to have trouble going out and preparing meals. She eats oatmeal in the morning, crackers with soda for lunch, and food from Safeway at dinner.

It comes here not frozen, one of my nieces goes and buys it. That is my lunch. That is it. Then, it comes with chicken, potatoes, it comes with, who knows what it is, it comes there, I see it like potato puree"

Her niece or niece's husband brings food every week, which keeps in the freezer. She stated as follows:

Sometimes she comes over. Sometimes she comes over and gives me the things because maybe her husband can't come over. (mumbling). I can't talk, I get stuck. I can't stand it anymore, sister, I am too bored. Very sad.

Those participants with low support retain the culture of familism and often lament how their children have changed in the US.

I: Do you see your grand daughter?

116

P: No, can you believe this? We can't talk because she is North American and I am Hispanic. I don't speak English and she doesn't speak Spanish. I don't want to talk about those things because I am suffering. I can't say that I am not feeling sad. I am suffering. Can you believe that in this time of my life I can say that I don't have family? Because there is nothing that my kids in Cuba can do?

These participants did not prepare themselves to be independent enough to deal with bureaucratic systems in old age because they thought that their children would take good care of them. They thought their children would take them to the hospital and run errands and provide them with a warm meal. Therefore, they thought that they would not need to deal with the social security office in order to have housing assistance, meal delivery, transportation services, personal care services, and other assistances. In reality, they have to arrange for these social services if they want to avoid institutionalization. Many simply are not adequately prepared to do so.

In summary, one explanation of the difference between those who accessed social resources and those who cannot is the acceptance of their current situation and the development of skills needed to deal with bureaucratic systems of the mainstream society before old age. With the exception of a few participants, the participants in both groups (the participants with formal support only and the participants with low support) had expectations of adult children to support them. However, the participants with formal support adjusted to their situation and started to deal with formal organizations in order to solve the problems of their daily lives. On the other hand, the participants with low support group cannot adjust and cannot access various social resources.

However, the difference does not only stem from the acceptance of the situation. In order to access resources by themselves, they have to know how to manage bureaucratic systems. If they have a foundation or basis in dealing with formal agencies, they may be able to develop this kind of skill in the U.S. On the other hand, those who

cannot access social resources may not know how to deal with these systems because of their lack of experience.

The ability to deal with bureaucracy and life experiences before the immigration

In addition to differences in expectations of family members, their different life experiences in their home countries provide for different abilities in dealing with problems. Although they are treated as a homogenous group of "low-income Latino elderly" in U.S. society, they belonged to different classes in their home countries. Each participant had a different occupation, family status, and educational level in their home countries. Class differences translated into varying perceptions and behaviors.

There are substantial differences in the ways participants seek and advocate for social resources among the participants with formal support only and participants with low support. Some participants with formal assistance developed these skills when they realized that they can not depend on their children. Others cannot develop this skill. I argue that it is a shortcoming to attribute this difference to personal characteristics, such as assertiveness, passiveness, aggressiveness, or depression. Rather, these differences are systemic

All participants in this study are low-income and had little contact with the U.S. mainstream society. Most participants worked in unskilled, low-paying jobs in the US, which often did not provide them with benefits and Social Security. Because their jobs often did not provide health insurance and they earned a little money, they did not go to hospitals often. Therefore, they had limited contact with medical organizations. Furthermore, they had little contact with formal organizations while they were working because of their limited English language ability. For instance, many participants had

worked in jobs that did not require English proficiency. Moreover, most participants avoided authority because they came to the U.S. as an illegal immigrant and only received legal residency later. These conditions provided them with little chance to engage with formal organizations in the mainstream society, such as hospitals, Social Security Agency, and other formal agencies.

However, the qualitative data indicates that the participants with formal support often had some opportunities to deal with formal agencies and people in authority through their work, friends, or family members in their home countries. These people tend to have a higher education level, worked in a professional or clerical capacity, or have a family status in their home countries. It may be that these experiences were internalized giving them an idea of how to deal with bureaucratic agencies. This may have reduced their feelings of fear in dealing with formal agencies in the U.S. Thus, they could go out of the Latino community to deal with bureaucratic, American agencies and seek resources in order to resolve their life problems.

Some participants worked as teachers, professionals, or semiprofessionals(e.g. accountant) before immigration. Other participants owned a small business. Some participants did not work in their home countries, but had family status. For instance, one participant came from a family, in which her father and brothers were physicians. Another participant worked as a teacher and had relatives who were part of the political elite in El Salvador. One participant indicated that her son is a wealthy pastor with prestige in El Salvador. These backgrounds helped the participants to foster skills for dealing with formal agencies and authorities if they have to.

For example, another 81 year-old woman from Nicaragua, who has a grade school educational level and supported her children as a single mother working an accounting job in a formal organization states:

I worked in a store. Didn't I tell you that I visited each department collecting the payments. I had an active life. I worked more than eight hours. ……….. I was working for one store but I didn't have fixed salary. The more I worked the more I earned so I didn't care working from 8 am to 8pm. Every morning, I reported to the store and give them the information. I worked for that store, and I made the store grow. "The kind of job I had let me be in touch with people.

Similarly, a 78 year-old woman who came to the U.S. 15 years ago from El Salvador had a small business with her husband. They were selling lottery tickets to retailers and owned property to rent to tenants. She had both occupational skills and prestige before she came to the US. She described how she worked as follows:

I worked hard when I was living in my country. With the king of job I had; I had to dress well because I went to sell ticket to the employees in the offices. I wear always nice. I did was hard because my work was intellectual and after getting home I had to keep register of my profit and expenses for every day, I had to cook, take care of the family, and also control my sellers and know how much they owed me and when were they will me back the money. In this country is easier for me because I just get my check and if I want to sleep all day or walk all day.

Although these people worked in low paying jobs in the U.S. (e.g. janitors or baby-sitter) and remained in the Latino community once they came to the U.S., they had an active life dealing with people from various types of formal agencies. These traits are different from the participants with less formal and family help.

It may be that the manners of bureaucratic agencies or professionals in the U.S. are not completely foreign for those who have experience dealing with organizations and authorities in their home countries. Thus, they tend to manage to negotiate with these agencies effectively. Moreover, this familiarity helped participants to reduce the feelings

of fear or uncomfortably with formal organizations. Although the amount of services they garner may not be adequate, they make actions to get. Them they receive some sort of help.

On the other hand, the participants with low support tend to have few experiences with formal agencies both in the U.S. and their home countries. They often worked as unskilled laborers or farmers in s small villages before immigrating to the U.S. They also have no or few year education. After they immigrated to the U.S., they avoided formal agencies and authorities because of their immigration status and inability to speak English. These people had few opportunities to deal with formal agencies or people with authority both in the U.S. and in their home countries. For these participants, physicians and Medicare/Medicaid may be their first contact with formal agencies.

Thus, those who have limited access to social services may feel helpless because they do not know the language and are not assimilated in the U.S. society. One participant who has lived in the U.S. for 38 years expressed her feeling of sadness as follows:

I went to the General Hospital and there it was a doctor...the doctor who was checking me has always a translator with him. One time I start crying a lot and she... the lady asked me the reason to cry. I told her I feel pain, sadness and very ashamed to see how many years I have been in this country and I couldn't learn English. I have to tell my things to another person to communicate myself.

Because she could not learn the language, she tries to minimize her communication in English, which means avoiding contact with mainstream society. In a description elaborated below, she describes how she gets by without communicating with the mainstream society:

I; When you go to the store what do you do?
P: I speak Spanish.
I; What do you do when you want to buy clothes?
P; Here at home. Vira sells me clothes.

It may be that these participants cannot negotiate effectively with formal agencies because they feel uncomfortable dealing with them. They tend to show a strong fear of venturing into the U.S. mainstream society to get necessary social resources. They tend to show feelings of helplessness in complicated bureaucratic systems. As a consequence, they cannot take action to seek social resources outside of the Latino community and cannot effectively negotiate with bureaucratic agencies.

Chapter 8: Discussion and Conclusion

8.1. Discussion

In this dissertation, I have examined access to Home and Community-Based services (HCBS) and other social resources, including Supplemental Security Income (SSI), General Assistance (GA), and government-sponsored housing assistance among low-income older Latinos. The purpose of this study is to suggest other factors that may influence elderly Latinos' access to these services. More specifically, I have shown how life experiences, which are partly the result of class-related conditions, influence an individual's ability to access social services. For this purpose, I have examined service use among a sample of elderly Latinos using both quantitative and qualitative methods. More precisely, I have examined their access from the expanded behavioral model for vulnerable populations using quantitative methods. I have also explored how other factors influence service use with qualitative method.

The findings from the qualitative analysis may be well understood from the theoretical perspectives of political economy and habitus. While quantitative analysis suggests that the significant predictors of service use are physical functional ability and availability of informal assistances, narrative analysis suggests that access is also influenced by the ability to deal with bureaucratic systems in U.S. society, especially Social Security.

In this concluding section, I will first summarize the findings of the quantitative analysis in relation to the behavioral model. Then, I will discuss how elderly Latinos' knowledge about or ability to deal with bureaucratic systems are an important factor that

influences access to home and community-based long-term care services and other social resources, drawing on the perspectives of political economy and habitus.

The expanded behavioral model

The expanded behavioral model that incorporates vulnerability factors suggests that the need domain, which refers to an individual's subjective and objective health status, is the most important determinant of service use. Consistent with the expanded behavioral model for vulnerable populations, the results from the statistical analysis in this project indicate that physical functional status alone is a significant predictor of access to county-provided services (home delivered meal, assistance with transportation, and senior information referral). In other words, only the IADLs have a significant association with the use of county-provided services. This result indicates that those who experience a decline in physical functional ability tend to use county-provided services.

In terms of personal care service, the correlation analysis indicates that the predisposing domain of demographics, the enabling domain of informal networks, and the need domain all have statistically significant relationships at .05 level. No vulnerability factors from any domain has a significant relationship with the use of personal care services. In terms of the predisposing domain, women and older participants use personal care services more than men or younger participants. Indicators of informal networks from the enabling domain are predictors of participant's knowledge of or awareness about available services. Among the factors from the enabling domain, marital status, living arrangement, and frequency of informal socializing have a statistically significant relationship with service use at .05 level. These results indicate that those who have frequent contacts with friends or neighbors, those who are unmarried, or those who do not

124

live with family members are more likely to use personal care services. Living arrangement and marital status may be significant because those who cannot receive informal care from family by way of cohabitation use services. The IADLs are the only statistically significant factor in the need domain at .05 level. Thus, the results indicate that those who use more services are people who are older, women, having difficulty performing the IADLs, living without family support, and having more contact with others.

In terms of the use of a <u>senior center</u>, the need domain (the IADLs and the Barthel Index Score) and vulnerability factors of the enabling domain (years live in the US and the immigration status) have a statistically significant relationship with access to services at .05 level. Those who participate in senior centers are more likely to have a higher functional ability, lived in the U.S. for a shorter period of time, and are citizens. It may be a contradiction that those who have higher participation rates have lived in the U.S. for a shorter period of time and have U.S. citizenship. However, the in-depth interviews suggest that length of time as a resident in the U.S. does not indicate having citizenship status.

In summary, the statistical analysis showed that the participant's physical functional ability is one important factor to predict one's service use in general. Participants tended to seek formal long-term care services only once they perceived their health status to be declining and consequently experienced difficulties in managing daily chores. In terms of personal care service, perceived need and social network are important factors that determine access to service. Those who do not have family support and perceive need for assistance in daily living use services. However, it is not necessarily the case that frequent contact with friends and neighbors indicates greater

125

service use because these individuals have more information regarding the availability

and accessibility of services than those who have less of a social network.   Rather, I

argue that those who have more frequent contact with friends and neighbors are more

exposed to and active within mainstream U.S. society. This result raises concern about

those who have less informal support from family or friends and have little information

about services. These people may be left alone, without any means to cope with declining

functional ability and corresponding difficulties in performing the ADLs and the IADLs.

Political economy and habitus: internalized practices and class conditions

In this section, I will discuss the findings from the narrative analysis, in which I

focused on 34 key participants. I categorized these 34 participants into three groups: 1)

participants with formal and family support; 2) participants with formal support only; and

3) participants with low support. The findings from the narrative analysis will be

discussed from the perspectives of political economy and habitus. I compare these

findings with those that resulted from quantitative analysis using the expanded behavioral

model for vulnerable populations.

While the analysis using the expanded behavioral model suggested that perceived

need and social network are important predictors of service use among study participants,

the narrative analysis indicates that these factors are not always significant determinants

of service use. More informal socializing does not always suggest more knowledge of or

awareness about services. In addition, the qualitative analysis indicates that knowledge or

awareness about services does not always increase service use. Rather, service use

increases among those who have gained experiential knowledge about how to deal with

bureaucratic systems. The narrative analysis shows that participants who do not use

service are also well aware of available services, particularly personal care service, by

observing their friends and neighbors. However, these participants do not know how or

are afraid to access these services themselves.

Moreover, the narrative analysis indicates that those who do not use services are

struggling with financial hardships and are unable to speak English, like the participants

from the other two groups (the participants with formal and family support and the

participants with formal support only). Thus, I argue that it is important to consider their

lack of service use and inability to deal with bureaucratic systems from the perspectives of

political economy and habitus. Narrative analysis gives us a picture of how those less

informal support from family or friends deal with their declining physical functional

ability.

The comparison of these three groups indicates that the participants with formal

and family support tend to depend on their adult children in the management of their

illness(es) and declining functional ability. Individuals in this group tend to have an

unclear understanding of how services were arranged and who their service provider is.

The dependency these participants exhibited upon their children stems from the traditional

culture of familism, which provides a moral obligation to assist older parents among

family members. The study participants have practiced this tradition across their life

course and most assisted their own elderly parents or elderly in-laws. Participants thereby

expected the same treatment from their own adult children when they researched old age,

as a reward for their hard work and child rearing. Their adult children also maintained

this cultural tradition, although their ability is limited because of the realities of life in the

U.S. Adult children are busy with their work and child rearing. Thus, both the

participants of this group and their adult children modified their expectations regarding actual support given the realities of American life. However, the participants are generally happy with the level of emotional and instrumental support they receive from their adult children.

On the other hand, the other two groups (participants with formal support only and participants with low support) have less family assistances, although they also retain cultural expectations associated with familism. Therefore, they feel sad because they do not have family members around them. However, those who organized services by themselves have less expectations of their adult children. They too have modified their expectations to fit their reality. Thus, they actively seek formal resources that may reduce burden in their daily lives, which results from their declining physical functional ability and financial constraints. Although they experienced difficulties and confusion in getting necessary services, these participants successfully negotiated with bureaucratic agencies to arrange for their needs.

On the other hand, those who have less formal and informal support failed to modify their expectations of adult children in order to fit with their reality. Thus, they are often depressed because they do not have emotional and instrumental support from their adult children as they had expected. Like those who accessed formal services, these participants are trying to accommodate themselves to their conditions given that they are unable to rely on their adult children. Thus, they tried or are trying to live independently by attempting to access formal services as an alternative to informal caregiving. However, they have difficulties in accessing formal assistance. This is partly because they are unable to deal with Social Security and other formal, bureaucratic organizations.

Participants' inability to negotiate bureaucratic systems can be partially attributed to their expectation of adult children due to the culture of familism as well as class-related conditions. Because participants expected their adult children to take care of them in old age, they did not prepare for age-related problems, such as arranging formal long-term care services and other kinds of necessary assistance. Consequently, they have fewer skills necessary to seek social resources and negotiate with bureaucratic agencies.

Their lack of ability to seek resources and deal with the system should not be attributed merely to the skills of an individual, but rather should be understood in relation to life experiences that are largely constrained by class conditions. As such, the inability to negotiate with bureaucratic systems is a consequence of macro-structural forces. This point can be better understood from the perspectives of political economy and habitus.

Similarities between service users and non-users

It may be helpful to stress the similarities between those who accessed services by themselves and those who cannot access to services in terms of their current life conditions, such as financial resources, knowledge/awareness of services, and English language ability. Looking at their similarities, we can see that these factors are not significant predictors for this population. Specifically, frequency of informal socializing, which was suggested as a powerful predictor in the statistical analysis, does not indicate knowledge about services.

In terms of the availability of financial resource, both the participants with low support and the participants with formal support only are low-income older immigrants. They worked in unskilled, low-paying jobs that did not provide them with enough money to save for old age through Social Security. The qualitative data reveals that the average

monthly income is $600 to $700 and participants generally pay around $400 per month in rent. In terms of health insurance, the nine participants who arranged for services by themselves have both Medicare and Medicaid. The majority of the participants from the group that lacks services also have a combination of Medicare and Medicaid (57% have Medicare or Medicaid). One participant is uninsured and three participants have private health insurance. Those who have Medicaid but have no formal assistances have difficulties accessing services that target low-income elderly. While some participants obtained services like home and community-based long-term care and SSI, others are struggling in their day-to-day lives without these assistances.

This does not mean that the participants with low support are not aware of available services. Indeed, they know that there are home and community-based services and SSI available by observing their friends and neighbors. Although they do not know the exact service name, like In-Home Supportive Services (IHSS) or Medicaid waiver programs, they at least know that some of their friends are getting personal care services that provide their friends with help in doing household chores. Some participants even consulted with others - such as staff in senior centers, neighbors, and social workers – about how to gain such services. However, these participants were often unclear about why their application was denied or why their attempt did not work out. Among them, one participant was denied because she owned a house and thereby did not qualify for Medicaid. Another person was denied because he has not resided in the U.S. long enough to garner Medicaid and other welfare services under the current immigration laws. It is not clear why other participants' attempts were denied. Moreover, they did not continue to try to gain services.

Lastly, unlike other studies that point to language barriers and the lack of bicultural services, participants obtained service help from Spanish speakers. Some participants hired their relative as a provider of personal care services under the Residual Program. Although their English language ability and the availability of bicultural/bilingual providers certain influenced their ability to access services, it is important to ask why some participants who are equally marginalized could access to services while others could not.

In summary, the participants from the two groups (the participants with formal support only and the participants with low support) are a relatively homogenous population. Yet, there are people who accessed some kinds of social resources by themselves and others who would not. They all lack financial resources and are unable to speak English. Like the participants who use services, the participants with low support perceive themselves as having difficulty maintaining their daily living requirements. Moreover, they actually consider themselves in need of assistance and wish to have it, as their friends are receiving.

Development of skills to deal with the system: political economy and habitus

If the current life conditions are similar across the participants with formal support only and the participants with low support, it may be that their ability to deal with bureaucratic systems is an important factor that determines access. As the behavioral model for vulnerable population model suggests, the ability to deal with the system may be essential for individuals to assert their needs to and negotiate with bureaucratic agencies. As I have showed in the previous chapters, this ability has developed through

131

life experiences, which are largely related to relationships with family members as well as class conditions both in the U.S. and before immigration.

This ability may be shaped through life experiences, which reflects class conditions. From the political economy perspective, class condition is produced and reproduced through the intersections of political, economic, and socio-cultural dynamics (Estes 1999). The intersections between these dynamics produces social structures that are power arrangements, including class, sex/gender, and race/ethnicity. These social structures and power arrangements inform and lead to social policies (Estes 1999). In the political economy perspective, the public (particularly those who are low-income and of an ethnic minority) are considered to be the most disadvantaged among the various classes in the construction of social structures that are reproduced through policies (O'Conner 1998; Wallace and Villa 1999).

Participants' class condition as low-income and racalized is often internalized into daily practices and perceptions, known as habitus. Habitus is a concept that was developed by Pierre Bourdieu. Bourdieu argues that habitus is comprised of class-related practices, perceptions, and tastes that make judgments about others as well as themselves. I argue that the participants with formal support can operate in the habitus of mainstream U.S. society. However, participants with low support cannot, making it harder for them to access various social resources The need and ability to conform to a different habitus is a consequence of political, economic, and socio-structural forces.

In the U,S., the participants of two groups have been marginalized because of multiple factors of their immigration status, lack of English language ability, work histories, and financial constraints. As I described earlier, these factors relate with and compound each other. First, the lack of English language ability and immigrant status

132

often resulted in low-paying jobs, which in turn result in financial constraints. Participants were usually employed in unskilled jobs, in small industries in a Latino community, or in a private household as a babysitter or a cleaning person. These jobs often did not provide benefits, including health care insurance and Social Security. Consequently, they had fewer opportunities to interact with formal agencies, such as hospitals, medical professionals, and other organizations like the IRS. In addition, most participants avoided authority because many came to the U.S. as illegal immigrants and received legal residency only later. Therefore, they had few chances to go to a hospital and deal with other formal organizations in the mainstream U.S. society. In other words, participants did not learn the habitus of mainstream, bureaucratic U.S. society.

Participants with formal support only could arrange services by themselves because they have lived in this kind of habitus. This made it possible for them to deal with formal agencies. This knowledge may have been gained through their life experiences in their home countries. Although they are marginalized in the U.S., many in this group were not marginalized in their home countries. These people either have higher levels of education, a background in professional or clerical work, or certain level of family status in their home countries. Their life experiences in their home country provided them with opportunities to interact with formal agencies or people in authority. These experiences were internalized into their practices and perceptions, which may give them certain ideas about how to deal with bureaucratic agencies or may reduce feelings of fear in dealing with formal agencies in the U.S. Thus, they could go out of the Latino community to deal with bureaucratic American agencies and seek resources in order to resolve their life problems.

Some participants worked as a teacher, as a professional, or in a semiprofessional job, such as an accountant. Other participants owned a small-scale business. Some participants did not work in their home countries, but had family status. For instance, one participant came from a family, in which both her father and brothers were physicians. Another participant worked as a teacher and had a relative who was a political elite in El Salvador. Yet another participant indicated that her son is a wealthy pastor with prestige in El Salvador. These backgrounds helped them to foster skills needed to deal with formal agencies and authorities if they have to. They can move between the habitus of the Latino community and the habitus of mainstream, bureaucratic U.S. society.

In short, these people have a dual habitus. Although they learned the habitus of low-income ethnic minorities living in the U.S., they are not completely the same as those who had never learned the ways of an upper/middle class habitus. Because the manners of bureaucratic agencies or professionals are not completely foreign to them, they tend to manage their way relatively well and successfully negotiate with them. Moreover, this familiarity helped them to reduce their feelings of fear or uncomfortable when engaging with formal organizations. Although their ways to negotiate or seek information may not be sophisticated and the amount of services they have may not be adequate, individuals in this group are able to take act to get some sort of help.

On the other hand, the participants with low support tend to have knowledge of a single habitus of the under-class. They usually have had few experiences in dealing with formal agencies, both in the U.S. and their home countries. They worked in unskilled labor settings or as farmers in a small village before immigrating to the U.S. They also have little to no education. After they immigrated to the U.S., they avoided formal agencies and authorities because of their immigration status and inability to speak English.

These people had few opportunities to deal with formal agencies or people with authority both in the U.S. and their home countries. For them, physicians and Medicare/Medicaid can be the first contact with formal agencies and authorities.

It may be that they cannot negotiate effectively with formal agencies because they feel uncomfortable. These participants tend to show sense of strong fear in venturing into the U.S. mainstream society in order to get necessary social resources. They tend to express feelings of helplessness in the face of complicated bureaucratic systems. Their lack of knowledge or confusion about the complicated U.S. welfare system seems to be further perpetuated by these feelings of fear and helplessness. As a consequence, participants believe that working with formal agencies to gain social resources is too difficult a task. Some participants attempted to get services by asking for a social worker or Social Security office and their application was denied for "unknown" reason. There may have been a valid reason, but they have no clear idea why their application was denied. Once they had this kind of experience, their fear of dealing with bureaucratic agencies grew further.

In summary, older Latino's ability to engage with formal agencies and acquire needed social services depends on their internalized habitus, which is an outcome of class status . If a person is marginalized across their life course, they have few chances to learn the habitus of other classes and the ways of formal organizations. This is exacerbated by language difficulties.

While the participants with the low support have lived in the U.S. for a certain period of time and are attached to the U.S. society, they have actually lived in a Latino community. Their cultural and ideological place is not the U.S. society, but is a Latino society. At the same time, their perceived everyday lives have been in the Latino society.

I use "perceived" daily lives because they have continued to live their lives using their own language, communicating with people from Latin culture, eating familiar foods, and working with people who speak the same language. Even though they have lived in the U.S., their everyday lives have been going on within a culturally and linguistically familiar environment. In short, they have little experiences in the mainstream U.S. society.

Confinement in a Latino society is enforced as well as the result of participants' own decisions. Participants are confined in the Latino community because of their lack of English ability and poor financial status. At the same time, the Latino community provides elderly Latinos with many advantages, such as a culturally consistent living environment and social support networks in their own language and manners. Furthermore, the Latino community becomes a buffer from discrimination due to language, racial, and cultural differences (Cota-Robles, 1980; Maldonado 1988). Thus, it is a forced and self-selective process.

However, the Latino community is ordered and controlled in accordance with U.S. norms. While the Latino community is influenced by macro-structural factors, their perceived day-to-day lives went by without dealing with these macro structural forces. Thus, there are discrepancies between their perceived reality of everyday life and the reality of social order, in which U.S. laws, politics, economics, and manners are operating.

It may be easier to think about our own daily life in order to understand this point. For those who work and live in the U.S. mainstream society, there are fewer discrepancies between their perceived reality and social realities because their perceived reality is in the US society. Those who are part of mainstream society deal with people who are also part of mainstream society. These people usually spend their everyday lives in organizations

136

(e.g., company or school) that are operated under prominent U.S. social orders. These people are constantly dealing with formal agencies, such as health professional, IRS, insurance agencies, people with whom they work, or school personals. These people have developed skills to deal with formal agencies and complicated bureaucracy through their life experiences.

Because the participants with low support had few opportunities to contact with the mainstream society, they did not develop these skills. Moreover, they did not develop these skills in their home countries. This lack in opportunities makes it harder for them to access social services.

Ineffectiveness of the US welfare system

If access is influenced by the ability to negotiate within bureaucratic systems, it follows that the current welfare and Social Security systems are not designed for those who are not familiar with these systems. More precisely, the U.S. welfare and Social Security systems may be designed for the US citizens who can well negotiate these complex organizations. Then, the question to ask is what legal residents and the U.S. citizens do to manage their declining physical functional ability if they cannot deal with these systems well.

Indeed, the U.S. provides a limited number of formal assistances for such marginalized populations. In terms of home- and community-based long-term care services, the U.S. provides services mainly through Medicaid waiver programs. However, the availability of home- and community-based services is limited despite the expansion of Medicaid Home and Community-Based Services (HCBS) during the 1990s (Miller et al., 2000; Harrington 2000). Many states try to limit the availability of HCBS through the

following procedures: 1) setting limits to benefits per participants; 2) the limiting the availability of service slots; 3) setting more stringent financial eligibility than institutional care, and: 4) using waiver waiting list (Kitchener, Ng, & Harrington, 2004).

For example, 33 percent of states were using more stringent financial eligibility standards than those used for institutional care in 2002. Those states used various eligibility standards, such as 100% or 150% of SSI as the financial eligibility criterion (Kitchener, Ng, & Harrington, 2004). Forty-two states used waiting lists in 1999 (Harrington 2000). Consequently, a national total of 74,526 people were on the elderly/disabled waiver waiting lists in 2002 (Kitchener, Ng, & Harrington, 2004:65). The most important reason for the use of waiting lists is the lack of state funding for the HCBS waiver program to match federal Medicaid dollars (Miller et al., 2000; Harrington 2000).

Additionally, the complexity and fragmentation of long-term care and welfare systems may make it harder to access services for elderly, first-generation Latinos. Indeed, the complexity and fragmentation of the long-term care system in California has been pointed out by previous studies as a barrier (Lutzky and Zuckerman, 2002; Harrington et al., 2000). Long-term care services at the state level are managed by several different agencies. For instance, personal care services are administered by the Department of Social Services. Meanwhile, the California Department of Aging (CDA) administers the Medic-Cal Adult Day Health Care programs and licenses all adult day health care centers in the state. Various agencies serve similar target groups with different eligibility rules, need criteria, funding sources, and application procedures. Furthermore, many of the state programs are administered through local government agencies and private nonprofit organizations. While the need for coordination among state

agencies is great, it has been historically lacking (Lutzky and Zuckerman, 2002:17). It is questionable if even those participants who have less difficulty negotiating bureaucratic systems can successfully access services in this complex long-term care structure. Thus, it likely to be even harder for the participants who are confused with the U.S. bureaucratic system to access to services.

Lastly, the U.S. welfare system is not designed to deliver systems for marginalized populations, particularly immigrant elders, because of political and economic forces. This is partly because long-term care and social services, which are usually provided by the state in other developed nations, are initiated by private sectors in the U.S. Privatization of long-term care and social services for the elderly causes problems because access to services becomes based on the ability to pay (Harrington and Pollock, 1998).

Privatization refers to any initiatives that increases the role of the market in areas previously considered the province of the state. Privatization can be achieved by the sales of state assets, deregulation, and contracting-out public services to private providers (Feigenbaum and Henig 1997). The final goal of privatization is to transfer payment responsibility from society to the individuals (Harrington and Pollock 1998:1805). Both the state and private capital have stakes in privatization. For the state, privatization is thought to allow for cost containment and the reduction of responsibilities. For private capital, privatization means the expansion of business and the reduction of government intervention. The justification for the state to promote privatization follows the ideology of economic primacy, particularly during times of economic crisis (Estes 1991). State theory views a healthy economy as increasing capital accumulation, which provides the state with financial resource to fund social programs and improve the unemployment rate (O'Connor 1998). Thus, privatization is considered a rational choice for the state.

139

In the area of long-term care, privatization has preceded funding cuts for

nonprofit providers and has encouraged the for-profit sector to enter into the long-term

care market. Historically, nonprofit organizations have been the major providers of long-

term care and received funds from the federal government to do so. Since the 1980s and

with the Regan Administration, the state increased the conduct of state business in long-

term care through the auspices of for-profit corporations (Estes 1991:68). Ideologies used

in this process are: 1) economic crisis; 2) the primacy of the economic, and; 3) claims that

for-profit corporations can provide services more efficiently and at a lower cost than non-

profit sectors.

With these ideologies, the state removed the historical advantage that nonprofits

had enjoyed regarding government service funding, bidding, and contracting. Under the

Bush Administration, "for services funded under the Older American Act, it was the first

time that proprietary were permitted to contract for services and the first time that

nonprofits were uniformly required to compete on bids for contracts with for-profit"

(Estes et al., 2001:63). The requirement to bid for service contracts at the lowest cost

against for-profits impaired the ability of nonprofit agencies to continue to provide

charitable services, which resulted in the fragmentation and loss of services in

communities (Estes et al., 2001:63). Under these conditions, there were changes in the

type of ownership and the delivery of services from nonprofit to for-profit by way of

mergers as well as horizontal and vertical integration. For instance, Harrington et al.,

(2001) reported that in 1998, 65.8% of nursing homes were investor owned, 27% were

owned by nonprofit, and 6.5% were public.

The private sector also supports privatization, although the most obvious way to

enhance their interests is to have the government subsidize the purchase of providers'

services. However, providers have been opposed to government-run programs. In the eyes of providers, public payment is poor. Consumers with private insurance or who pay out-of-pocket end up paying more. For example, the nursing home industry opposed Clinton's plan for long-term care because of its emphasis was on home- and community- based care that would negatively impact their business and the public payment is poor. The insurance industry supports privatization because limited resources in public programs encourage the purchase of private long-term care insurance (Wiener et al., 2001). Moreover, the introduction of governmental programs means tighter regulations and more governmental interventions for providers. This is because such a program would increase the cost of the program for the government greatly, which would result in the government developing a concentrated interest in controlling the provider's prices, utilization, and expenditures (Feldstein 1997: 223).

Under this policy trend, services for marginalized populations are limited because these groups cannot purchase services from private providers due to a lack of financial resources. However, the number of services that the state provides is insufficient. In addition, it is less likely that the welfare system will deliver needed services to marginalized populations. Indeed, the policy trend has been to reduce welfare for non-citizens. For instance, the Welfare Reform Act of 1996 made it harder for legal immigrants to access welfare services, such as Medicaid and SSI. While the proposal was being discussed in Congress, many participants in this study were fearful of losing their lifelines of SSI and Medicaid because they were not U.S. citizens. Thus, many participants tried to obtain citizenship. While some participants successfully passed the citizenship test, other participants could not because they were not old enough to take the test in Spanish due to legal regulations. Because Congress altered their decision to

reserve rights for those who entered the U.S. before 1996, many participants did not lose their benefits in the end. However, this policy trend indicates that the U.S. will be less likely to expand assistance for immigrant populations in the future.

8.2. Conclusion

This study examined access to home and community-based long-term care services and other social services, such as Supplemental Security Income, General Assistance, and housing services among low-income older Latinos. While their access is largely determined by financial ability, English language ability, and knowledge and awareness of services, access is also determined by the ability to deal with bureaucratic systems. An individual's ability to deal with the system has been shaped by their life experiences. Due to marginalization in the U.S. society, it is difficult for older Latinos to gain necessary skills needed to negotiate with bureaucratic agencies and advocate for their needs effectively. Also, older Latinos expected their adult children would care for them in their old age. In response, they did not develop the skills needed to deal with the system.

For these people who do not actively seek resources because the lack of knowledge regarding how to deal with the system, it is the state that should reach out to these people. However, this requires intensive work. This is because it takes time and money to find these people and explain available services. Someone may need to do necessary paper work for these people. However, the current U.S. welfare system does not do provide such generous services because of a lack of funding and political conditions that provide minimum assistance to those who need help.

Is it more costly for the state to provide home and community-based services or medical and institutional care for those who cannot access needed services? This becomes a critical question. These people are at risks of declining health because they are not eating properly, which means they are not managing their illness properly.

143

Furthermore, they are pushing themselves to manage daily chores, such as cooking and going groceries, without help and this can cause falls among other injuries. Inadequate illness management and falls can be costly for the state because more severe disability is likely to result, which may burden the state with even more costly medical care, such as emergency room use. Additionally, severe disability carries with it the possibility of institutionalization, which is more expensive than home and community-based long-term care services.

The second question to raise is what are the roles and goals of the welfare system and Social Security policies more specifically. The goal of welfare and Social Security policies for long-term care, including the Medicaid waiver, should be to assist people cannot purchase long-term care services by themselves , so that they can maintain independent living in their own community . However, this study indicates that there are participants who cannot access necessary services because of the complexity of the system. If a policy is not accessible for its target population, the policy is not designed adequately. Indeed, policies for these services have often been considered and designed from with "cost" alone in mind. Although it is certainly important for the nation to control the costs of welfare and Social Security, it is also important to consider and design these policies from the perspective of users.

The third question relates to the validity of current measurements to assess eligibility for state-funded program. If those who cannot access services are equally disabled with those who are getting help, this indicates failure on the part of objective measurements. Thus, there may be some deficiency in assessing the eligibility of applicants. Identifying deficiencies in assessment processes and measurements is not

within the scope of this study. However, it is important to examine the assessment process and the validity of measurements in the future.

Finding individuals in a vulnerable population has been a challenging issue for most developed countries because these people are often isolated and alienated from bureaucratic systems. Moreover, these people tend to have a less extensive social network when compare to those who have been able to access social resources. For instance, Japan has started several prevention programs for those who are at high risk. The aim of the state is to identify those who have a less extensive social network, risk for dementia, and risk of declining health in order to provide preventative programs. The goal is to contain costs of long-term care in the future. However, programs cannot identify those who are at risk because the state does not have such a system to identify individuals in vulnerable populations. As a result, the Japanese government and citizens are spending money for those who are healthy and have been already using various programs. Therefore, providing services to vulnerable populations require a system to identify those in need.

So far, the most effective way may be to utilize community organizations, such as senior center and church. This is because these organizations have more knowledge about the people who live in a community when compared to social welfare agencies or social workers. However, this research indicates that those who cannot access state-funded programs are also having difficulties going to a senior center, church, and/or other community activities because of their physical disability and corresponding pain. Indeed, this study also indicated that individuals who experience declining physical health stop visiting their senior center and begin to become more isolated from society. The statistical analysis for 85 participants indicated that those who participate in senior centers are more

likely to have higher IADLs. Moreover, the narrative analysis also indicates that the participants who experience sever pain stop going to senior centers. Indeed, some participants with low support do not know who to ask for help in order to arrange for services because they have been so isolated due to their health problems. Therefore, it may be important for the state to develop a system that strengthens community-based organizations and social support systems in the community in order to reach out to these people who need social resources. This may prevent them from needing more costly medical services and institutionalization. Additionally, it is important for the U.S. to increase the amount of available of services for marginalized populations. Otherwise, these people identified by community services will not have anywhere to go. It may appear costly, but this is a more cost-saving approach for the state in the long run.

References:

Americans With Disabilities Act. 1990. 42. U.S.C.A. 12101 et seg. (28 C.F.R. Section 41.51).

Administration on Aging. 2004. "Aging Internet Information Notes: Senior Center." Washington, D.C.   http://www.aoa.gov/prof/notes/notes_senior_center.asp

Administration on Aging. 2006. "A Statistical Profile of Hispanic Older Americans Aged 65 +." Washington, D.C.
http://www.aoa.gov/PRESS/fact/pdf/Attachment_1303.pdf

Ailinger, Rita L. & Maria Recio Causey. 1993. "Home Health Service Utilization by Hispanic Elderly Immigrants: a Longitudinal Study." *Home Health Care Services Quarterly.* 14 (2/3): 85 – 96.

Alford, Robert R. 1972. "The Political Economy of Health Care: Dynamics without Change." *Politics and Society*. Winter. Pp127 – 164.

Andersen, Ronald M. 1968. "A behavioral Model of Health Service Use" in A Behavioral Model of Families' Use of Health Services. Pp. 10-12. Center for Health Administration Studies University of Chicago.

Andersen, R.M., Giachello, A.L. & Aday, L.A. 1986. "Access to Hispanics to Health Care and Cuts in Services: A State-of-the Art Overview." *Public Health Reports*. 101:238 – 252.

Andersen, Ronald M. 1995. "Revisiting the Behavioral Model and Access to Medical Care: Does It Matters?". in *Journal of Health and Social Behavior*. 36: 1-10

Aranda, Maria P and Bob G. Knight. 1997. "The Influence of Ethnicity and Culture on the Caregiver Stress and Coping Process: a Sociocultural Review and Analysis." *The Gerontologist*. 37(3): 342 – 354.

Aroian, Karen J, Galina Khatutsky, Thanh V. Tran, & Alan L. Balsam. 2001. "Health and Social Service Utilization Among Elderly Immigrants from the Former Soviet Union." *Journal of Nursing Scholarship*. 33 (3): 265–271.

Becker, Gay. Yewoubdar Beyene, Edwina Newsom, & Nury Mayen. 2003. "Creating Continuity Through Mutual Assistance: Intergenerational Reciprocity in Four Ethnic Groups." *Journal of Gerontology: Social Sciences*. 58B (3): S151 – S159.

Becker, Gay. 1997. *Disrupted Lives: How People Create Meaning in a Chaotic World*. University of California Press. Berkeley Los Angeles London.

Beyene, Yewoubdar. Gay Becker, & Nury Mayen. 2002. "Perception of Aging and Sense of Well-Being among Latino Elderly." *Journal of Cross-Cultural Gerontology.* 17: 155 – 172.

Becker, Gay. Yewoubdar Beyene, Edwina Newsom, & Nury Mayen, Denise V. Rodgers. 1998. "Knowledge and Care of Chronic Illness in Three Ethnic Minority Groups." *Family Medicine,* 30(3): 173 – 178.

Becker, Gay. 2002. "Dying Away From Home Quandaries of Migration for Elders in Two Ethnic Groups." *Journals of Gerontology Series B: Psychological Sciences and Social Science.* 57: S79 – S95.

Becker, Gay. Yewoubdar Beyene, and Pauline Ken. 2000. "Health, Welfare Reform, and Narratives of Uncertainty Among Cambodian Refugees." *Culture, Medicine, and Psychiatry*. 24(2): 139- 163.

Bourdieu, Pierre. "Distinction: A Social Critique of the Judgment of Taste." In *Social Stratification: Class, Race, and Gender in Sociological Perspective*. Edited by David B. Grusky. Pp404 – 429. Westview Press. Boulder,

Bowling, Ann., Morag Farquhar, and Peter Browne. (1991). "Use of Services in Old Age: Data from Three Surveys of Elderly People." *Social Science and Medicine.* 33(6): 689 – 700.

Bradley, Elizabeth H., Sarah A. McGraw, Leslie Curry, Alison Bucker, Kinda L. King V. Kasl, and Ronald Andersen. "Expanding the Andersen Model: the Role of Psychosocial Factors in Long-Term Care Use." *Health Service Research*. 37(5): 1221 – 1242.

Burnette, Denise & Ada C. Mui. 1999. "Physician Utilization by Hispanic Elderly Persons: National Perspective." *Medical Care.* 37 (4): 362 – 374.

Burr, Jeffrey A. & Jan E. Mutchler. 2003. "English Language Skills, Ethnic Concentration, and Household Composition: Older Mexican Immigrants." *Journal of Gerontology: Social Sciences.* 58 (2): S83 – S92.

California Association of Area Agencies on Aging. (2005). Service and Programs. http://www.c4a.info/service.html

California Department of Social Services, Research and Development Division, Data Analysis and Publication Branch, Adult Programs Analysis Team. 2001. "In-Home Supportive Services: IHSS Providers: Characteristics of Caregivers in the In-Home Supportive Services Program." October.

Cho, Pill Jay. 1998. "Awareness and Utilization: A Comment." *The Gerontologist.* 38(3): 317 – 319.

Choi, Namkee G. 1994. "Patterns and Determinants of Social Service Utilization: Comparison of the Childless Elderly & Elderly Parents Living with/Apart from Their Children." *The Gerontologist.* 34 (3): 353- 362.

The Commonwealth Fund Quarterly. 2001. "Medicare + Choice Doesn't Add Up for Seniors." *The Commonwealth Fund Quarterly.* 7 (3)

Coleman, Barbara. Wendy Fox-Grage, & Donna Folkemer. 2003. "State Long-Term Care: Recent Developments and Policy Directions. 2003 Update." Forum for State Health Policy Leadership National Conference of State Legislatures.

Cota-Robles, F. 1980. "Chicano Culture and Mental Health among the Elderly." In *Chicano Aging and Mental Health.* Edited by M. Miranda and R. Ruiz. Pp. 38 – 75. Rockville, MD: National Institute of Mental Health.

Coulton, Claudia, Abbie K. Frost. 1982. "Use of Social and Services by the Elderly." In *Journal of Health and Social Behavior.* 23: 330-339.

Cox, C. & D.E. Gelfand. 1987. "Familial Assistance, Exchange and Satisfaction among Hispanic, Portuguese, and Vietnamese Ethnic Elderly." *Journal of Cross-Cultural Gerontology.* 2: 241 – 255.

Cox, C. & Monk, A. 1990. "Minority Caregivers of Dementia Victims: a Comparison of Black and Hispanic Families." *Journal of Applied Gerontology.* 9: 340 – 354.

Curiel, Herman & Marta Sotomayor. 1988. "Future Directions and the Development of Programs for the Hispanic Elderly " in *Hispanic Elderly: A Cultural Signature.* Edited by Marta Sotomayor & Herman Curiel. A Publication of National Hispanic Council on Aging. Pan American University Express. Edinburg, TX. Pp 247 – 253.

Denzin, Norman K. & Yvonna S. Lincoln. (2000). "Introduction: the Discipline and Practice of Qualitative Research." In *Handbook of Qualitative Research: Second Edition.* Edited by Norman K. Denzin & Yvonna S. Lincoln. Sage Publications, Inc. Thousand Oaks, London, New Delhi. Pp1 – 28. qualitative method. P45/

Dietz. T.L. 1995. "Patterns of Intergenerational Assistance within the Mexican American Family." *Journal of Family Issues.* 16: 344 – 356.

Derose, Kathryn Pitkin & David W. Baker. 2000. "Limited English Proficiency and Latinos' Use of Physician Services." *Medical Care Research and Review.* 57 (1): 76 – 91.

Duckett, M J & M R Guy. 2000. "Home and Community-Based Services." Health Care Financing Review. 22(1): 123 – 126.

DuBos, Barbara C., Carol H. Yavno, & Percil Stanford. 2001. "Care Options for Older Mexican Americans: Issues Affecting Health & Long-Term Care Service Needs." In *Age*

Through Ethnic Lenses. Edited by Laura Katz Olson. Pp71 – 85. Rowman & Littlefield Publishers Inc, Lonham, Boulder. New York, Oxford.

Embry, D. & Russell, N. 1996. "Silver Strands of Mexico: Support Systems for the Elderly." *Journal of Multicultural Nursing and Health.* 2: 34 – 38.

Espino, D. 1993. "Hispanic Elderly and Long Term Care: Implications for Ethnically Sensitive Services." In *Ethnic Elderly and Long-Term Care.* Edited by C. Barrest & D. Stull. Pp 101 – 114. New York: Springer.

Estes, Carroll L., Karen W. Linkins, & Elizabeth A. Binney. 2001. "Critical Perspective on Aging" in *Social Policy and Aging: A Critical Perspective.* Pp23-44. Sage Publications. Thousand Oaks, London, New Delhi.

Estes, Carroll L., Charlene Harrington, and David N. Pellow. (2001). "Medical-Industrial Complex." In *Health Policy: Crisis and Reform in the U.S. Health Care Delivery System.* Third Edition. Edited by Charlene Harrington and Carroll L. Estes. Pp136 – 148. Sudbury, Massachusetts: Jones and Bartlett Publishers.

Estes, Carroll. L. 1991. "The Regan Legacy: Privatization, the Welfare State, and Aging in the 1990s." in *States, Labor Markets, and the Future of Old-Age Policy.* Edited by J. Myles and J. Quadragno. Pp59 – 83. Philadelphia, PA: Temple University Press.

Estes, Carroll. 1999. "Critical Gerontology and the New Political Economy of Aging." In *Critical Gerontology: Perspectives from Political and Moral Economy.* Edited by Meredith Minkler and Carroll L. Estes. pp17 – 35. Baywood Publishing Company, Inc.: Amityville, New York

Estes, Carroll L. and Karen W. Linkins. 1999b. "Devolution and Aging Policy: Racing to the Bottom in Long-Term Care." In *Critical Gerontology: Perspectives from Political and Moral Economy.* Edited by Meredith Minkler and Carroll L. Estes. pp169 – 183. Baywood Publishing Company, Inc.: Amityville, New York.

Estes, Carroll L., Robert R. Alford, and Anne Hays Egan. 2001. "The Transformation of the Nonprofit Sector: Systemic Crisis and the Political Economy of Aging Services." In *Social Policy and Aging: A Critical Perspective.* Edited by Carroll L. Estes and Associates. Pp61 – 94. Thousand Oaks: Sage Publications.

Facio. Elisa. 1996. *Understanding Older Chicanas: Sociological and Policy Perspectives.* Sage Publications. Thousand Oaks, London, New Delhi.

Feldstein, P.J. 1997. "The Demand for Legislation and National Health Reform." In *Health Politics and Policy.* Third Edition. Pp220 – 230. Albany, NY: Delmar Publishers Inc.,

Feigenbaum, Havery. B. and Jeffrey R. Henig. 1997. "Privatization and Political Theory." *Journal of International Affairs.* 50 (2): 339 – 355.

Fiscella, Kevin., Peter Franks, Mark P. Doescher, and Barry G. Saver. 2002. "Disparities in Health Care by Race, Ethnicity, and Language Among the Insured: Findings from a National Sample." *Medical Care.* 40 (1): 52 – 59.

Freedman, Vicki A., Jeannette Rogowski, Steven L. Wickstrom, John Adams, Jonas Maraine, & Jose J. Escarce. 2004. "Socioeconomic Disparities in the Use of Home Health Services in a Medicare Managed Care Population." *Health Services Research.* 39(5): 1277 – 1298.

Garcia, Alejandro. 1988. " An Examination of the Economic Support System of Elderly Hispanic." in *Hispanic Elderly: A Cultural Signature.* Edited by
Marta Sotomayor & Herman Curiel. A Publication of National Hispanic Council on Aging. Pan American University Express. Edinburg, TX. Pp227 – 246

Garro, Linda C. & Cheryl Mattingly. 2000. "Narrative as Construct and Construction." In *Narrative and the Cultural Construction of Illness and Healing.* Edited by Cherl Mattingly and Linda C. Garro. Pp1 – 49. University of California Press. Berkeley Los Angeles London.

Gavaria, M. & G. Stern. 1980. "Problems in Designing and Implementing Culturally Relevant Mental Health Services for Latinos in the U.S." *Social Science & Medicine.* 14: 65 – 71.

Gelberg, Lillian. Ronald M. Andersen, & Barbara D. Leake. 2000. "The Behavioral Model for Vulnerable Populations: Application for Medical Use and Outcomes for Homeless People." *Health Service Research.* 34(6): 1273 – 1302.

Glick, Jennifer E. & Jennifer Van Hool. 2002. "Parents' Coresidence with Adult Children: Can Immigration Explain Racial and Ethnic Variation?" *Journal of Marriage and Family.* 64: 240 – 253.

Goins, R. Turner & Gerry Hobbs. (2001). "Distribution and Utilization of Home- and Community- Based Long-Term Care Services for the Elderly in North Carolina." Journal of Aging & Social Policy. 12(3): 23 – 42.

Greene, V.L. & D.J. Monahan. 1984. "Comparative Utilization of Community Based Long-Term Care Services by Hispanic and Anglo Elderly in a Case Management System." *Journal of Gerontology.* 39: 730 – 735.

Grumbach, Kevin and Thomas Bodenheimer. 2002. "A Primary Care Home for Americans: Putting the House in Order." *Journal of American Medical Association.* 288 97): 889 – 893.

Habermas, Jurgen. 1975. "Crisis Tendencies in Advanced Capitalism." in *Lagitimation Crisis.* Pp33-94. Beacon Press. Boston.

Hall, P. A. 1987. "Minority Elder Maltreatment: Ethnicity, Gender, Age, and Poverty." *Ethnicity and Gerontological Social Work.* 9: 53 – 72.

Hanson, S.L., Sauer, W.J. & Seelbach, W.C. 1983. "Racial and Cohort Variations in Filial Responsibility Norms." *The Gerontologist.* 23:626 – 630.

Harrington, Charlene and Allyson M Pollock. 1998. "Decentralization and Privatization of Long-Term Care in UK and USA". *The Lancet.* 351(13):1805-1808.

Harrington, Charlene., Helen Carrillo, Valerie Wellin, Nancy Miller, & Allen LeBlanc. 2000. "Predicting State Medicaid Home and Community Based Waiver Participants and Expenditures, 1992 – 1997." *The Gerontologist.* 40(6): 673 – 686.

Harrington, Charlene., Helen Carrillo., Valerie Wellin., Fannie Norwood., Nancy Miller., 2001. "Access of Target Group to 1915(c) Medicaid Home and Community Based Waiver Services." Home Health Care Service Quarterly. 20(2): 61 – 80.

Harrington, Charlene & David N. Pellow. 2001. "The Uninsured and Their Health: Micro-Level-Issues." In *Health Policy: Crisis and Reform in the U.S. Health Care delivery System. Third Edition.* Edited by Charlene Harrington & Carroll L. Estes. Pp 56 – 64. Jones and Bartlett Publishers International. London.

Harrington, Charlene., Steffie Woolhandler, Joseph Mullan, Helen Carrillo, and David Himmelstein. 2001. "Does Investor Ownership of Nursing Home Compromise the Quality of Care?" *American Journal of Public Health*. 91(9): 1 – 5.

Harrington, Charlene & Janis O'Meara. 2004. "Report on California's Nursing Homes, Home Health Agencies, and Hospice Programs." Prepared for the California Health Care Foundation for California Nursing Home Search.

Harris. Lisa E., Simon Mungai, and William M. Tierney. 2000. "Satisfaction with Care in Minority Populations." In *Minority Health in America: Findings and Policy Implications from the Commonwealth Fund Minority Health Survey*. Edited by Carol J. R. Hogue, Martha A. Hargraves, and Karen Scott Collins. The Johns Hopkins University Press. Baltimore and London. Pp 160 – 175.

Health Policy Institute. 2004. "Medicaid and an Aging Population." Long-Term Care Financing Project. Georgetown University.

Health Care Financing Administration. 1996. Home and Community-Based Services Waivers. HCFA Fact Sheet. Baltimore, MD. May.

Hendryx, Michael S., Melissa M. Ahern, Nicholas P. Lovrich, and Arthur H. McCurdy. 2002. "Access to Health Care and Community Social Capital." *Health Service Research*. 37 (1): 85 – 101.

Hernandez, Mauro & Rick Zawadski. December 2003. "An Analysis of Medicaid and IHSS Services for the Long Term Care Medicaid Population in San Francisco." Department of Aging and Adult Services City and County of San Francisco.

Himmelstein, David U & Steffie Woolhandler. 1997. "Care Denied: US Residents Who are Unable to Obtain Needed Medical Services." In *Health Policy and Nursing: Crisis and Reform in the U.S. Health Care Delivery System. Second Edition.* Edited by Charlene Harrington and Carroll L. Estes. Jones and Bartlett Publishers. Sudbury, Massachusetts.

Holmes, D., J. Teresi, & M. Holmes. 1983. "Differences Among Black, Hispanic, and White People in Knowledge about Long-Term Care Services." *Health Financing Review.* 5: 51 – 67.

Himmelstein, David U., Steffie Woolhandler, Ida Hellander, and Sidney M. Wolf. 2001. "Quality of Care in Investor-Owned vs Not-for-Profit HMOs." In *Health Policy: Crisis and Reform in the U.S. Health Care Delivery System*. Third Edition. Edited by Charlene Harrington and Carroll L. Estes. Pp223 – 229. Sudbury, Massachusetts: Jones and Bartlett Publishers.

Hogan, D.P.., Eggebeen, D.J. & Clogg, C.C. 1993. "The Structure of Intergenerational Exchange in American Families." *American Journal of Sociology.* 98: 1428 – 1458.

Hooyman, Nancy R and Judith Gonyea. 1995. "Changing Health Care Needs and Long-Term Care Services." *Feminist Perspectives pf Family Care: Policies for Gender Justice.* Sage Publications. Thousand Oaks. London New Delhi. Pp75 – 104.

Hudson, Robert B. 1999. "The Evolution of the Welfare State: Shifting Rights and Responsibilities for the Old." in *Critical Gerontology: Perspective from Political and Moral Economy.* Pp329 – 343. Edited by Meredith Minkler & Carroll L. Estes. Baywood Publishing Company, Inc. Amityville, New York.

Idler, E. L., S.V. Hudson, & H. Leventhal. 1999. "The Meaning of Self-Reported Health: A Qualitative and Quantitative Approach." *Research on Aging.* 21(3): 458 – 476.

IUPLR. 2002. "Population 65 Years and Over Projection for 2005 by the State." http://www.nd.edu/~iuplr/cic/population65_4_4_02/pop_65.html#begin.

Jacobi, Catharina E., Mattanja Triemstra, Ines Rupp, Huibert J. Dinant, and Geertrudis A. M. Van Den Bos. 2001. "Health Care Utilization Among Rheumatoid Arthritis Patients Referred to a Rheumatology Center: Unequal Needs, Unequal Care?" *Arthritis Care & Research.* 45: 324 – 330.

Johnson, Robert J. & Fredric D. Wolinsky. 1996. "Use of Community-Based Long-Term Care Services by Older Adults." *Journal of Aging and Health*. 8(4):512 – 537.

Johnson, Rebecca A., Valerie Schwlebert, Partricia Alvarado-Rosenmann, Glenda Pecka, & Norman Shirk. 1997. "Residential Preferences and Eldercare Views of Hispanic Elders." *Journal of Cross-Cultural Gerontology*. 12: 91 – 1997.

John. Robert, Rosalva Resendi, and Kubda W. DE Vargas. 1997. "Beyond Familism?: Familism as Explicit Motive for Eldercare among Mexican American Caregivers." *Journal of Cross-Cultural Gerontology.* 12: 145 – 162.

Kassner, Enid. 2005. "Medicaid and Long-Term Services and Supports for Older People." AARP Public Policy Institute. February.

Kassner, E., & L Williams. 1997. "Taking Care of Their Own: State Funded Home and Community-Based Care Programs for Older Persons." Washington, DC: Public Policy Institute.

Katz, S., For A B., Moskowitz, R. W., Jackson B A., Jafee, M. W. 1963. "Studies of Illness in the Aged: the Index of Biological and Psychosocial function." JAMA. 185: 914 – 919.

Kenyon, Gary M & William L. Randall. 2001. "Narrative Gerontology: an Overview." In *Narrative Gerontology: Theory, Research, and Practice.* Edited by Gary Kenyon, Phillip Clark, and Brian de Vries. Pp3 – 18. Springer Publishing Company. New York.

Kitchener, Martin., Terence Ng, & Charlene Harrington. 2004. "Medicaid 1915(c) Home and Community-Based Services Waivers: A National Survey of Eligibility Criteria, Caps, and Waiting Lists." *Home Health Care Services Quarterly*. V23(2): 55 – 69.

Kitchener, Martin, Micky Willmott, and Charlene Harrington. 2004. "Home & Community-Based Services: State-Only Funded Programs." http://www.pascenter.org/state_funded/index.php?print=yes

Kitchener, Martin., Terence Ng, and Charlene Harrington. 2005. "Medicaid 1915(c) Home and Community-Based Service Programs: Data Update." *Kaiser Commission on Medicaid and the Uninsured*. July

Kitchener, Martin., Terence Ng, Nancy Miller, & Charlene Harrington. 2005. "Medicaid Home and Community-Based Services: National Program Trends." Health Affairs. 24(1): 206 – 212.

Ku, Leighton, Donna Cohen Ross, & Melanie Nathanson. 2002. State Medicaid Cutbacks and the Federal Role in Providing Fiscal Relief to States." Center on Budget and Policy Priorities. August.

Lawton MP. & Brody. EM. 1969. "Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living." *Gerontologist.* 9:179 – 186.

LeBlanc, Allen, Christine Tonner, and Charlene Harrington. 2000. "Medicaid 1915 (c) Home and Community-Based Services Waivers Across the States." *Health Care Financing Review.* 22(2): 159 – 174.

Lee, Geum-Yong and Ronald J. Angel. 2002. "Living Arrangements and Supplemental Security Income Use among Elderly Asians and Hispanics in the United States: the Role of Nativity and Citizenship." *Journal of Ethnic and Migration Studies*. 28(3): 553 – 563.

Lee, Philip. R. and Benjamin, A.E. 1994. "Health Policy and the Politics of health Care." in *The Nation's Health.* Fifth Edition. Boston: Jones and Bartlett Publishers. Pp 121-137.

Leiyu, Shi. 1999. "Experience of Primary Care y Racial and Ethnic Groups in the United States." *Medical Care.* 37 (10): 1068 – 1077.

Light, Donald W. 2001. "Cost Containment and the Backdraft of Competition Policies." *International Journal of Health Services*. 31 (4): 681 – 708 .

Light, Donald W. 1997. "The Restructuring of the American Health Care System." In *Health Politics and Policy*. 3rd Edition. Edited by T.J. Litman and L.S. Robins. Albany, NY: Delmar Publishers Inc. pp. 46 – 63.

Long, Sharon K., Korbin Liu, & Kirsten Black. 2005. "Getting by in the Community: Lessons from Frail Elders". *Journal of Aging & Social Policy*. 17(1):19 – 44.

Lutzky, Amy Westpfahl & Stephen Zuckerman. (2002). "Recent Changes in Health Policy for Low-Income People in California." State Update No. 14, March. An Urban Institute Program to Assess Changing Social Policies. Confusion of California welfare system. The Urban Institute.

Madsen, W. 1969. "Mexican-Americans and Anglo-Americans: a Comparative Study of Mental Health in Texas." In Changing Perspectives in Mental Illness. Edited by S.C. Plog & R.B. Edgerton. Pp217 – 242. New York: Holt, Rinehart, and Winston.

Mahoney, FI. & DW. Barthel. 1965. "Functional Evaluation: the Barthel Index." Md State Med JMental 14: 61 – 65.

Mental Health in Texas." In Changing Perspectives in Mental Illness. Edited by S.C. Plog & R.B. Edgerton. Pp217 – 242. New York: Holt, Rinehart, and Winston.

Maldonado, David. 1979. "Aging in the Chicano Context." in *Ethnicity and Aging: Theory, Research, and Policy.* Pp. 175 – 183. Edited by D.E. Gelfand & A.J. Kutzik. Springer Publishing Company. New York.

Maldonado, David. 1985. "The Hispanic Elderly: A Socio Historical Framework for Public Policy." *The Journal of Applied Gerontology.* 4: 18 – 27.

Maldonado, David. 1988. "El Barrio: Perceptions and Utilization of the Hispanic Neighborhood." In H*ispanic Elderly in Transition: Theory, Research, Policy, and Practice.* Pp136 – 142. Edited by Steven R. Applewhite. Greenwood Press. NY. Westport, Connecticut, London.

Markides, K.S., H.W. Martin, & E. Gomez. 1983. *Older Mexican Americans: A Study in an Urban Barrio.* Austin: University of Texas Press.

Markides, Kyriakos and Jeannine Coreil. 1988. "The Health Status of Hispanic Elderly in the Southwest." In *Hispanic Elderly in Transition: Theory, Research, Policy, and Practice.* Pp35 – 59. Edited by Steven R. Applewhite. Greenwood Press. NY. Westport, Connecticut, London.

Markides, Kyriakos S., Christine A. Stroup Benham, James S. Goodwin, Linda C. Perkowski, Michael Lightenstein, and Laura A. Ray. 1996. "The Effect of Medical Conditions on the Functional Limitations of Mexican-American Elderly." *AEP.* 6(5): 386 – 391.

Marx, Karl. 1978. "German Ideology" Pp 146 – 200 & "Wage Labour and Capital" Pp203 – 217 from *The Marx – Engels Reader.* Edited by Robert C. Tucker. W.W. Norton & Company. New York. London.

Mayoralas, Gloria Fernandez. Vicente Rodriguez. Fermina Rojo. 2000. "Health Service Accessibility among Spanish Elderly." In *Social Science and Medicine.* 50:17-26.

McKinley. John B. 1984. "Introduction". In *Issues in the Political Economy of Health Care. Contemporary Issues in Health, Medicine, and Social Policy*. Edited by John B. McKinley. Pp1 – 19.

Miller, B., R.T. Campbell, L. Davis, S. Furner, A. Giachello, T. Prohaska, J. E. Kaufman, M. Li, and C. Perez. 1996. "Minority Use of Community Long-Term Care Services: A Comparative Analysis." *Journal of Gerontology: Social Sciences.* 51B (2): S70 – 81.

Miller, Robert H. 1998. "Health Care Organizational Change: Implications for Access to Care and its Measurement." In *Health Policy: Crisis and Reform in the U.S. Health Care Delivery System*. Third Edition. Edited by Charlene Harrington and Carroll L. Estes. Pp326 – 340. Sudbury, Massachusetts: Jones and Bartlett Publishers

Miller, Nancy A. (1992:163). "Data Watch: Medicaid 2176 Home and Community-Based Care Waivers: The First Ten Years". 162 – 171,

Miller, Nancy A., Sarah Ramsland, Elizabeth Goldstein, and Charlene Harrington. 2000. "Use of Medicaid 1915 (c) Home- and Community-Based Care Waivers to Reconfigure State Long-Term Care Systems." *Medical Care Research and Review.* 58(1): 100 – 119.

Miller, Nancy A., Sarah Ramsland, & Charlene Harrington. 1999. "Trends and Issues in the Medicaid 1915 (c) Waiver Program*." Health Care Finance Review*. 20(4):139 – 160.

Miranda, M. 1991. "Mental Health Services and the Hispanic Elderly." In *Empowering Hispanic Families: a Critical Issue for the '90s*. Pp 141 – 151. Edited by M. Sotomayor. Family Service America. Milwaukee.

Mitchell, Jim & John A. Krout. 1998. "Discretion and Service Use Among Older Adults: The Behavioral Model Revisited." *The Gerontologist.* 38 (2): 159 – 168.

Mui, Ada C. & Denise Burnette. 1994. "Long-Term Care Service Use by Frail Elders: Is Ethnicity a Factor?" in *The Gerontologist*. 34(2): 190-198

National Conference of State Legislatures. 2000. "Facts about Home and Community-Based Services." *Promising Practices*. August.

Navarro, Vicente. 1987. "Federal Health Policies in the United States: An Alternative Explanation". *The Milbank Quarterly*. 65 (1): 81 – 111.

Navarro, Vicente. 1995. "The Politics of Health Care Reform in the United States, 1992 – 1994: A Historical Review." *The International Journal of Health Services*. 25 (2): 185 – 201.

Navarro, Vicente. 2001. "Why Congress did not Enact Health Care Reform." In *Health Policy: Crisis and Reform in the U.S. Health Care Delivery System*. Third Edition. Edited by Charlene Harrington and Carroll L. Estes. Pp391 – 396. Sudbury, Massachusetts: Jones and Bartlett Publishers.

Neuman, W. Lawrence. (1997). "Science and Research." In *Social Research Methods: Qualitative and Quantitative Approaches. Third Edition*. Pp1 – 17. Allyn & Bacon. Neeldham Heights, MA.

Oberlander, Jonathan. 2002. "The US Health Care System: On a Road to Nowhere?" *Canadian Medical Association Journal (CMAJ)*. 167 (2): 163 – 168.

O'Connor, James. 1973. *The Fiscal Crisis of the State*. Pp13-95. St Martines Press. New York

O'Connor, 1998. "Introduction" in *Natural Causes: Essays in Ecological Marxism*. Pp 1-18. New York: Guilford Press.

O'Donnell,R.M. 1989. "Functional Disability Among the Puerto Rican Elderly." *Journal of Aging and Health.* 1(2): 244 – 264.

Osacar, Maria Luisa. 2004. "A Report on the Status of Services for Hispanic/Latino Seniors and Adults with Disabilities in San Francisco." Institute of Aging.

Parra, Ernest O. & David V. Espino. 1992. "Barriers to Health Care Access Faced by Elderly Mexican Americans." *Clinical Gerontologist.* 11 (): 171 – 177.

Peng, Timothy R., Maryam Navaie-Waliser, & Penny H. Feldman. 2003. "Social Support, Home Health Service Use, and Outcomes Among Four Racial-Ethnic Groups." *The Gerontologist*. 43 (4): 503 – 513.

Peterson. Mark A. 1997. "Introduction Health Care into the Next Century." *Journal of Health Politics, Policy, and Law.* 22 (2): 291 – 313.

Phillips, Kathryn A, Kathleen R. Morrison, Ronald Andersen, Lu Ann Aday. 1998. "Understanding the Context of Healthcare Utilization: Assessing environmental and Provider-related variables in the behavioral model of Utilization." *Health Service Research.* 33 (3): 571 – 594.

Pollock, Donald. 2000. "Physician Autobiography: Narrative and the Social History of Medicine." In *Narrative and the Cultural Construction of Illness and Healing*. Edited by Cherl Mattingly and Linda C. Garro. Pp.108 – 127. University of California Press. Berkeley Los Angeles London.

Purdy, Julie K. & David Arguello. 1992. "Hispanic Familism in Caretaking of Older Adults: Is It Functional?" *Journal of Gerontological Social Work.* 19(2): 29 – 43.

Ragin, Charles C. (1994). *Constructing Social Research.* Thousand Oaks, CA: Pine Forge Press.

Ramirez, Robert R. & G. Patricia de la Cruz. 2003. "The Hispanic Population in the United States: March 2002. Current Population Reports. June 2003. US Census Bureau.

Randall, William L. 2001. "Storied Worlds: Acquiring a Narrative Perspective on Aging, Identity, and Everyday Life" In *Narrative Gerontology: Theory, Research, and Practice.* Edited by Gary Kenyon, Phillip Clark, and Brian de Vries. Pp31 – 62. Springer Publishing Company. New York.

Richardson, J.L., G. Marks., J.M. Solis, L.M. Collins, L. Berba, & J.C. Hisserich. 1987. "Frequency and Adequacy of Breast Cancer Screening Among Elderly Hispanic Women." *Preventive Medicine.* 16: 761 – 774.

Roy, Lonnie C., Tracy L. Dietz, & Robert John. 1996. "Determining Patterns of Formal Service Use Among Mexican American Elderly: Improving Empirical Techniques for Policy & Practice." *Journal of Gerontological Social Work.* 26 (3/4): 65 – 81.

Sabogal, Fabio, Gerardo Marin, Regina Otero-Sabogal, Barbara Van Oss Maarin, and Eliseo J. Perez-Stable. 1987. "Hispanic Familism and Acculturation: What Changes and What Doesn't?" *Hispanic Journal of Behavioral Science.* 9(4): 397 – 412.

Schur, C.L., L.A.Albers, & M.L.Berk. 1995. "Health Care Use by Hispanic Adults: Financial vs. Non-Financial Determinants." *Health Care Financing Review*. 17:71 – 88.

Shanas, E. 1979. "Social Myth as Hypothesis: The Case of the Family Relations of Old People." *Gerontologist.* 19(1): 3 – 9.

Simonsick, Eleanor M., Judith D. Kasper, and Caroline L. Phillips. 1998. "Physical Disability and Social Interaction: Factors Associated with Low Social Contact and Home Confinement in Disabled Older Women (The Women's Health and Aging Study)." *Journal of Gerontology.* 53B (4): S209 – S217.

Speare, A., R. Avery, & L. Lawton. 1991. "Disability, Residential Mobility, and Changes in Living Arrangements." *Journal of Gerontology: Social Sciences.* 46: S133 – S142.

Starrett, Richard A., C.H. Mindel, & R. Wright 1983. "Influence of Support Systems on the Use of Social Services by the Hispanic Elderly." *Social Work Research and Abstract.* 19: 35 – 40.

Starrett, Richard A., Alicia M. Todd, James T. Decker, and Gary Walters. 1989. "The Use of Formal Helping Networks to Meet the Psychological Needs of the Hispanic Elderly." *Hispanic Journal of Behavioral Sciences.* 11(3): 259 – 273.

Starrett, Richard A., Charles Bresler, Gary T. Walters, and Dan Rogers. 1990. "The Role of Environmental Awareness and Social Support Networks in Hispanic Elderly Persons' Use of Formal Social Services." *Journal of Community Psychology.* 18: 218 – 227.

Starrett, Richard A., D Rofers, & James T. Decker. 1992. "The Self-Reliance Behavior of the Hispanic Elderly in Comparison to Their Use of Formal Mental Health Helping Networks." Clinical Gerontologist. 11: 157 – 169.

Steinmo, Sven and Jon Watts. (1995). "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America". *Journal of Health Politics, Policy and Law*. 20(2):329-372.

Sotomayor, Marta & Suzanne Randolph. 1988. "A Preliminary Review of Caregiving Issues Among Hispanic Elderly." in *Hispanic Elderly: A Cultural Signature*. Edited by Marta Sotomayor & Herman Curiel. A Publication of National Hispanic Council on Aging. Pan American University Express. Edinburg, TX. Pp137 – 162.

Sotomayor, Marta & Steve R.   Applewhite. 1988. "The Hispanic Elderly and the Extended Multigenerational Family." In H*ispanic Elderly in Transition: Theory, Research, Policy, and Practice.* Pp122 – 133. Edited by Steven R. Applewhite. Greenwood Press. NY. Westport, Connecticut, London.

Swan. James H & Carroll L. Estes. 1993. "Access to Nursing Home and Health Care Services". In *The Long Term Care Crisis: Elders Trapped in the No-Care Zone.* Edited by

Carroll L. Estes, James H. Swan, and Associates. Pp132 – 154. SAGE publications, Inc. Newbury Park, California.

Talamantes, Melissa., W. Ross Lawler, & David V. Espino. 1995. "Hispanic American Elders: Caregiving Norms Surrounding Dying and the Use of Hospice Services." *The Hospice Journal*. 10(2): 35 – 49.

Tran, Thanh V, Surjit S. Dhooper, & Kathleen Mclnnis-Dittrich. 1997. "Utilization of Community-Based Social and Health Services Among Foreign Born Hispanic American Elderly". In Journal of Gerontological Social Work. 28(4): 23-42.

Trevino, Margarita C. 1988. "A Comparative Analysis of Need, Access, and Utilization of Health and Human Services." In *Hispanic Elderly in Transition: Theory, Research, Policy, and Practice*. Pp62 – 71. Edited by Steven R. Applewhite. Greenwood Press. NY. Westport, Connecticut, London.

Uccello, Cori E. & L. Jerome Gallagher. 1997. "General Assistance Programs: the State-Based Part of the Safety Net." Urban Institute. January.
http://www.urban.org/publications/307036.html

U.S. Bureau of the Census. 2000. *National Population Projection: NP-T4*. Washington, DC: U.S. Government Printing Office. Available online:
http://www.census.gov/population/www/projections/natsum-T3.html

Wallace, S. O. & Facio, E.L. 1987"Moving beyond Familism: Potential Contributions of Gerontolotical Theory to Studies of Chicano/Latino Aging." In *Aging, Self, and Community: a Collection of Readings*. Pp 207 – 224. Edited by J.F. Gubrium & K. Charmaz. JAI Press. Greenwich, CT.

Wallace, Steven P. & Lew-Ting, C. 1992. "Getting by at Home-Community-Based Long-Term Care of Latino Elders, in Cross-Cultural Medicine – a Decade Later." *Western Journal of Medicine*. 157:337 – 344.

Wallace, Steve P., Kevin Campbell, & Chih-Yin Lew-Ting. 1994. "Structural Barriers to the Use of Formal In-Home Services by Elderly Latinos." *Journal of Gerontology: Social Sciences*. 49(5):S253 – S263.

Wallace, Steven P., Lene Levy-Storms, and Linda R. Ferguson. 1995. "Access to Paid In-Home Assistance among Disabled Elderly People: Do Latinos Differ from Non-Latino Whites?" *American Journal of Public Health*. 85(7): 970 – 975.

Wallace, Steven P. & Valentine M. Villa. 1999. "Caught in Hostile Cross-Fire: Public Policy and Minority Elderly in the United States." in *Critical Gerontology: Perspective*

from Political and Moral Economy. Pp237 – 255. Edited by Meredith Minkler & Carroll L. Estes. Baywood Publishing Company, Inc. Amityville, New York.

Wan Thomas T.H., Barbara Gill Odell. 1981. "Factors Affecting the Use of Social and Health Services Among the Elderly." in *Aging and Society.* 1(1): 95-115

Waterstone, Debi. Taewoon Kang, Cristina Flores, Candace Howes, Charlene Harrington, & Robert Newcomer. 2004. California's In-Home Support Services Program: Who is Served? " Report prepared for California Healthcare Foundation.

Weber, Max. 1967. "Class, Status, Party". Pp180-195. in *From Max Weber: Essays in Sociology.* Edited by Gerth H.H. & C. Wright Mills. Oxford University Press. New York.

White-Means, Shelley I. & Rose M. Rubin. 2004. "Is There Equity in the Home Health Care Market? Understanding Racial Patterns in the Use of Formal Home Health Care." *Journal of Gerontology: Social Sciences.* 59B (4):S220 – S229.

Wiener, Joshua & L H Illston. 1994. Health care reform in the 1990s: where does long-term care fit in?" *The Gerontologist.* 34(3): 402-408

Wiener, Joshua A. Carroll L., Estes, Susan M. Goldenson, and Sheryl C. Goldberg. 2001. "What Happened to Long-Term Care in the Health Reform Debate of 1993 – 2994? Lessons for the Future." *The Milbank Quarterly.* 79 (2): 207 – 252.

Wilmoth, Janet M. 2001. "Living Arrangements Among Older Immigrants in the United States." *The Gerontologist.* 42 (2): 228 – 238.

Yeatts. Dale E, Thomas Crow, Edward Folts. 1992. "Service Use Among Low-Income Minority Elderly: Strategies for Overcoming Barriers." *The Gerontologist.* 32(1):24-32.

Zsembik, Barbara A. 1993. "Determinants of Living Alone Among Older Hispanics." *Research on Aging.* 15(4): 449 – 464.

Publishing Agreement

It is the policy of the University to encourage the distribution of all theses and Dissertations. Copies of all UCSF these and dissertations will be routed to the library via the Graduate Division. The library will make all theses and dissertations accessible to the public and will preserve these to the best of their abilities, in perpetuity.

Please sing the following statement:

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis or dissertation to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

_____   5 - 8 - 2007
Author Signature   Date